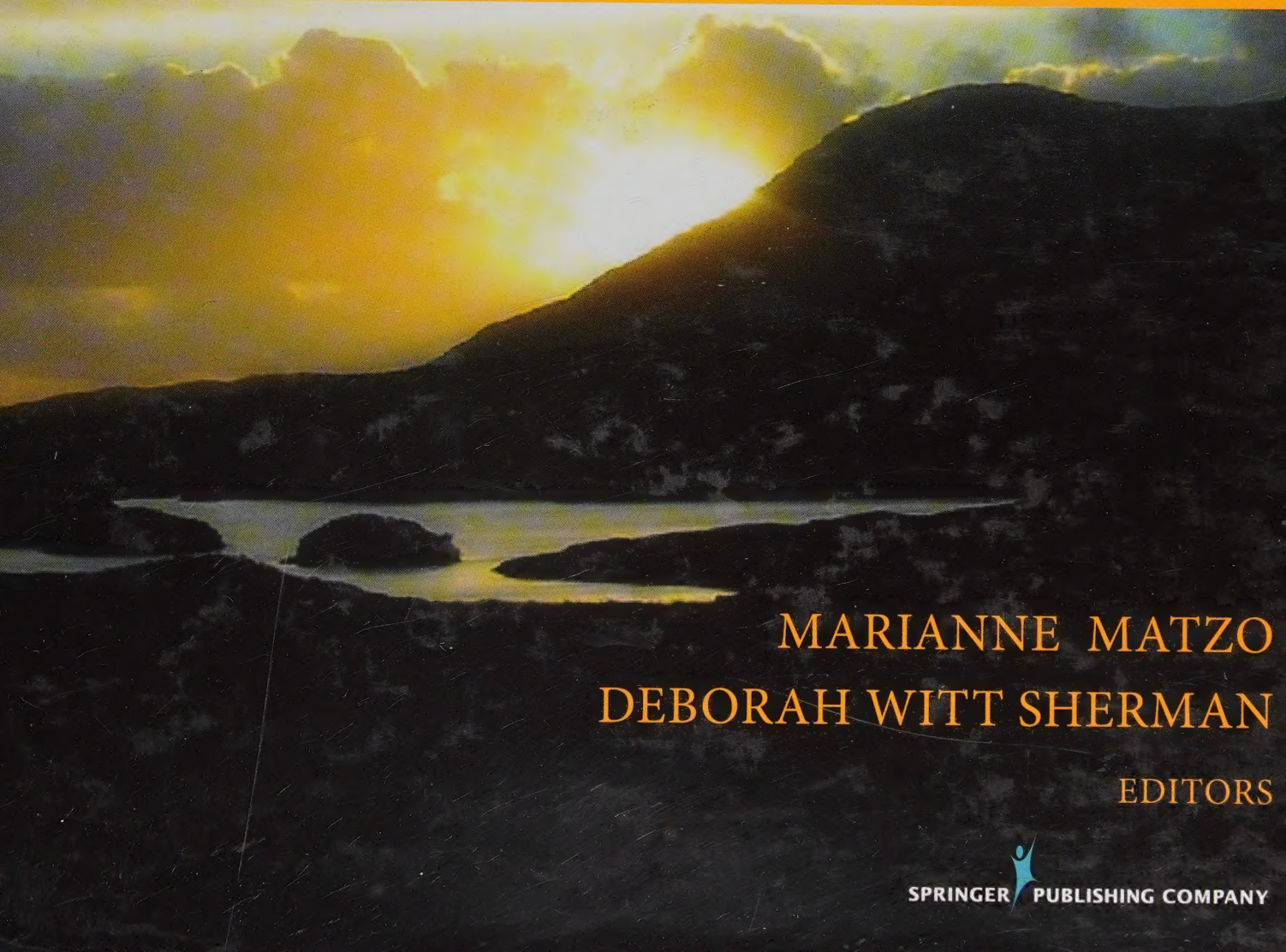



FOURTH EDITION

# Palliative Care Nursing


*Quality Care to the End of Life*



MARIANNE MATZO  
DEBORAH WITT SHERMAN  
EDITORS

SPRINGER  PUBLISHING COMPANY





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# Palliative Care Nursing

Quality Care to the End of Life

Fourth Edition

Katherine M. Nelson

Deborah W. Wilson

Editors



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**Deborah Witt Sherman, PhD, ARNP, ANP-BC, ACHPN, FAAN**, is the associate dean of academic affairs and professor with tenure at the Nicole Wertheim College of Nursing and Health Sciences at Florida International University. She is certified as an adult nurse practitioner and a palliative care nurse practitioner. In 2009, she received the Hospice and Palliative Care Nurses Associations' "Leading the Way Award," the highest honor, recognizing her implementation of the first Palliative Care Nurse Practitioner Program in the United States. In November 2011, she was awarded the Lifetime Achievement Award in Nursing from MD Anderson Cancer Center in Houston, Texas. She has also served as faculty of Tenshi College in Hakkaido, Japan, where she implemented Japan's first Palliative Care Master's Program in Nursing. Dr. Sherman was awarded the Prestigious Project on Death in America Faculty Scholars Fellowship, funded by the Soros Foundation. She served for 7 years as the codirector and faculty of the Bronx VA Medical Center Interprofessional Palliative Care Fellowship Program. She has been faculty for the End-of-Life Nursing Education Consortium (ELNEC) and served as a member of the steering committee in developing the National Consensus Guidelines for Quality Palliative Care. She received a postdoctoral AIDS Research Fellowship Award from the Aaron Diamond Foundation and has a strong program of palliative care research as well as breast cancer research with two studies funded by the National Institutes of Health. She is on several nursing and palliative care editorial boards, and has served as an NIH grant reviewer. In addition to palliative care textbooks, she has numerous peer-reviewed, data-based articles, scholarly papers, and media products. She is an invited keynote speaker on palliative care topics nationally and internationally.



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## *Quality Care to the End of Life*

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Marianne Matzo, PhD, APRN-CNP, FPCN, FAAN

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*Editors*



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*This book is dedicated to my sister, Kathleen Enderton, and my best friend, Catherine Graham,  
who both died in 2011. I miss you both so much.*

*I have shared every edition of this book with my girls, LeaRose and Giuliana LaPorte.  
You were both babies when this book was conceived...and are now fine young women  
as this fourth edition is published. It is such a joy to be a part of your lives.*

—Marianne Matzo

*With the passage of time, my joy centers on the accomplishments of my children, Ben, Rachael,  
and Joe—all health professionals—each committed to the care and well-being of others—in celebrating  
their wonderful marriages and blessed lives—in the happiness I feel as I play with Austin, my dear grandson,  
and the gratitude and love I have for my mother, Mary, dear Heloise, my sisters  
Kathy and Diane, brother Jim, extended family and friends. We only have one life to live—it is these  
special relationships that make life precious—I love you all.*

—Deborah Witt Sherman





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# Foreword: What Changes; What Remains

It has been 12 years since publication of the first edition in 2001 of *Palliative Care Nursing* by Drs. Marianne Matzo and Deborah Witt Sherman. The publication of this fourth edition is a testament to their dedication to the field of palliative nursing, which has witnessed tremendous growth over these years.

This fourth edition is a tribute to both what has changed and what remains. What has changed is that palliative nursing has come of age. Palliative care has moved from a new specialty hardly recognized by the health care system to now serving as an anchor amid a health system that resembles a Titanic ship in stormy waters. The health care ship is in threat of sinking due to the weight of an aging society, costly care that is consuming our national economy, and the emergence of chronic illnesses that are best treated with aggressive palliative care. Palliative care is no longer an unknown visitor to the health care world. It is now a force with the potential to impact the biggest demands on the drowning systems of care. At the helm of the ship is nursing.

Nurses are leading palliative care programs across settings of care. They are transforming hospice programs to continue to serve populations in most need and they are increasingly assuming the primary care role through advanced practice. The chapters of this book reflect these changes. They address numerous chronic illness populations that are now targets for palliative care. Topics such as palliative nursing care amid health care reform, in survivorship care, and in rehabilitation are examples of our field's dissemination into the most critical areas of health care.

This fourth edition fortunately continues to serve as an excellent resource for what remains in palliative care. Palliative nursing care is built on expert evidence that supports patients and families facing serious illnesses and at the end of life. Exquisite attention to symptom management remains a hallmark of palliative care, and the professional at the bedside providing that care is a nurse.

This edition also serves as an excellent resource for symptom assessment and management. Another enduring characteristic of the field is recognition that palliative care is more than relief of physical symptoms. Pioneers in palliative nursing firmly established models of care that include psychological, social, and spiritual aspects of care. This fourth edition has captured the whole-person focus of palliative nursing throughout, but specifically in chapters on topics addressing sexuality, spirituality, family caregivers, and peri-death nursing care.

This text is a blend of what has changed and what remains. It is a timely addition to the literature that can serve as a map to guide the field of palliative care through the stormy waters ahead. There is much at stake and there is even more to be gained by a health care system infused with palliative nursing care to provide the quality of care we would seek for anyone we love facing serious illness.

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# Preface

Palliative care is moving into the mainstream of health care as a highly structured and organized system of care (National Consensus Project, 2013). Palliative care is a philosophy of care that provides a combination of disease-modifying and supportive, compassionate therapies intended to alleviate pain and other symptoms while addressing the emotional, social, cultural, and spiritual needs of patients and families who are experiencing life-threatening progressive illness (National Consensus Project, 2013; [www.nationalconsensusproject.org](http://www.nationalconsensusproject.org)). It embraces comprehensive, patient and family centered care which match treatments with the values and preferences of the patient and family (Meier, 2010).

Built on the foundation of hospice care, palliative care addresses care of the mind, body, and spirit and is offered to patients experiencing a wide range of illnesses, including neonates with congenital anomalies or intrauterine health conditions, individuals with progressive, chronic, or debilitating illness or life-limiting injuries, as well as those with advancing diseases, such as cancers, end-stage organ diseases, HIV/AIDS, neurodegenerative disorders, and dementia (National Consensus Project, 2013). The difference between hospice and palliative care is that palliative care begins at the time of diagnosis with such illnesses and continues through the death of the patient and into the bereavement period for families, while hospice care is provided during the last 6 months of life. Unlike hospice care, palliative care is not dependent on prognosis and can be provided in the context of curative treatments, curing what can be cured, but with the concurrent attempt of alleviating symptoms caused by disease or its treatment. Both palliative and hospice care can be the main focus of care when solely comfort and supportive interventions are desired to promote quality of life until its end (Sherman et al., 2011). Currently, palliative and

hospice care are considered on a continuum of care, with palliative care beginning earlier in the illness trajectory and potentially continuing until death, as compared to hospice care, which is at the end of the illness trajectory, supporting patients and families in the last stages of life.

As Project on Death in America faculty scholars, the editors have assumed the responsibility in their roles as nurse practitioners, educators, and researchers to work collaboratively with nursing colleagues in developing, implementing, and evaluating nursing initiatives in palliative care within the United States as well as internationally.

Palliative care allows practitioners of various health disciplines to bring their specialized competencies and expertise to focus on serious and complex health problems. Palliative care practitioners combine their clinical expertise and judgment with the best evidence available through research and an understanding of the preferences of patients and families, known as evidence-based care (Sherman et al., 2011).

*Palliative Care Nursing: Quality Care to the End of Life*, in its first through fourth editions, was written as a contribution to the initiatives of the nursing profession regarding palliative care. This text is applicable to students, educators, and practicing nurses. Nursing students enrolled in advanced practice palliative care master's programs, including nurse practitioner, postmaster's certificate, and clinical nurse specialist programs, will find this book an asset in providing care to patients with complex physical, emotional, social, and spiritual needs across health care settings. With knowledge of advanced pathophysiology, pharmacology, and physical assessment, advanced practice palliative care nurses can prescribe a vast array of pharmacological and nonpharmacological interventions that are discussed in this book. Throughout the illness and dying trajectory, graduate nurses also



assume leadership roles, as members of interprofessional palliative-care teams develop standards of care, clinical guidelines, and health care policies, and serve as consultants in the development of clinical practice, education, and research initiatives. Advanced practice palliative care nurses also educate and mentor undergraduate-prepared nursing colleagues and participate in or develop research proposals to support evidence-based practice. The information presented in this text therefore will serve as a foundation to advanced palliative care competencies.

This text emphasizes the importance of a holistic perspective and an understanding of the patient and family as individuals with diverse needs and expectations. Section I introduces the reader to palliative care, its responsiveness to health care reform in America and internationally, as well as the ethical and legal issues related to palliative care. In Section II, the holistic care of patients and families is addressed with consideration of cultural, spiritual, and sexual needs, the importance of focusing care on not only patients but also their family caregivers, communication as a central tenet to quality care, and the needed support through the many stages of loss and grief. Section III covers the physical aspects of living with serious, life-threatening illness, specifically information related to various disease states such as cancer, end-stage organ diseases, neurological disorders, and HIV/AIDS. Section IV addresses the assessment and management of pain and symptoms associated with acute, chronic, and progressive illness. The authors believe that decisions regarding physical interventions must be addressed based on knowledge of the spiritual, social, and psychological beliefs, values, expectations, and wishes of the patient and family.

With the largest number of health care professionals in the country, nurses can capitalize on the individual's desire for autonomy and control of his or her life by reinforcing the importance and value of actively participating in the decisions throughout the illness trajectory and at the end of life. As nurses

frame the discussion of illness as well as dying and death within the context of hope and meaning and as an opportunity for choices and continued achievement of goals, uncertainty is replaced with certainty, hopelessness with faith, and despair with empowerment. The possibility exists that illness, dying, and death are meaningful and significant acts of life, which inform us about what is important in life and direct us how to live life.

This text emphasizes that palliative care is a humanistic imperative to ensure that quality of life is promoted during all phases of the illness experience for both patients and their family caregivers (Sherman & Cheon, 2012) as well as an economic imperative in reducing the cost of health care. Palliative care nurses advance the science and the art of palliative care through clinical practice, administration, research, education, and advocacy. With a focus on ensuring quality care within the context of a changing health care environment, palliative care and hospice nurses promote the awareness of palliative and hospice care, acknowledgment of its value to patients and families and the health care community, ways of promoting access to care, and actions to ensure the integration of palliative care into the health care system.

“Palliative care ensures that the person is viewed in his or her entirety, not as a collection of organs and medical problems” (National Palliative Care Research Center, 2011, p. 12). As leaders of health care, palliative care nurses have the knowledge and skills to bring together patients, families, communities, health institutions and practitioners, legislators, payers, and insurers to move us ahead by advancing local, national, and global palliative care initiatives. Palliative care is responsive to health care reform in America and palliative care nurses play a leading role to ensure quality of life for patients and families across the illness trajectory.

*Deborah Witt Sherman & Marianne Matzo*

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# Palliative Care Nursing





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# Understanding Palliative Care

S E C T I O N





# The Interprofessional Practice of Palliative Care Nursing

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## KEY POINTS

- The standards of practice in hospice and palliative care nursing describe a competent level of generalist and advanced practice registered nursing care as demonstrated by the nursing process, involving assessment, diagnosis, outcome identification, planning, implementation, and evaluation.
- The standards of professional performance describe competent professional role behaviors, including activities related to quality of practice, education, professional practice evaluation, collegiality, collaboration, ethics, research, resource utilization, and leadership.
- Hospice and palliative nurses' professionalism is enhanced through membership in their professional organizations, certification in their specialty, and professional development through academic and continuing education.
- In order to deliver quality, comprehensive, whole-person care, the goals of curative and palliative care (PC) are woven together concurrently and delivered throughout the disease continuum.
- The foundation for the PC philosophy and PC nursing is family-centered care, where the patient and family rather than the disease are the primary focus.
- Excellent PC embraces cultural, ethnic, and faith differences and preferences while interweaving the principles of ethics, humanities, and human values into every patient and family care experience.
- A core value of PC is the commitment to collaborate through an interprofessional process. Understanding the distinction between interprofessional and multidisciplinary practice is imperative for successful delivery of PC.
- A dynamic and outcome-oriented interprofessional team requires collaboration, leadership, coordinated decision making, and conflict resolution.

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## CASE STUDY

In May 2014, Rose graduated from an accredited master's-level program as an adult nurse practitioner. After American Nursing Credentialing Center certification, Rose decided to enroll in a post-master's palliative care (PC) program and became a member

of the Hospice and Palliative Nurses Association (HPNA). With 500 clinical hours in PC, Rose had achieved the required hours of practice in PC; thus, she sought the opportunity to become certified in hospice and palliative nursing by the National Board for Certification of Hospice and Palliative Nursing. One patient that Rose will never forget was Ms. K., a divorced 58-year-old woman with metastatic ovarian cancer with malignant bowel obstruction transitioning out of the hospital to home. Rose was a member of the Palliative Care Consult team when Ms. K. was admitted to the hospital with nausea, projectile vomiting, and severe abdominal pain. She was diagnosed with a partial bowel obstruction, secondary to recurrence of her cancer, and initially treated with a nasogastric (NG) tube, intravenous octreotide, and opioids for pain. On day 4, Ms. K. requested removal of the NG tube, because “the tube hurts worse than my stomach pain did.” After much discussion with the interprofessional team, Rose was able to advocate for Ms. K.’s desire to have the NG tube removed and receive palliative medication. Rose told Ms. K. that the team was concerned that she would begin frequent vomiting again after the tube removal, but Ms. K. wanted to continue only the medication.

On her next assessment, Rose asked Ms. K. what else she needed. Ms. K. said, “I need to get home as soon as possible.” When asked about her sense of urgency, as the vomiting was still not under control, Ms. K. replied, “I feel so much better having the tube out, and just vomiting one time per day or so. I also don’t have much time left. I want to label all of my things at home to give away, so there is no fighting among my family. And I need to list out important prayers and songs for my funeral. My son is in the Army, and I don’t want to burden him with these decisions.” She added tearfully, “I’m not sure I will even see him again.”

The scope of hospice and palliative care nursing continues to evolve as the science and art of palliative care (PC) develop. Hospice and palliative care nursing reflects a holistic philosophy of care implemented across the life span and across diverse health settings. In a matrix of affiliation, including the patient and family and other members of the interprofessional team, hospice and palliative care nurses provide evidence-based physical, emotional, psychosocial, and spiritual or existential care to individuals and families experiencing life-limiting, progressive illness. The goal of hospice and PC nursing is to promote and improve the patient’s quality of life (QOL) through the relief of suffering along the course of illness, through the death of the patient, and into the bereavement period of the family (Hospice and Palliative Nurses Association [HPNA], 2011). In assessing a patient with advanced illness and acute, severe symptoms, it is important that goals of care, which encompass physical, spiritual, and psychosocial issues, be addressed. Once immediate physical symptoms are managed or improved, the interprofessional team needs to elicit the patient’s goals of care so as to most efficiently implement a care plan that reflects the patient’s priorities.

This chapter describes the evolution of hospice and palliative care nursing, including the scope, standards, and competencies of this nursing specialty. The value of nurses as members of the interprofessional team and the complex dimensions of the nursing role in hospice and palliative care is presented.

The field of PC is one response to the changing profile of death in the 20th century, as it focuses on the prevention and relief of suffering through the management of pain and other symptoms and attention to the emotional, spiritual, and practical needs of patients and family from the early to the final stages of an illness (Field & Cassel, 1997). PC builds upon the template of hospice care, with hospice care now recognized as a type of PC that is offered toward the EOL. PC is the combination of active and compassionate therapies intended to comfort and support individuals who are living with and dying from life-threatening illness. The rise in hospice programs in the United States from 1 program in 1979 to more than 5,300 programs in 2011, along with a rise in the number of patients and families served from 128,000 in 1985 to 1.65 million in 2011, support the projection of future needs for hospice/palliative care services (National Hospice and Palliative Care Organization [NHPCO], 2012).

Hospice and palliative nursing is provided for patients and their families in a variety of care settings, including, but not limited to, acute care hospital units, long-term care facilities, assisted-living facilities, inpatient, home or residential hospices, PC clinics or ambulatory settings, private practices, and prisons. Practice settings for palliative and hospice care nursing are changing in response to the dynamic nature of today’s health care environment.



Hospice and palliative care nurses are licensed, registered nurses who are educationally prepared and are qualified for specialty practice at two levels: generalist and advanced. These levels are differentiated by educational preparation, complexity of practice, and performance of certain nursing functions.

Hospice- and palliative-licensed practical/vocational nurses are also educationally prepared and licensed, but at a different level of complexity in their practice. Hospice and palliative nursing assistants are educationally prepared through local- and state-mandated processes to meet the requirements of the specific setting in which they function. These requirements differ significantly across the United States, although hours-of-education requirements are specifically defined in the home care, hospice, and long-term care settings on a national basis. There are no licensure requirements for the nursing-assistant level of hospice and palliative caregiver.

According to an article entitled “History of the Hospice Nurses Association, 1986–1996” (Amenta, 2001), the founding of the Hospice Nurses Association (HNA) occurred as follows:

[I]n spring 1986 a group of nurses attending the Third Western Hospice Nursing Conference sponsored by the Hospice Organization of Southern California in San Diego, frustrated by the failure of national groups to develop adequate standards and networking structures for hospice nurse, put out the call to start a national hospice nursing organization. (p. 13)

Membership in the organization grew rapidly. In 1998, the word “palliative” was added to the organization’s name, now known as the Hospice and Palliative Nurses Association. By the year 2000, 2,800 nurses had joined this growing organization. With a pattern of continued growth, membership to date has reached more than 10,000 (HPNA, 2013). The mission of HPNA relates to providing leadership in the specialty by:

- Promoting the highest professional standards of hospice and palliative nursing
- Studying, researching, and exchanging information, experiences, and ideas leading to improved nursing practice
- Encouraging nurses to specialize in the practices of hospice and palliative nursing
- Fostering the professional development of nurses, individually and collectively
- Responding to the changing needs of HPNA members and the population they represent
- Promoting the recognition of hospice and palliative care as essential components within the health care system

## ■ EVOLUTIONARY PERSPECTIVE OF HOSPICE AND PALLIATIVE CARE NURSING

Nationally, there has been a growing interest in palliative and hospice care and an emphasis on the education of health professionals in this area. Billings and Block (1997), in the early years of the specialty of PC, identified the following forces that have increased national attention regarding PC:

1. A growing interest in death and dying
2. The development of hospice programs
3. Increasing integration of pain and symptom management into conventional care
4. Concern about the high cost of dying
5. Increasing national focus on pain management
6. Greater attention to the role of medicine in caring rather than curing
7. National debates on physician-assisted suicide and euthanasia

These factors combined to create a dramatically increased demand for health care providers, including nurses, who are educated at all levels to provide expert, comprehensive palliative and hospice care.

The landmark “Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment” (SUPPORT; SUPPORT Study Investigators, 1995) highlighted an urgent need for health care professionals who were prepared and committed to improving the QOL of seriously ill and dying patients and their families. The findings indicated a lack of communication between patients and their providers, particularly related to EOL preferences, aggressiveness of medical treatments, and a high level of reported pain by seriously ill and dying patients. The SUPPORT Study Investigators (1995) believed that improving the experience of seriously ill and dying patients requires an individual and collective commitment of health care providers, as well as proactive efforts at shaping the caregiving process.

In 1997, the Institute of Medicine (IOM) released a significant report entitled *Approaching Death: Improving Care at the End of Life* (Field & Cassel, 1997). This report identified gaps of knowledge regarding the care of the seriously ill or dying. Based on this report, Field and Cassel reiterated that “the need for consensus and action to improve care for those approaching death is growing more urgent” (p. 17). On average, Americans live longer than they did in the 19th century, with more than 70% of the population dying after the age of 65 years. According to the Centers for Disease Control and Prevention, the average life expectancy in the United States is nearly 78.7 years (CDC, 2013). Over the past 100 years, the leading causes of death have changed from primarily infectious processes to

chronic illnesses experienced by an aging population. Although some people die suddenly and unexpectedly, the dying process for many has been extended, with some individuals, such as those with cancer, facing a steady and fairly predictable decline, whereas others have long periods of chronic illness punctuated by crises that are often fatal (Field & Cassel, 1997). The result is a national increase in the number of individuals who require PC.

Although hospice and palliative care has been delivered mainly to patients with cancer, other patients with incurable diseases are also candidates for these services, including the growing number of older adults, those suffering from chronic diseases such as cardiovascular, pulmonary, neurological, and renal disease, as well as patients with AIDS (Doyle, Hanks, Cherney, & Calman, 2001; Mitchell, Noble, Finlay, & Nelson, 2012; Haley, 2013). More recently, the IOM collaborated with the National Cancer Policy Board and the National Research Council to release a follow-up report called *Improving Palliative Care for Cancer* (Foley & Gelband, 2001), which further supports the need for changes in care of the dying. The report details the undertreatment of distressing symptoms resulting from continued deficiencies in the training of health care professionals.

In the IOM report titled *Crossing the Quality Chasm: A New Health System for the 21st Century* (Foley & Gelband, 2001), the IOM argued that professional associations should commit to professional development and competency enhancement by developing curricula, disseminating information, and promoting practice guidelines and standards related to hospice and palliative care. In April 2004, the standards and guidelines of PC were defined by the National Consensus Project (NCP) Steering Committee in its Clinical Practice Guidelines for Quality Palliative Care. This document was the culmination of 2 years of collaboration by 20 representatives from five leading national hospice and palliative care organizations, specifically the American Academy of Hospice and Palliative Medicine, Center to Advance Palliative Care, HPNA, NHPCO, and the former Last Acts organization. A need for consensus had been defined by practitioners to provide credible, broad-based guidelines for practice in an effort to standardize and improve the quality of PC in the United States. That need was affirmed when, in the first 2 weeks following publication, 90,000 copies of the guidelines were downloaded from the National Consensus website ([www.nationalconsensusproject.org](http://www.nationalconsensusproject.org)).

Based on the National Consensus Project Guidelines, the National Quality Forum (NQF, 2012) released *A National Framework and Preferred Practices for Palliative and Hospice Care Quality* in recognition of the services increasingly being rendered within the

health care system. This report endorsed the framework of preferred practices to improve hospice and palliative care and has been utilized as the first step in developing quality measures (NQF, 2012). Both documents attempt to formalize the concept of PC by providing extended descriptions and definitions differentiating PC from other types of care, and each structures the theory and practice of PC into eight domains. The domains of quality palliative care: (1) structure and processes of care; (2) physical aspects of care; (3) psychological and psychiatric aspects of care; (4) social aspects of care; (5) spiritual, religious, and existential aspects of care; (6) cultural aspects of care; (7) care of the imminently dying patient; and (8) ethical and legal aspects of care (National Consensus Project, 2013). The guidelines are for all settings in which the NQF framework has implications for reimbursement, development of quality measures, and accreditation. These documents are companion pieces serving to complement the process of improving PC quality (NCP, 2012). One of the baseline assumptions of the NCP guidelines is that the qualifications of caregivers are determined by the organizations that grant professional credentials and programmatic accreditation. As a specialty organization, the Hospice and Palliative Care Nurses Association has identified the scope and standards of hospice and palliative care nursing and the competencies at all levels of nursing practice, specifically nursing assistants, licensed vocational nurses, professional registered nurses, and advanced practice nurses.

## ■ EDUCATIONAL PREPARATION

It has been recognized that educational preparation for EOL care is inconsistent at best, and neglected for the most part, in both undergraduate and graduate curricula (American Association of Colleges of Nursing [AACN], 1997). In accordance with the International Council of Nurses' mandate that nurses have a unique and primary responsibility for ensuring the peaceful death of patients, the AACN, supported by the Robert Wood Johnson Foundation, convened a roundtable of expert nurses to discuss and initiate educational change related to PC. It was concluded that precepts underlying hospice care are essential principles for all EOL care. Such precepts include the assumptions that persons are living until the moment of death; that coordinated care should be offered by a variety of professionals with attention to the physical, psychological, social, and spiritual needs of patients and their families; and that care should be sensitive to patient and family diversity. It was proposed that these precepts be foundational to the educational preparation of nurses. Based on these precepts, the



document entitled *Peaceful Death* was developed, which outlined baccalaureate competencies for palliative and hospice care and content areas where competencies can be taught (AACN, 1997).

Emphasizing the role of nursing in EOL care, the American Nurses Association formulated a position statement regarding the promotion of comfort and relief of pain of dying patients, reinforcing nurses' obligation to promote comfort and ensure aggressive efforts to relieve pain and suffering. Specialized PC educational initiatives began in medicine and nursing, such as Education for Physicians on End of Life Care (EPEC) and the nursing initiative End of Life Nursing Education Consortium (ELNEC). The original goal of ELNEC was to train nurse educators from associate and baccalaureate programs. The ELNEC curriculum has also been modified and specialized for graduate education, geriatrics, pediatrics, oncology, and for veterans.

### ■ DEVELOPING THE SCOPE, STANDARDS, AND COMPETENCIES OF PALLIATIVE AND HOSPICE NURSING PRACTICE

By developing and articulating the scope and standards of professional nursing practice, the specialty defines its boundaries, informs society about the parameters of nursing practice, and guides the development of rules and regulations for the specialty. As in all nursing specialties, PC nurses must accept professional practice accountability and ensure that their practice remains within the scope of their state's Nurse Practice Act, their professional code of ethics, and professional practice standards.

To ensure provision of quality hospice and palliative nursing care, standards have been defined by a credible body of peers who were charged with this responsibility. The standards of hospice care were defined by the NHPCO in 1986. The standards of hospice and palliative nursing practice were first defined by the HNA in 1995, with subsequent revisions to the name of the organization to include PC. Scope and standards of hospice and palliative nursing care define the body of knowledge needed in terms of the standards of practice and the standards of performance. Standards of practice refer to the basic level of care that should be provided to all hospice and palliative care patients and families. Standards of performance for palliative and hospice care nurses describe the standards for activities related to quality of care, performance appraisal, education, collegiality, ethics, collaboration, participation in research, and resource utilization. Documents such as agency standards, guidelines, policies, procedures, and protocols may further direct the individual's performance. Standards

are defined in broad terms to define the scope of the specialty of palliative and hospice care nursing.

The standards of palliative and hospice care nursing practice are authoritative statements described by the HPNA for the nursing profession, which identifies the responsibilities for which palliative and hospice care nurses are accountable. Standards reflect the values and priorities of PC nursing and provide a framework for the evaluation of practice. The standards are written in measurable terms and define palliative and hospice care nurses' accountability to the public and the individual and family outcomes for which they are responsible.

Standards remain stable over time, as they reflect the philosophical values of the profession; however, the criteria should be revised to incorporate advancements in scientific knowledge, technology, and clinical practice. Criteria must be consistent with current nursing practice and reflect evidence-based practice.

### Standards of Practice

Standards of practice (HPNA, 2007) describe a competent level of generalist and advanced practice registered nursing care as demonstrated by the nursing process, involving assessment, diagnosis, outcomes identification, planning, implementation, and evaluation. The development and maintenance of a therapeutic nurse-patient and family relationship is essential throughout the nursing process. The nursing process forms the foundation of clinical decision making and encompasses all significant actions taken by hospice and palliative care nurses in providing care to individuals and families. The precepts of nursing practice include the following:

1. Providing age-appropriate, culturally, ethnically, and spiritually sensitive care and support
2. Maintaining a safe environment
3. Educating patients and families to identify appropriate settings and treatment options
4. Assuring continuity of care and transitioning to the next appropriate setting
5. Coordinating care across settings and among caregivers
6. Managing information and protecting confidentiality
7. Communicating promptly and effectively

A fundamental practice focus for hospice and palliative care is the plan of care, which is developed with the patient and family as the unit of care and members of the interprofessional team. At the very minimum, the interprofessional team includes the physician, nurse, social worker, and clergy. Care responsibilities extend beyond the death of the patient and offers



bereavement care to families for a minimum of 1 year. Relief of suffering and QOL for individuals and families are enhanced by:

- Providing effective pain and symptom management
- Addressing psychosocial and spiritual needs of patient and family
- Incorporating cultural values and attitudes in developing a plan of care
- Creating a healing environment to promote a peaceful death
- Supporting those who are experiencing loss, grief, and bereavement
- Promoting ethical and legal decision making
- Advocating for personal wishes and preferences
- Utilizing therapeutic communication skills in all interactions
- Facilitating collaborative practice
- Ensuring access to care and community resources through influencing and developing health and social policy
- Contributing to improved quality and cost-effective services
- Creating opportunities and implementing initiatives for PC education for patients, families, colleagues, and community
- Participating in the generation, testing, and evaluation of PC knowledge and practice

Registered nurses at the generalist level have completed a nursing program and passed the state licensure examination for registered nurses. Registered nurses who practice in PC settings may provide direct patient and family care, and may function as educators, case managers, administrators, and in other nursing roles. Advanced practice nurses develop and implement advanced plans of care based on the synthesis of complex health-assessment data. Advanced practice nurses are expert clinicians, leaders, educators, consultants, and researchers. The standards apply to both generalist and advanced practice nurses. There is specific notation of standards that apply only to the advanced practice nurse.

**Standard 1: Assessment.** The hospice and palliative registered nurse collects comprehensive data pertinent to the patient's health or the situation.

**Standard 2: Diagnosis.** The hospice and palliative registered nurse analyzes the assessment data to determine nursing diagnoses or issues.

**Standard 3: Outcome identification.** The hospice and palliative registered nurse, in partnership with the interprofessional health care team, identifies expected outcome for a plan of care individualized to the patient or the situation.

**Standard 4: Planning.** The hospice and palliative registered nurse develops a plan of care that

describes strategies and alternatives to attain expected outcomes.

**Standard 5: Implementation.** The hospice and palliative registered nurse implements the identified plan of care.

**Standard 5A: Coordination of care.** The hospice and palliative registered nurse coordinates care delivery.

**Standard 5B: Health teaching and health promotion.** The hospice and palliative registered nurse employs strategies to promote health and a safe environment.

**Standard 5C: Consultation.** The hospice and palliative registered nurse and the nursing role specialist provide consultation to influence the identified plan, enhance the abilities of others, and effect change.

**Standard 5D: Prescriptive authority and treatment.** The advanced practice hospice and palliative registered nurse uses prescriptive authority, procedures, referrals, treatments, and therapies in accordance with state and federal laws and regulations.

**Standard 6: Evaluation.** The hospice and palliative registered nurse evaluates progress toward attainment of outcomes.

## Standards of Professional Performance

Standards of professional performance (ANA and HPNA, 2013) and the associated measurement criteria describe professional role behaviors, including those related to ethics, education, evidence-based practice and research, quality of practice, communication, leadership, collaboration, professional practice evaluation, resource utilization, and environmental health. Hospice and palliative nurses must be self-directed and purposeful in seeking necessary knowledge and skills to develop and maintain their competency. Hospice and palliative nurses' professionalism is enhanced through membership in their professional organizations, certification in their specialty, and professional development through academic and continuing education.

**Standard 7: Ethics.** The hospice and palliative registered nurse integrates ethical provisions in all areas of practice.

**Standard 8: Education.** The hospice and palliative registered nurse attains knowledge and competency that reflects current hospice and palliative nursing practice.

**Standard 9: Evidence-based practice and research.** The hospice and palliative registered nurse integrates research findings into practice and generates new knowledge related to the specialty.

**Standard 10: Quality of practice.** The hospice and palliative registered nurse systematically enhances the quality and effectiveness of nursing practice.

**Standard 11: Communication.** The hospice and palliative registered nurse communicates effectively with members of the interprofessional team and contributes to the professional development of peers and colleagues.

**Standard 12: Leadership.** The hospice and palliative registered nurse provides leadership in the professional practice setting and the profession.

**Standard 13: Collaboration.** The hospice and palliative registered nurse collaborates with the patient, the family, the interprofessional team, and others in the conduct of nursing practice.

**Standard 14: Professional practice evaluation.** The hospice and palliative registered nurse evaluates one's own nursing practice in relation to professional practice standards and guidelines, relevant statutes, rules, and regulations.

**Standard 15: Resource utilization.** The hospice and palliative registered nurse considers factors related to safety, effectiveness, cost, and impact on practice in the planning and delivery of nursing services.

**Standard 16: Environmental health.** The hospice and palliative promotes a healthy environment.

Standards of Practice and Standards of Professional Performance are also written for palliative- and hospice-licensed practical/vocational nurses and for palliative and hospice nursing assistants. Variations to each standard are made to adapt to scopes of practice and statutory regulations.

## Competencies

According to HPNA (2007), competencies represent the “quantifiable knowledge, attitudes, and skills that practitioners demonstrate in the performance of safe, consistent, compassionate, state-of-the-art, evidence-based EOL care, which conforms to the patients’ and their families’ wishes.” This definition applies to all levels of nursing practice, although the specific clinical judgments and core competencies vary with each level. The competencies for the palliative and hospice generalist and advanced practice nurse were initiated in 2001. Subsequently, competencies for the palliative- and hospice-licensed practical/vocational nurse and nursing assistant were also written.

The basic competencies of PC nursing represent the knowledge, skills, and attitudes demonstrated when providing evidence-based physical, emotional, psychosocial, and spiritual care. The care is provided in a collaborative manner across the life span in diverse settings to individuals and families experiencing progressive illness. The generalist-level competencies and the related general statements are written as follows with special notation when applicable only for advanced practice nurses.

**Clinical judgment.** At the generalist level, the palliative and hospice nurse demonstrates critical thinking, analysis, and clinical judgment in all aspects of palliative and hospice care of patients and families experiencing life-limiting illness through the use of the nursing process to address the physical, psychosocial, and spiritual/existential needs of patients and families. At the advanced practice level, the palliative and hospice nurse must be able to respond to all disease processes with advanced clinical skills.

**Advocacy and ethics.** The palliative and hospice nurse incorporates ethical principles and professional standards in the care of patients and families who are experiencing life-limiting illnesses or progressive illness, as well as identifying and advocating for their wishes and preferences. Promoting ethical and legal decision making, advocating for personal wishes and preferences, and ensuring access to care and community resources through influencing or developing health and social policy are ways for the nurse to incorporate ethical principles and professional standards in the care of patients and their families.

**Professionalism.** The palliative and hospice nurse demonstrates knowledge, attitude, behavior, and skills that are consistent with the professional standards, code of ethics, and scope of practice for palliative and hospice nursing.

**Collaboration.** The palliative and hospice nurse actively promotes dialogue with patients and families, the health care team, and the community to address and plan for issues related to living with and dying from chronic, life-limiting progressive illness.

**Systems thinking.** The palliative and hospice nurse utilizes resources necessary to enhance QOL for patients and families experiencing life-limiting progressive illness through knowledge and negotiation within the health care system.

**Cultural competence.** The palliative and hospice nurse demonstrates cultural competence by respecting and honoring the unique diversity and characteristics of patients, families, and colleagues in palliative and hospice care.

**Facilitation of learning.** The palliative and hospice nurse facilitates learning of patient, family, self, members of the health care team, and the community through the development, implementation, and evaluation of formal and informal education related to living with and dying from life-limiting progressive illnesses.

**Communication.** The palliative and hospice nurse demonstrates the use of effective verbal, nonverbal, and written communication with patients and families, members of the health care team, and the community in order to address therapeutically and convey accurately the palliative and hospice care needs of patients and families.



Advanced practice hospice and palliative nurses are held to the same competencies but at an advanced level because they exercise a high degree of critical thinking, analysis, and independent judgment, within the framework of autonomous and collaborative interprofessional practice. Advanced practice nurses are distinguished by their ability to synthesize complex data, implement advanced plans of care, and provide leadership in palliative and hospice care. The roles of the advanced practice hospice and palliative nurse include, but are not limited to, expert clinician, leader, or facilitator of interprofessional teams, educator, researcher, consultant, collaborator, advocate, and administrator. Advanced practice palliative and hospice nurses who have fulfilled the requirements established by their state's Nurse Practice Acts may be authorized to assume autonomous responsibility for clinical role functions, which may include prescription of controlled substances, medications, or therapies. To practice as an advanced practice palliative and hospice nurse, national certification in advanced practice palliative and hospice nursing is recommended, although it is recognized that the advanced practice palliative and hospice nurse may have concurrent advanced practice certification in another specialty.

Competencies for the licensed practical nurse focus on decision making instead of clinical judgment. For the nursing assistant, clinical judgment is rooted in observation and reporting. Although the core competencies are very similar in all four levels of nursing, the criteria are specific to the various scopes of practice.

## ■ CERTIFICATION IN HOSPICE AND PALLIATIVE CARE NURSING

Incorporated in 1987, the HNA became the first professional nursing organization dedicated to promoting excellence in the practice of hospice nursing. In March 1994, the National Board for the Certification of Hospice Nurses (NBCHN) offered the first certification examination and the credential of Certified Registered Nurse Hospice (CRNH). In 1999, the NBCHN became the National Board for Certification of Hospice and Palliative Nurses (NBCHPN), offering a new designation to recognize base competence in hospice and palliative nursing: Certified Hospice and Palliative Nurse (CHPN). For the licensed generalist, it is recommended to have a minimum of 2 years of clinical experience in palliative and hospice care. By 2013, (Hospice and Palliative Nurses Association, 2013) more than 11,000 registered nurses were certified as CHPNs.

Recognizing the need to offer an examination for advanced practice hospice and palliative nurses, in 2000 the NBCHPN began discussions with New York University and the American Nursing Credentialing Center (ANCC) to collaborate for this purpose. In an effort to expand the portfolio of examinations, NBCHPN successfully negotiated a buy-out of the partnership with American Nursing Credentialing Center effective December 2004 and has been successfully certifying these nurses as Advanced Certified Hospice and Palliative Nurses (ACHPN). Eligibility for this level includes having a current unrestricted registered nurse license; graduation from an accredited institution granting graduate-level academic credit for a master's or higher degree in nursing; and having a minimum of 500 hours of supervised advanced practice in PC as a Clinical Nurse Specialist or Nurse Practitioner. As of 2013, (HPNA, 2013) nearly 800 individuals are certified ACHPNs.

Through a commitment to a strategic plan to provide certification for all levels of caregivers, NBCHPN began certifying nursing assistants in hospice and palliative care in 2001 as Certified Hospice and Palliative Nursing Assistant (CHPNA). To be eligible for the examination, the nursing assistant must have a minimum of 2,000 hours in palliative and hospice care as validated by the nursing supervisor. By 2013, nearly 4,000 nursing assistants were certified as CHPNAs. Continuing with the strategy of providing certification for all levels of caregivers, NBCHPN in 2002 began the process of developing the scope, standards, and competencies for the licensed practical/vocational hospice and palliative nurse. To be eligible for the examination, the palliative and hospice practical/vocational nurse (CHPLN) must be licensed, and it is recommended to have 2,000 clinical hours in the prior 2 years. In 2013, (HPNA, 2013) more than 1,000 CHPLNs had successfully completed the certification requirements.

Certification, as defined by the American Board of Nursing Specialties (ABNS), is "the formal recognition of the specialized knowledge, skills, and experience demonstrated by the achievement of standards identified by a nursing specialty to promote optimal patient care." Certification is valued for the following reasons:

- Certificates achieve a tested and proven competency across the spectrum of hospice and palliative care
- Certificates increase their knowledge of hospice and palliative care by seeking and maintaining certification
- Certificates demonstrate a commitment to their specialty practice by pursuing certification



- Certificates demonstrate dedication to professional development in their careers by attaining the credential
- Certificates are assets to themselves because the commitment to certification improves patient outcomes, provides compensation incentives, and gains industry-wide recognition
- Certificates are assets to their employers because certification is a recognized quality marker by patients, physicians, providers, quality organizations, insurers, credentialers, and the federal government in an atmosphere of increasing awareness regarding quality in health care and appropriate utilization of services

## ■ PRINCIPLES OF PALLIATIVE CARE

A core principle of PC across the entire disease spectrum and in all settings is the concept that the patient and family constitute the unit of care. The patient and family, rather than the disease, are the primary focus of care. The constructs of family-centered care form the foundation of the PC philosophy. PC addresses the meaning of disease, suffering, life, and death within the context of each family unit (National Consensus Project, 2009). PC recognizes that each family member will experience the disease process and all of its implications within the context of his or her particular worldview, and individual care plans are developed to reflect these worldviews. Another core PC principle is the commitment to collaborate through an interprofessional team process (Cairns & Yates, 2003; Leslie, Adams, & Kutner, 2002; Meier & Beresford, 2008; National Consensus Project, 2013). In order to assist a family in crisis to establish and then achieve mutually agreed-upon goals, the PC team integrates and coordinates the assessment and interventions of each team member and creates a comprehensive plan of care.

Good PC is significant in the manner in which it embraces cultural, ethnic, and faith differences and preferences, while interweaving the principles of ethics, humanities, and human values into every patient- and family-care experience (Dy, Lupu, & Seow, 2012; Loscalzo & Zabora, 1998; Morrison & Meier, 2004). Furthermore, clinical ethics is an essential footprint for the provision of palliative and EOL care. Although clinicians often learn the theoretical principles behind ethics (Beauchamp, 2003; Beauchamp & Childress, 1994; Morrison & Meier, 2004; Dy, Lupu, & Seow, 2012), PC necessitates that these principles be incorporated into the practice or “put into motion” 24 hours a day, 7 days a week (Block, 2007; Bruera & Hui, 2012; Roy & MacDonald, 1998). PC embodies this concept of ethics in motion,

as each interprofessional team member, including patient and families, contemplates the ethical questions in advanced disease and in EOL decision making. Ethical challenges present themselves to the PC interprofessional team on an hourly basis.

## ■ PALLIATIVE CARE FRAMEWORKS

### Conceptual Model of Care

To relieve suffering, PC nursing utilizes a conceptual framework for palliative and EOL care practice. An effective model of care for the delivery of palliative nursing, adapted from hospice nursing, is Dame Cicely Saunders’s conceptual model of “whole-person” suffering. Saunders espouses that whole-person suffering has four dimensions: physical, psychological, spiritual, and social (Krammer, Muir, Gooding-Kellar, Williams, & von Gunten, 1999; Mount, Hanks, & McGoldrick, 2006; World Health Organization, 2007). Under this concept, suffering affects each domain of the bio-psycho-social-spiritual aspects of care. This conceptual model forms the basis for the description of PC nursing practice in this chapter.

### Delivery Model of Care

Within the traditional medical model of care lies a perceived dichotomy between curative/death-defying care and PC. It is almost as though the goal of care is *first* and *only* cure; and then, only if unable to cure, to relieve suffering. Often, this perceived dichotomy prevents or delays the introduction of PC measures for patients and their families. For provision of quality, comprehensive, whole-person care, should not the goals of curative and palliative care be woven together concurrently? It would seem to be generally appropriate to relieve suffering *at the same time* as pursuing curative life-prolonging therapies (Ferrell et al., 2007; Von Gunten & Muir, 2000; World Health Organization, 2007).

An effective framework for the delivery of PC throughout the disease continuum can be most readily visualized as an “umbrella of care.” Debate exists as to the beginning and end of the umbrella’s arch. For some health care clinicians, PC starts with the initial diagnosis of an illness, at which time the management of symptoms and the psychosocial stressors of the disease upon the patient and family are vigorously addressed with active curative-focused therapy. Although this scope may be considered ideal, the majority of PC providers emphasize the maximization of function and QOL in those with far-advanced disease. For all providers, PC culminates in the management of complex physical, psychological, social, and spiritual issues that

patients and members of their families will experience during the final phase of life and will include bereavement care for the family (Dy, Lupu, & Seow, 2012; Krammer et al., 1999; Twycross, 2003).

With the emergence of PC as a distinct medical specialty (Cairns & Yates, 2003; Enck, 2009; Leslie, Adams, & Canter, 2002; Von Gunten & Lupu, 2004), an ever growing number of hospitals have begun to develop comprehensive, academic PC programs (Carlson et al., 2011; Elsayem et al., 2004; Ferrell et al., 2007; Morrison, Maroney-Galin, Kralovec, & Meier, 2005), consisting of one or all of the following program elements: acute PC inpatient units (Carlson et al., 2011; Ferrell et al., 2007; Santa-Emma, Roach, Gill, Spayde, & Taylor, 2002); palliative consultation teams (Carlson et al., 2011; Ferrell et al., 2007; Virik & Glare, 2002); outpatient PC clinics (Carlson et al., 2011; Strasser et al., 2004); and home hospice programs. By providing a continuum of care, patients with advanced progressive disease and their families have access to PC expertise in all settings, which is coordinated and collaborative manner to achieve mutually established goals. With a comprehensive PC program, the interprofessional team will utilize the same philosophy and model of care as they work throughout the continuum with the patient and family in a coordinated and collaborative manner to achieve mutually established goals.

## The Interprofessional Team

PC's reliance upon the interprofessional team as a key factor for successful outcomes requires an understanding of the distinction between interprofessional and multidisciplinary practice. In the traditional multidisciplinary team, the physician primarily directs care of the patient, and the family needs may or may not be considered (see Table 1.1). Multiple disciplines of the health care team may be involved in the individual assessments and in the delivery of care, although efforts by these team members are often uncoordinated and independent. The primary mode of communication among disciplines is the medical chart. The result is often incomplete communication between professions, lack of accountability, and tendency for each discipline to develop its own patient care goals. Family needs are often unidentified and most often are not incorporated into the overall plan of care.

In contrast, in an interprofessional model, communication and decision making among team members is collaborative, with leadership shared and based upon primary patient and family needs and goals (Crawford & Price, 2003; O'Connor & Fisher, 2011). The identity of the interprofessional team supersedes personal identities and agendas (Cummings, 1998; Porchet,

2006; O'Connor & Fisher, 2011), and the concept of the "whole is greater than the sum of its parts" is valued and respected. The interprofessional model facilitates team members to (a) directly interact with the patient and family, (b) share information among team members, (c) provide consultation to one another, and (d) work interdependently together to achieve the goals identified by the patient and family.

Table 1.1 lists the most common members of the PC interprofessional team, explains their function within the team, and discusses their interrelationship with the PC nurse. As a coordinator of care and a core member of the interprofessional team, the nurse has the responsibility to spearhead the development of therapeutic relationships, not just between him-/herself and the patient and family, but also with all pertinent members of the team, which in turn ensures effective and goal-driven supportive communication and patient outcomes. The PC nurse needs to continually reassess the goals of the patient and family, their treatment preferences, and support. A hallmark of quality PC is the collaborative role that the nurse develops with the physician and other interprofessional team members. Often, the physician has had a long-term relationship with the patient and family, and as the needs for traditional medical model "curative" care lessen and PC measures increase, this may represent a "loss" for the physician. As the nurse develops a relationship with the patient and family, the collaborative relationship with the physician may also be a source of support for the physician personally as well as professionally for decision making. The nurse is a primary conduit for information, critical assessments, and evaluation of the patient and family goals within the interprofessional team. A critical aspect of PC involves the identification and subsequent resolution of often divergent goals of the patient, family, or the health care team. The PC nurse is often in the ideal position to be instrumental in coordinating and effecting a comprehensive family-focused plan of care.

## ■ Characteristics of an Effective Interprofessional Team.

A dynamic and outcome-oriented interprofessional team requires collaboration, leadership, coordinated decision making, and conflict resolution. *Collaboration* is defined as the ability to work with others, especially on intellectual endeavors (Merriam-Webster, 2013). It is the process of collaboration that empowers team members to act as decision makers within the group. For example, if a question on nausea and vomiting arises, various members of the team may provide observations and opinions in an effort to maximize the relief of all components of nausea and vomiting. Using a true collaborative process, the ultimate decision maker regarding this aspect of care would not come to a conclusion solely benefiting one member or



**TABLE 1.1 The Interprofessional Team Member's Role, Function, and Interrelationship With the Palliative Care Nurse**

<b>Advanced Practice Nurse</b>
<p><i>Function:</i> Incorporates the role of advanced clinician, educator, researcher, and consultant to families, staff, colleagues, and communities</p> <p><i>Interrelationship:</i> Acts as a consultant, educator, role model, and mentor to the palliative care (PC) nurse to synergistically achieve quality outcomes for patients and families</p>
<b>Bereavement Counselor</b>
<p><i>Function:</i> Identifies through interprofessional team assessment high-risk family members for bereavement and provides anticipatory grief counseling. Coordinates bereavement services for families, including counseling sessions, grief support groups, memorial services, and community outreach programs</p> <p><i>Interrelationship:</i> Relies on the PC nurse's assessment of the family upon a patient's death in order to begin bereavement care. Values the PC nurse's role in identifying high-risk family members for grief and bereavement</p>
<b>Patient/Family</b>
<p><i>Function:</i> The focus of care of the interprofessional team. The goals identified by the patient/family direct the participation of other members of the team</p> <p><i>Interrelationship:</i> The patient/family understands that the PC nurse is the coordinator of interprofessional care and continuously confers with the PC nurse regarding patient/family needs</p>
<b>Palliative Care Physician</b>
<p><i>Function:</i> Consults with primary care physician and collaborates with interprofessional team to provide expertise in pain management, communication, and treatment decisions at the end of life for patients and families</p> <p><i>Interrelationship:</i> Understands that the PC nurse has the greatest prolonged contact with the patient and family and relies upon the holistic assessment and interventions of the nurse in order to develop a comprehensive medical care plan in collaboration with the interprofessional team</p>
<b>Pastoral Care Counselor</b>
<p><i>Function:</i> Provides in-depth assessment of the spiritual needs of patient/family, including search for meaning and purpose of life. Acts as a liaison with community clergy and a resource for the interprofessional team regarding ethical questions, faith traditions, and world religions</p> <p><i>Interrelationship:</i> Respects the spiritual assessment of the PC nurse and is consulted when family issues require advanced assessment and intervention. Acts as a resource for PC nurse when needing to debrief after a difficult death or experience</p>
<b>Primary Care Physician</b>
<p><i>Function:</i> Initiates a relationship with the palliative care team with referral of a new patient/family. Provides a medical history of the patient's illness and any other pertinent medical and psychosocial information; continues to be the primary physician or transfers the role to the PC physician</p> <p><i>Interrelationship:</i> Assessments and interventions of the PC nurse and those of the interprofessional team are coordinated with the primary physician to establish a comprehensive plan of care for the patient and family</p>
<b>Social Worker</b>
<p><i>Function:</i> Provides history (via genogram) regarding the strengths, resources, and realities of patient/family system. Interventions include emotional support through individual, family, high-risk, and bereavement counseling. Provides referrals for families to the community as needed for social services</p> <p><i>Interrelationship:</i> Delivery of care involves ongoing collaboration with PC nurse who is continuously identifying psychosocial needs and outcomes of the patient and family</p>
<b>Therapies (Pharmacy, Occupational, Physical, Dietary, Speech, Art, Music, Touch, Massage)</b>
<p><i>Function:</i> Provide education and/or "hands-on" therapy of specialized discipline to maximize independence and quality of life of patient and family</p> <p><i>Interrelationship:</i> Participates in plan of care when consulted by PC nurse and reports outcomes of interventions through collaboration with the PC nurse</p>

(continued)



**TABLE 1.1 The Interprofessional Team Member's Role, Function, and Interrelationship With the Palliative Care Nurse (continued)**

<b>Volunteer</b>
<i>Function:</i> Gives time freely to contribute to patient and family needs by direct service, administrative support of the palliative care program, public relations, and community education <i>Interrelationship:</i> Reports observed family dynamics to the PC nurse to facilitate revision of plan of care if needed
<b>Volunteer Coordinator</b>
<i>Function:</i> Recruits, screens, educates, supervises, and retains volunteer staff to provide supportive services to patients and families <i>Interrelationship:</i> Plans assignments of volunteers based upon identified needs of family by the PC nurse; involves the PC nurse in volunteer training

one member's own perspective, but rather would make a decision reflecting the team's total input. Through collaboration, effective patient- and family-driven quality outcomes are achieved (Bruera & Hui, 2012; Dobrof, Heyman, & Greenberg, 2011; Porter-O'Grady, Alexander, Blaylock, Minkara, & Surel, 2006).

The principles and tenets of PC are applicable throughout the life span. From the very young to the older adult, each group faces unique circumstances as they endure a life-limiting illness (Bolmsjo, 2008; Browning & Solomon, 2005; Haley, 2013; Himelstein, Hilden, Morstad Boldt, & Weissman, 2004; Kapo, Morrison, & Liao, 2007; Malloy, Sumner, Virani, & Ferrell, 2007). An effective interprofessional team will attend to these particular needs and will include specialists as warranted by the distinctive characteristics of the patient and family. For example, in the setting of a pediatric patient, in addition to the core interprofessional team members, the interprofessional team may consist of pediatric specialists such as child life specialists, pediatric advanced practice nurses, and chaplains trained in pediatrics; whereas an elderly patient's interprofessional team may include, among others, physical and occupational therapists trained in the aging population, a geriatrician, and a geriatric nurse practitioner. It is the responsibility of the interprofessional team to continually assess and make changes in the interprofessional team members as appropriate.

PC differs from the traditional medical model in which the physician is the sole leader of the multidisciplinary team. In the PC model, leadership is filled by the member of the interprofessional team who is best educated and qualified to address and focus upon specific patient or family goals. In addition to achieving patient and family outcomes, leadership is essential to facilitate and optimize the professional potential of each team member's contribution (NCP, 2013).

Also, in the traditional multidisciplinary team, the physician, as team leader, is the primary decision maker for the care team. In contrast, in a true interprofessional team process, coordinated decision making

among team members is necessary to achieve quality patient and family outcomes. In order to sort out which member or members of the team would be the most appropriate in contributing to the decision-making process, the following questions, should be considered: "Who has the information necessary to make the decision?" "Who needs to be consulted before the decision is made?" "Who needs to be informed of a decision after it is made?" (Cummings, 1998; & Fisher, 2011; Porchet, 2006). Certain levels of decision making may be made by individual members of the team (e.g., titrating a pain medication based on patient needs), whereas other levels will require input from the entire team as a whole (e.g., developing a care plan). Poor, fragmented decision making results from failure to include appropriate team members in the decision-making process (Cummings, 1998; O'Connor & Fisher, 2011; Porchet, 2006).

Because of the interdependency among interprofessional team members, professional conflict will inevitably arise, which may be beneficial and stimulating to an interprofessional team. Respect and trust in each team member's skills, knowledge, expertise, and motivation are imperative. Lack of respectful conflict will result in group uniformity, which may stifle the creativity and the professional advancement and development of team members. Diverse ideas and opinions are often the impetus for innovative solutions for patient care problems, and in the process may deepen the professional dialogue within the team. However, conflict becomes destructive when it is personalized or viewed as a threat to a member's role. Thus, the art in managing conflict is not to avoid it, but to manage it effectively so that team members, patients, and families can receive its full benefits.

### The Nurse's Role in Interprofessional Care

The following case example is that of an advanced practice nurse (APN) bringing a specific and well-

defined set of qualities, knowledge, and judgments to caring for individuals and families facing serious, progressive or life-threatening illness. This includes advanced scientific and biophysical knowledge, analytical skills, and mastery of a broad repertoire of communication and interpersonal skills. Specialized knowledge and proficiency in the ability to incorporate ethics, humanities, cultural diversity, family, spiritual, and psychological issues into care are also demanded (Bruera & Hui, 2012; Coyne, 2003; Kuebler, 2003; Meier & Beresford, 2006).

The Calkin model of advanced nursing practice (Bryant-Lukosius, Dicenso, Browne, & Pinelli, 2004; Spross & Baggerly, 1989) serves as an excellent model on which to base PC advanced practice nursing. Calkin defines the clinical judgment abilities of three nursing practice levels as novice, expert by experience, and the master's-prepared nurse. The following case study illustrates Saunders's four dimensions of human suffering within the context of Calkin's model. The case study also demonstrates the APN subroles of expert clinician, educator, consultant, researcher, and

collaborator (Callaway, 2012; Chulk, 2008; Spross & Baggerly, 1989).

## ■ CONCLUSION AND FUTURE DIRECTIONS

PC is an emerging specialty within health care and nursing. The philosophy and delivery of PC transcends all areas of nursing where suffering accompanies illness. The PC nurse is a true leader within the interprofessional team and hence is in an ideal position to establish standards for consistent practice, foster education, and promote research. It is a professional privilege to be in the field of PC nursing, as it brings hopefulness to areas of EOL care that traditionally have been avoided—for example, ethics, pain, and human suffering. Equally applicable to the art of PC nursing practice is Thoreau's (1971) *prosen* in which he states: "It is something to be able to paint a picture, or to carve a statue, and to make a few objects beautiful. But it is far more glorious to carve and paint the atmosphere in which we work, to affect the quality of the day—this is the highest of the arts" (p. 90).

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## CASE STUDY

Mrs. S. is a 52-year-old woman who is suffering from the sequelae of Stage 4 metastatic breast cancer for the past 3 years. All curative interventions, including surgical resection, chemotherapy, radiotherapy, hormone therapy, and experimental therapy, have failed to halt the progression of her disease, which now affects her lung, liver, and bones, most notably her spine. Mrs. S.'s major distressing physical symptom is severe neuropathic pain, which radiates around her back to her abdomen. This pain has limited her ability to bathe, cook, eat, get dressed, and walk. Essentially all activities of daily living have been stripped from her and she is now confined to bed under the care of her husband. Prior to her cancer, she prided herself on being extremely independent. Currently, her neuropathic pain is being managed by steroids, tricyclic antidepressants, neuroleptics, and methadone. Mrs. S. has two teenage children, and has been on disability from her job as a television personality for the past several months. She is Baptist and is an active member in her church.

## ASSESSMENT OF THE PATIENT AND FAMILY

Through daily interactions with Mrs. S. and her family, the APN on the PC unit built a therapeutic relationship that focused on all dimensions of human suffering: physical, psychological, spiritual, and psychosocial. Despite the aggressive titration of pharmacotherapy being used to treat Mrs. S.'s pain, she continued to suffer from intense neuropathic discomfort. Her pain rating consistently was 8/10 or above on a visual analog scale, and over time, her sense of despair about dying in such agony was increasing. In consultation with other interprofessional team members, the APN was analyzing current research and consulting with other pain experts for novel approaches in treating neuropathic pain. The use of intravenous lidocaine has been successful in similar scenarios, and after critical analysis by the APN, the interprofessional team decided to try this therapy. The APN presented all the literature regarding the use of intravenous



lidocaine in refractory neuropathic pain to the hospital's quality committee. The committee granted permission for immediate use and requested that the APN develop an evidence-based guideline to be used for future for patients with neuropathic pain. The APN quickly developed an evidence-based guideline, as the neuropathic pain was escalating daily. The next step was to educate all team members, specifically the nursing and pharmacy staff, as well as the patient and family, about the etiology, sequelae, and rationale for choosing this intervention. Mrs. S. received a test dose of the lidocaine and her pain decreased about 10% within 1 hour. Thus, the intravenous lidocaine was deemed appropriate to continue. Over the next days, her pain level decreased to 2/10. Respecting the value of nonpharmacological measures in relieving pain, the APN assisted in having Mrs. S. offered massage and music therapy. She declined guided imagery.

While Mrs. S. was experiencing her pain crisis, the APN spent a lot of time with her, thus allowing an opportunity for Mrs. S. to express her feelings and fears. She revealed that she felt close to death and was struggling with guilt about one of her desires upon dying—that of spending her last minutes alone, if possible. She was fearful that this request would offend her very protective and involved family. But she had lived a very independent life and wanted to die that way. The APN listened, reflected, and assessed the situation and reported her findings to the interprofessional team. Based on the APN's observations and recommendations, the interprofessional team members set forth a plan to help Mrs. S. and her family deal with these very important issues. Social work and chaplaincy intensified their involvement.

Through interventions by the interprofessional team, Mrs. S.'s family was learning to become more comfortable with respecting their mother's request and were working through their feelings of "abandoning" their wife and mother in time of need. This would continue to be a process.

With in-depth knowledge of family systems theory, the APN identified the need for the interprofessional team to address the already actualized loss of Mrs. S.'s role within the family, including mother and wife. The APN consulted the bereavement counselor as an early intervention for high-risk grief status, as Mrs. S.'s family was still dealing with their loved one's request of dying alone.

Progressively, Mrs. S. showed signs and symptoms of nearing death. As her pain increased, the APN adjusted Mrs. S.'s pain regimen so that she would remain comfortable. The APN and the interprofessional team increased support to Mrs. S.'s family to help them honor her wish at the time of death.

## DISCUSSION OF THE ADVANCED PRACTICE NURSE ROLE

**Clinician.** The APN utilized sophisticated and appropriate assessment strategies to evaluate pain and symptoms. The APN interfaced with other interprofessional team members to develop and implement a comprehensive plan of care. The APN identified novel approaches to the treatment of neuropathic pain and developed hospital-based standards of practice to reflect and support this treatment strategy, and executed interventions. Advanced clinical knowledge of complex pain syndromes and comfort measures to address symptoms was demonstrated through utilization of innovative, ethically sound, scientifically based practice.

**Educator.** The APN facilitated complex philosophical, ethical, and clinical management discussions, assisting the patient and family and all interprofessional team members to achieve a positive outcome. The APN assessed the learning needs of Mrs. S. and her family and the entire staff. The APN presented scientifically based education on the following issues: (a) the management of neuropathic pain, (b) potential for role conflict, (c) actual loss/anticipatory grief, and (d) potential for high-risk bereavement. The APN educated other disciplines also, for example, the quality committee and pharmacy staff, through in-service and guidelines on the philosophy of PC and individualized treatment strategies, and most notably, the use of intravenous lidocaine for intractable neuropathic pain.



**Researcher.** The APN generated new knowledge and through research and the translation of evidence into practice. The APN investigated and integrated PC research strategies, for example, the use of intravenous lidocaine, to formulate an individualized plan of care for Mrs. S.

**Collaborator.** The APN mentored staff in bio-psycho-social and spiritual assessments and interventions. The APN built and preserved collaborative relationships, and identified resources and opportunities to work with PC colleagues. The APN facilitated the development and implementation of staff forums, in-services, physician–nurse collaboration, and quality committee consultation. The APN demonstrated the value of collaboration with the patient and family, the interprofessional team, and other health care professionals in order to facilitate the best possible outcome.

**Consultant.** The APN consulted with the PC physician, PC colleagues, and quality committee representatives to determine the appropriate treatment strategies for meeting the needs of the patient and family. Also, the bereavement counselor was consulted after the APN identified the actualized loss experienced by Mrs. S.'s family. As a consultant, the APN was consistently available to the patient and family, interprofessional team members, and other health care professionals to discuss and explain issues surrounding the PC philosophy.

By maintaining a consistent presence with the patient and family and among interprofessional team members, the APN helped to minimize decision-making conflicts. With advanced knowledge in the humanities, the APN, through language and image, gave expression to the experience of illness, death, grief, and human suffering.

## Evidence-Based Practice

Wager, J., Zernikow, B., Drake, R., Papadatou, D., Hubner-Mohler, B., & Bluebond-Langner, M. (2013). International multiprofessional course in pediatric palliative care: Benefits and challenges. *Journal of Palliative Medicine*, 16(1), 96–99.

With the rapid adoption of the interprofessional team approach into innumerable palliative care PC programs in the United States and all over the world, a growing need exists to ensure that high-quality care is being provided by ensuring that an interprofessional team is well prepared to work together toward a common goal. The interprofessional team maintains a great responsibility in managing PC for each individual patient. PC programs should consider providing education to members of the interprofessional team in order to establish an effective working relationship among members, define roles, and improve the overall care that the patient receives. The demand for interprofessional educational courses is represented in one course evaluation by the presence of attendees from 35 countries, representing multiple disciplines ranging from physicians and nurses to social workers and psychologists. More research is needed to determine the most effective methods of providing interprofessional team education, as opposed to training individuals on a profession-specific basis. The effects of one educational program have been studied and are outlined as follows.

### INTERNATIONAL MULTIPROFESSIONAL COURSE IN PEDIATRIC PALLIATIVE CARE: BENEFITS AND CHALLENGES

#### Purpose

The study analyzed the reasons for attendee enrollment in the course. The aim of the 7-day course was to (a) explore the principles of pediatric PC, (b) develop skills and

training in PC, (c) share experiences and network, and (d) improve interprofessional collaboration.

### Rationale/Significance

Few resources exist that focus on training members from multiple disciplines in collaborating to provide high-quality and standardized pediatric PC. This study analyzes the value of delivering PC instruction to a group of participants from various disciplines.

### Methods

Content analysis was conducted on primary data in order to analyze attendee's reasons for enrollment in the course. Data concerning attendee's origin, demographics, professional background, and reason for attending the course were collected in the first and second years that the course was offered.

### Results/Conclusions

Attendees reported that reasons for attending the multiprofessional course for pediatric PC were to increase knowledge, network among professions, and learn more about the interprofessional approach to PC. Although challenges exist in offering interprofessional courses in PC, this study demonstrates the need and desire for professionals specializing in PC to participate in interprofessional education. More course development and research are needed to investigate the most effective delivery of interprofessional instruction.

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# Palliative Care: Responsive to the Need for Health Care Reform in the United States

Hospice care originated in the 11th century and was afforded to weary travelers on religious pilgrimages; later it was identified as the care of the sick and dying. By the 14th century, the term “palliate” was coined, which meant “to cloak” or “soothe” the symptoms associated with illness or its treatment (Connor, 1998). The principles of hospice care embrace holistic patient- and family-centered care, offered by an interprofessional team of practitioners. Built on the foundation of hospice care, palliative care (PC) addresses care of the mind, body, and spirit as health practitioners develop the most effective and appropriate plan of care for and with patients and families experiencing serious, life-threatening, progressive, or chronic illnesses. The difference between hospice care and PC is that PC begins at the time of diagnosis with such illnesses and continues until the death of the patient and into the bereavement period for families, whereas hospice care is provided during the last 6 months of life. Unlike hospice care, PC is not dependent on prognosis, and can be provided in the context of curative treatments, curing what can be cured, but with the concurrent attempt to alleviate symptoms caused by the disease or its treatment. Both palliative and hospice care can be the main focus of care when solely comfort and supportive interventions are desired to promote quality of life (QOL) until its end (Sherman et al., 2011). Currently, palliative and hospice care are considered on a continuum of care, with PC beginning earlier in the illness trajectory and potentially continuing until death, as compared to hospice care, which is at the end of the

illness trajectory, supporting patients and families in the last stages of life. However, not all patients who are dying choose hospice, nor do they meet the eligibility criteria to be enrolled in hospice care, which is a Medicare benefit.

## ■ PALLIATIVE CARE: MOVING INTO THE MAINSTREAM OF HEALTH CARE

PC is moving into the mainstream of health care as a highly structured and organized system of care (National Consensus Project, 2013). PC addresses the physical, emotional, social, and cultural needs of patients and their families. It embraces an inherent philosophy of comprehensive and patient- or family-centered care, which matches treatments with the values and preferences of the patient and family (Meier, 2010). PC promotes positive health outcomes, such as alleviation of pain and other symptoms, optimization of function, and social support, as well as spiritual and personal growth (National Consensus Project, 2013).

PC is offered to patients experiencing a wide range of illnesses, including neonates with congenital anomalies or intrauterine health conditions; individuals with progressive, chronic, or debilitating illness or life-limiting injuries; and those with advancing diseases, such as cancers, end-stage organ diseases, HIV/AIDS, neurodegenerative disorders, and dementia (National Consensus Project, 2013). PC allows practitioners of various health disciplines to bring their specialized competencies and expertise to focus on serious and

complex health problems. PC practitioners combine their clinical expertise and judgment with the best evidence available through research and an understanding of the preferences of patients and families, known as evidence-based care (Sherman et al., 2011). At the various stages of disease, PC provides relief of pain and symptoms, increases communication about care and continuity of care, offers support for family caregivers, improves survival, and reduces health care costs (Meier & Beresford, 2009).

There are several clinical models of PC, including programs offered by consultation services within a hospital or on a designated PC unit, as well as in assisted living facilities, nursing homes, community home-based programs, or ambulatory clinics. Similarly, hospice care is most often offered in the home, but can be provided in hospitals, assisted-living facilities, nursing homes, or residential hospices (Sherman et al., 2011).

## ■ PALLIATIVE CARE AND HEALTH CARE REFORM IN AMERICA

Seminal data provided by the SUPPORT study (1995) constituted the failing report card of U.S. hospitals in the care of the seriously ill and dying. Yet, 10 years later, Teno et al. (2004) reported that 25% of patients continued to report inadequate pain management, 33% of families reported inadequate emotional support, and 33% of patients indicated that they were not educated about the treatment of their symptoms nor were arrangements for follow-up care provided upon hospital discharge. The Joint Commission now recognizes the value of PC with a voluntary process of PC accreditation, and there is evidence that PC services improve pain management, and provide continuity of care, as well as emotional and spiritual support, to patients and their families (Teno et al., 2004). Within the context of health care reform, it is realized that PC promotes quality health outcomes, providing added value while lowering costs.

In the United States, the federal government has estimated that the population of individuals aged 85 and older will grow from 5.3 million in 2006 to nearly 21 million by 2050 (Federal Interagency Forum on Aging Related Statistics, 2008). Furthermore, the U.S. per capita spending on health care is greater than anywhere else in the world. It is reported that \$2.4 trillion was spent on health care in 2008 (Medicare Payment Advisory Commission, 2009). There is also a rapid growth in the eligible nursing home population, which represents 6% to 7% of the Medicaid population and more than half of all Medicaid expenditures (Huskamp, Stevenson, Chernew, & Newhouse, 2010; Kaiser Family Foundation, 2011;

Meier, Lim, & Carlson, 2010; Mitchell et al., 2009). In response to current economic crises and the escalating costs of health care, hospitals are responding by reducing services and staffing, creating mergers with other institutions, and divesting assets, all of which have significant implications for quality health care (American Hospital Association, 2008). It is also realized that increased health care costs do not necessarily result in better care. This is supported by data indicating that the highest mortality rates are associated with regions with highest utilization, with the highest number of specialists, and the greatest number of ICU patients and hospital days (Fisher, Wennberg, Stukel, & Gottlieb, 2004; Fisher et al., 2003; Mitka, 2006).

As a new paradigm of health care, PC is responsive to the need for health care reform in America and globally (Sherman & Cheon, 2012). It is positioned to become a universally accepted approach to health care with the imperative of improving QOL and quality of dying across the illness/dying trajectory and into the bereavement period of families.

With the passage of the Affordable Care Act in March 2010 ([www.whitehouse.gov/healthreform/healthcare-overview](http://www.whitehouse.gov/healthreform/healthcare-overview)), there is expanded access to health care for more than 30 million Americans (Pelosi, 2010). Individuals are guaranteed insurance coverage for preexisting conditions, along with the expansion of Medicaid to include more low-income Americans (Foster, 2009; Keehan et al., 2011). There is also a projected reduction of \$400 billion in Medicare expenditures over a 10-year period (Pelosi, 2010). Under the Affordable Care Act of 2010, the Centers for Medicare & Medicaid Services (CMS) are required to implement a 3-year demonstration project. This project allows patients to receive aggressive treatment and palliative/hospice care concurrently (Office of the Legislative Counsel, 2010). This will require an evaluation of the current hospice eligibility criteria; the expectation is that criteria will have to be less relaxed regarding the current prognosis of 6 months or less to live for patients with advanced illness (Casarett, 2011). Additional project outcomes to be measured are the cost saving of palliative home health care programs and evaluation of patients' and families' QOL. A hypothesis of this project is that there will be improved survival rates, as compared to usual care, when PC is offered in addition to life-sustaining treatments (Temel et al., 2010). Meier and Beresford (2009) emphasize that PC is extremely relevant in promoting health care reform and ensuring effective, quality, consistent health care delivery. Data indicate that when PC is offered in conjunction with aggressive disease treatment, there is a reduction in health care utilization and costs (Brumley et al., 2007; Temel et al., 2010).



## ■ THE VALUE OF PALLIATIVE CARE IN THE UNITED STATES

PC not only lowers the cost of health care but also improves health-related outcomes for patients and families. As more and more individuals express their desire to remain at home during an illness and to die at home, PC allows the shift of care from hospital to home (Brumley et al., 2007). The result is fewer hospital days, fewer emergency department or physician office visits, and fewer days in a skilled nursing facility. PC/hospice partnerships create a commonsense allocation of health care resources as patients move across the illness trajectory and approach the end of life (EOL). Morrison et al. (2011) reported that PC, when compared to usual care, reduced the total costs of ICU admissions by \$2,642, lowered the cost per day by \$279, lowered the direct costs per admission by \$1,696, and also reduced laboratory costs. It was further indicated that for a hospital with 400 beds, annual cost savings from PC is more than \$1.3 million per year. Based on a report by the Institute of Medicine, if PC were fully integrated into the nation's hospitals, there would be a projected total cost savings of greater than \$6 billion per year (Morrison et al., 2011).

Further research by Penrod et al. (2010) indicates that for patients who receive PC on the hospital units, 44% are less likely to be admitted to an ICU when compared to usual-care patients. Overall, studies conclude that PC reduces the overuse of marginally effective, ineffective, and unnecessary treatments, and results in fewer hospital readmissions, allowing greater continuity of care and the development of safe transition plans upon initial discharge (Morrison et al., 2008; Penrod et al., 2006; Penrod et al., 2010; Smith et al., 2003).

Additional positive health outcomes of PC include:

- Management of pain and other symptoms
- Emotional, spiritual, and social support of patients and families
- Improvement of QOL for patients and families
- Improvement in patient/family satisfaction
- Handling of time-intensive family/patient/team meetings
- Better coordination of care
- Specialty-level assistance to attending physicians
- Support for discharge planning staff
- Improvement in nurse and physician satisfaction (National Consensus Project, 2013)

Based on the National Palliative Care Research Center's (2011) State-by-State Report Card, PC has grown rapidly in the U.S. health system, with 85% of large hospitals with 300 or more beds now having a

PC team. In contrast, only 26% of for-profit hospitals, 37% of community hospitals, and 54% of public hospitals offer PC (National Palliative Care Research Center, 2011).

Although 92% of people polled believe that palliative services should be available at all hospitals, access to PC remains elusive for millions of Americans. Despite a 138% increase in the number of PC programs nationally, there is state-to-state and region-to-region variability in accessibility and availability of PC (National Palliative Care Research Center, 2011).

More promising are survey results from 2008 to 2011, which indicate that there has been an overall improvement in the PC grade of institutions (National Palliative Care Research Center, 2011). Grades have improved from a grade of C to a grade of B, showing that by 2011, most states exceeded the minimal standards of quality PC. Issues related to availability may rest in part with a shortage of trained professionals in PC, particularly in public and community provider hospitals, which serve Americans who are without health care insurance or those who live in geographically isolated areas. The current voluntary certification in PC, as recommended by The Joint Commission, as well as the expectation for hospitals to achieve Magnet status, supports the mandate for health care reform in America and the provision of PC for patients and families.

## ■ AN EXEMPLARY PALLIATIVE CARE ACTION PLAN DEVELOPED IN MARYLAND

In 2011, the State of Maryland focused on promoting health care reform in America by convening an inter-professional taskforce to update the Maryland Cancer Control Plan for Palliative and Hospice Care. The goal was to promote quality and affordable health care in the state (Sherman et al., 2011; fha.maryland.gov/cancer/cancerplan). This "Blueprint for Success in Palliative and Hospice Care" came at a time when citizens of the United States most needed a complement to cancer care. This comprehensive "all hands on deck" approach to health care is critical given an aging population, an increase in the number of cancer diagnoses, and the increase in the number of survivors of cancer and other life-threatening illnesses, who live with their disease as chronic conditions, often with ongoing physical and emotional symptoms (Sherman et al., 2011).

The Blueprint endorses the belief that quality and affordable health care is important during any stage of the illness trajectory, and particularly as disease progresses and death approaches, and necessitates the active involvement and the ongoing, collaborative efforts of patients, families, communities, health

care professionals, institutions, health care policy makers, legislators, and payers. These key stakeholders can ensure quality of care and QOL, lowered cost, increased access to cancer care and PC, greater coordination and continuity of care, and the reduction of health disparities (Sherman et al., 2011).

The key stakeholder groups in palliative and hospice care include:

1. Patients, families, and communities

- *Patients*: Individuals with a diagnosis of cancer at any phase of the illness experience
- *Family*: Any individual who provides direct or indirect support of a patient experiencing cancer
- *Community*: A group of interacting people living in a common location and who share common values or interests

2. Health care professionals and associated staff

- *Health care professionals*: All members of the PC and hospice interprofessional team, including physicians, nurses, social workers, psychologists, chaplains, pharmacists, and physical or occupational therapists, as well as the patient's oncologist or primary care physician
- *Associated staff*: All individuals involved in the caring process who offer direct or indirect support in the care of oncology patients and their families across all health care settings

3. Institutions

- All health care delivery systems that provide palliative or hospice care, such as medical centers, hospitals, rehabilitation hospitals, subacute and long-term care facilities, assisted-living facilities, hospices (inpatient, home, or residential), or related office/outpatient clinics

4. Health care policy makers, legislators, and payers

- State and congressional legislators, the state executive branch of government, the CMS and the Centers for Disease Control and Prevention (CDC), insurers, philanthropists, caregiver advocacy organizations, as well as the business community, including employers (Sherman et al., 2011, p. 3)

Sherman et al. (2011) proposed that Maryland's Action Plan for Palliative and Hospice Care highlights

the critical need to achieve what they have identified as the "four As": Awareness, Acknowledgment, Access, and Action by each of the identified stakeholder groups as identified in Table 2.1.

For each of the identified stakeholder groups, there is the need to develop an awareness of PC, acknowledge its value, promote access to quality palliative and hospice care, and take action to implement a standard of practice in palliative and hospice care (Sherman et al., 2011).

According to Maryland's Action Plan, the education of patients, families, and communities regarding palliative and hospice care, including advanced care planning, are imperatives. Such knowledge will result in further conversations with health care providers, hospital administrators, policy makers, and insurers, as PC becomes consumer driven. With increased awareness and improved communication, there will also be the expectation that patients and families will be involved in personal health care decisions, with consideration of their wishes and preferences and greater assurance of individualized, patient-, and family-focused care (Sherman et al., 2011).

In addition, health care professionals must be educated to ensure adequate staffing of PC programs, particularly given the increase in the number of programs. To increase the preparation of PC practitioners, medical, nursing, and social work schools are not only integrating PC into their curriculum, but are also creating graduate programs with a focus on PC. In addition, several interprofessional fellowship programs in PC are offered across the country, which reinforce the importance of interprofessional collaboration and teamwork. The development of PC and hospice competencies for health professionals requires the advancement of research in PC so that the knowledge from science, as well as the art of healing, can be integrated into clinical education and practice (Sherman et al., 2011).

At the institutional level, administrators are important stakeholders as they acknowledge national priorities, incorporate PC goals and tactics into the institution's strategic plan, and provide substantial budgetary resources to ensure appropriate utilization of PC. With acknowledgment of the PC outcomes of

**TABLE 2.1 The "Four As" of Maryland's "Blueprint for Success" Action Plan**

*Awareness* implies knowledge and appreciation gained through one's perceptions or by means of information about palliative and hospice care.

*Acknowledgment* is the recognition and acceptance of the value of palliative and hospice care.

*Access* is the right, privilege, or ability to make use of resources and information related to palliative and hospice care.

*Action* is the development, implementation, and evaluation of initiatives to promote palliative and hospice care, which will lead to inclusion of palliative and hospice care in the standards of care and setting of future goals.



cost savings, cost avoidance, quality care, and patient and family satisfaction, administrators must work to secure philanthropic contributions for hiring skilled and credentialed interprofessional health professionals (Sherman et al., 2011).

As an important group of stakeholders, health care legislators, policy makers, and payers must be informed of barriers to accessing PC and the importance of incorporating access to quality PC within the “Patient’s Bill of Rights.” These stakeholder groups can facilitate change in quality standards, health policy, reimbursement, and incentives, which promote PC education and quality care across the illness trajectory. State governments can also promote the development of Centers of Excellence in palliative care, which support community provider hospitals and the care offered in urgent care centers and clinics. As data are tracked regarding the number of PC consults, patient and family outcomes, health care professional outcomes, and financial and economic

outcomes, legislative agendas can be developed to further expand access to quality PC and address complex issues related to reimbursement for PC services. The time has also come for studies that focus on the comparative effectiveness of PC and hospice with traditional hospital care, bundled payments, and the funding of demonstration projects that test the integration of comprehensive PC in the care of patients with complex medical needs (Sherman et al., 2011). As a stakeholder group, legislators, policy makers, and payers can ensure the implementation of PC initiatives that will slow the nation’s total health care expenditures while improving the quality of health care in America (Sherman et al., 2011).

Cornerstones of Maryland’s Blueprint for Success Action Plan for palliative and hospice care include identified goals, objectives, and strategies related to palliative and hospice care, which have been described in relation to each of the “four As” (see Table 2.2) for each of the stakeholder groups.

**TABLE 2.2 Goals, Objectives, and Strategies of the Maryland Blueprint for Success**

**Goal:** To implement a blueprint for success for palliative and hospice care for patients and families experiencing cancer in the state of Maryland.

**Objective 1 (Awareness):** By 2015, develop an awareness campaign to educate Maryland citizens about palliative and hospice care within 50% of Maryland jurisdictions.

**Strategies (by stakeholder group):**

- 1) *Patients/families/communities* should seek information on palliative and hospice care and advanced care planning from their health care providers, public library, national and local cancer agencies, and local health department.
- 2) *Health care professionals and associated staff* should increase communication related to palliative care issues in patient conversations, health care publications, and media/marketing.
- 3) *Institutions* should initiate palliative care activities with the goal of obtaining buy-in from various constituencies.
- 4) *Health care legislators/policy makers/payers* should conduct an internal education effort on strategies to reduce barriers that Maryland residents face in regard to quality palliative and hospice care. The education effort should include widespread distribution, discussion, and the development of an action plan based on:
  - The 2009 *Workgroup Report on Hospice Care, Palliative Care, and End of Life Counseling*, released by the Maryland Attorney General’s Counsel for Health Decisions Policy workgroup, and
  - Reports of the Maryland State Advisory Council on quality of care at the end of life.

**Objective 2 (Acknowledging the Value):** By 2015, increase the participation in and support of palliative and hospice care initiatives by stakeholders as outlined in the strategies.

**Strategies (by stakeholder group):**

- 1) *Patients/families/communities* should participate in campaigns that support/promote palliative and hospice care and advanced care planning.
- 2) *Health care professionals and associated staff* should actively participate in palliative education and palliative care initiatives as demonstrated by attendance at national conferences, increase in certification and credentialing rates, and referral to palliative care services and hospice care.
- 3) *Institutions* should develop a strategic plan that incorporates goals and related tactics to institutionalize palliative care as it relates to ongoing professional education, implementing and maintaining supportive services for patient/families, supporting research and evidence-based practice, and driving health care policy and legislative initiatives that promote palliative care.
- 4) *Health care legislators/policy makers/payers* should conduct outreach efforts via e-mail, town halls, and focus groups to educate constituents about the knowledge, financial, and administrative barriers Maryland cancer patients and their families face in regard to palliative and hospice care and get their input on options to reduce them.

(continued)



**TABLE 2.2 Goals, Objectives, and Strategies of the Maryland Blueprint for Success (continued)**

**Objective 3 (Access):** By 2015, increase access to palliative and hospice care services in Maryland.

**Strategies (by stakeholder group):**

- 1) *Patients/families/communities* should request access to palliative and hospice services.
- 2) *Health care professionals and associated staff* should develop and implement educational programs (formal and informal) related to palliative and hospice care.
- 3) *Institutions* should
  - Develop a mechanism to track the percentage of palliative care consultations for hospital patients admitted with cancer, and
  - Ensure clinical support through hiring a skilled and credentialed/certified team of interprofessional palliative care professionals and associated support staff in order to implement a palliative care consult service or other delivery models (such as an inpatient unit, outpatient clinic, homecare program, and/or establishing partnerships with community hospices).
- 4) *Healthcare legislators/policy makers/payers* should explore legislative options for expanding access to and payment for palliative and hospice care, building on best practices.

**Objective 4 (Action):** By 2015, stakeholders will take ownership of the Blueprint for Success and act on 70% of the strategies recommended for each stakeholder group.

**Strategies (by stakeholder group):**

- 1) *Patients/families/communities* should advocate for effective and compassionate palliative care across health care settings to ensure that the goals of care are achieved.
- 2) *Health care professionals and associated staff* should incorporate the National Quality Forum Preferred Practices of Palliative Care as a standard of care within the institution.
- 3) *Institutions* should initiate quality improvement studies to evaluate the provision of quality palliative care by tracking the following:
  - Requests for palliative care consults
  - Patient/family and community outcomes
  - Health care professional outcomes
  - Economic outcomes
- 4) *Health care legislators/policy makers/payers* should support pilot programs that test the following:
  - The feasibility and impact of training lay workers to serve as palliative and hospice care counseling coaches and navigators
  - Reimbursement models for providing end-of-life care counseling
  - The impact of innovative clinical–financial models of palliative and hospice care for cancer patients and their families designed to reduce knowledge, financial, and administrative barriers to their use

*Note:* A more detailed version of the goals/objectives/strategies can be found on the Palliative and Hospice Care page of the Maryland Cancer Plan website: [www.marylandcancerplan.org](http://www.marylandcancerplan.org).

*Source:* Sherman et al., 2011, pp. 8–9.

## ■ PALLIATIVE CARE AS A GLOBAL IMPERATIVE

PC is not only a national imperative in the United States but also a global imperative, given that 56 million people die each year in developed and developing countries (Seymour et al., 2009). “At the end of the first decade of the 21st century, the provision of PC is beginning to feature in the political and policy agendas of many different countries as they seek to respond to the challenges of epidemiological and sociodemographic change, particularly given aging populations” (Seymour, 2011, p. 18).

In many countries, access to PC is being considered a human right (Sherman & Cheon, 2012). Wright, Wood, Lynch, and Clark (2008) have described the typology of PC globally by mapping its availability, specifically: (a) no identified hospice/palliative care activities; (b) the capacity for developing PC, with no

palliative services available; (c) the provision of localized PC; and (d) countries where PC is being integrated with mainstream health care services. Based on this mapping, PC services were reported in 115 out of 234 countries. However, there was no identified activities in 78 (33%) countries; 41 (18%) countries had the capacity to build PC services; 80 (34%) countries had only localized provision of PC; and 35 (15%) countries approached integration. As nearly half of the world’s countries do not have PC, there are many challenges to improve awareness of PC through education, to increase access to opioid medications for the management of pain and other symptoms, and secure institutional and political support for PC.

Centeno et al. (2007) suggested that there is a need to implement differing models of PC service delivery beyond traditional PC or hospice consultations or inpatient units, to the use of day centers, such as

those available in Great Britain, and the possible use of mobile PC teams. Globally, there are recommendations to sustain, optimize, and expand the 8,000 dedicated PC services that currently exist in the world (Gomes, Harding, Foley, & Higginson, 2009).

### **International Recommendations for the Advancement of Palliative Care**

To direct the international future of PC, a meeting of clinicians, health economists, researchers, policy makers, and advocates was convened with the identification of seven recommendations: (a) the importance of shared definitions of PC; (b) recognition of the strengths and weaknesses of different payment systems; (c) identification of country-specific and international research priorities; (d) determination of appropriate economic evaluation methods; (e) evaluation of PC costs; (f) the imperative to support interprofessional PC education and training programs; and (g) the development of national standards to regulate and determine PC planning and development (Gomes et al., 2009; Lynch et al., 2009). As leaders of health care globally, the United States, United Kingdom, Canada, and Australia are at the forefront of providing quality palliative and hospice care and addressing these international recommendations.

Australia, as a world leader in hospice and palliative care, is visionary in overcoming funding and financing issues, as there are shared responsibilities for managing the health care system for both the State and its Territories (Gordon, Eagar, Currow, & Green, 2009). It rests on the premise that, because there is no national model for funding inpatient or community PC services, states and territories must fund PC services. PC funding varies by the type of care offered and whether those who offer it are generalist providers, specialist providers, or those offering support services in nongovernment, private, and public sectors. PC continues to evolve rapidly as a health care service in Australia with flexible evidence-based models of care delivery that consider not only the type of provider but also diverse patient groups (Gordon et al., 2009).

### **■ PALLIATIVE AND HOSPICE CARE NURSES: LEADERS OF HEALTH CARE REFORM**

Nursing is the world's largest and most trusted profession, with approximately 19.4 million nurses working globally (World Health Organization, 2012). The integration of scientific, aesthetic, personal, and ethical knowledge in nursing supports the leadership of nursing in reshaping societal perspectives regarding illness, dying, and death. Indeed, nurses who are educated in PC nursing "facilitate the caring process

through a combination of science, presence, openness, compassion, mindful attention to detail, and teamwork" (Coyle, 2006). As members of the interprofessional PC team, nurses, along with colleagues from other professions, create an effective and compassionate plan of care for patients and families facing serious, chronic, or life-threatening illness, which promotes the quality of their lives.

Both in generalist and specialist roles in palliative and hospice care, nurses are leaders of health care reform in the United States as they combine knowledge, experience, and commitment to advancing the specialty and promoting quality palliative and EOL care. Certified at the basic level of competency, the nurse may be licensed as a licensed practical nurse or registered professional nurse who has gained competencies in palliative and hospice care through general educational programs, professional work experiences, and ongoing continuing education. By virtue of graduate education and related clinical expertise, the advanced practice PC nurse is a specialist who demonstrates greater depth and breadth of knowledge and skill in theory, research, and practice reflected in the standards of care of PC and hospice nursing (Hospice and Palliative Care Nurses Association, 2002).

The standards of care reflect the values and priorities of PC nursing and provide a framework with which to evaluate practice. The standards of care are written both at the basic and advanced practice levels and reflect the nursing process, which involves assessment, diagnosis, outcome identification, planning, implementation, and evaluation. Foundational to the standards of care are the following tenets:

- Care should be age-appropriate and culturally sensitive
- A safe environment is to be maintained
- Education of patients and families is essential
- Coordination and continuity of care across settings and caregivers must occur
- Communication and the management of information must be effective (Hospice and Palliative Care Nurses Association, 2002)

Nurses in palliative and hospice care, particularly those in advanced practice, consider not only the physical and emotional needs of patients and families but also their cultural and spiritual beliefs and values, which may influence the patient's preference for treatment options. With consideration of developmental needs, advanced practice nurses empower patients and families to remain in control of their lives by being active participants in determining the plan of care. By discussing the expectations related to the illness trajectory, anticipated symptoms and associated pharmacological and nonpharmacological treatments,



advanced practice nurses can take into account not only the best evidence available through science and their own clinical judgment, but also the patients' and families' preferences, with optimal communication to health professionals across all care settings. PC and hospice nurses discuss the risks and benefits of tests, procedures, and treatments, considering the negative and positive impact on the patient's QOL and the economic implications (Meier & Brawley, 2011).

## ■ THE ROLES OF ADVANCED PRACTICE PALLIATIVE CARE NURSES

Meier and Beresford (2006) emphasize that "Advanced practice nurses often embody in a single person PC's focus on the whole person and the medical practitioner's ability to diagnose conditions, prescribe medications and order treatment interventions—while recouping salary costs through billing for consultations" (p. 624). Advanced practice nurses in PC often spearhead the development, implementation, and evaluation of PC services, assuming pivotal leadership roles not only as clinicians, but also as administrators, researchers, educators, advocates, and health policy makers.

Advanced practice nurses are often the health professionals who make the case to hospital administration to implement a palliative program and develop the business plan with consideration of interprofessional resources, feasibility and accessibility, cost control, revenue generation, integration and leveraging of existing services, and decisions regarding the structure and model of the programs (Center to Advance Palliative Care, 2011). They put forth to administration the operational plan for implementation of PC programs, such as space needs, staffing roles and requirements, basic policies and procedures, and projections of patient volumes and program capacity, as well as consideration of financial and strategic planning issues. The advanced practice nurse makes the case to administration regarding the hospital's financial viability, including the value of the program regarding length of stay at the hospital, daily census, hospital billing revenues, estimated cost savings, and potential contributions by philanthropy (Center to Advance Palliative Care, 2011). Given their advanced clinical knowledge and expertise related to health care systems, advanced practice nurses provide a futuristic perspective as to how PC can meet the expectations of quality care within the context of cost effectiveness and reform.

PC nursing research generates basic and applied knowledge to improve the care of patients and families with serious and life-threatening illness in areas of symptom management, psychological responses to illness, and the family caregiver experience (Ferrell,

2010). Nurse researchers who conduct qualitative studies in palliative and hospice care seek to develop theories based on the subjective experiences of patients and their families. PC nurse researchers also conduct quantitative studies to test theories, as well as to examine the incidence, prevalence, and severity of symptoms; evaluate models of care; and test the effectiveness of PC and hospice interventions.

Since the establishment of the National Institutes of Nursing Research as an institute within the U.S. National Institutes of Health in 1997, there has been increased funding of PC research and significant contributions made to science by PC nurse researchers. In addition, the Hospice Nurses Foundation in the United States has become a funding agency for PC nursing research. The Hospice Nurses Foundation agenda for 2009 to 2012 has focused on funding studies that investigate the symptoms of dyspnea, constipation, and fatigue (Hospice and Palliative Care Nurses Association, 2012).

The Hospice Palliative Nurses Association (HPNA) Research Agenda for 2012–2015 is based on the Clinical Practice Guidelines for Quality Palliative Care, and addresses the first three domains of the guidelines. The first domain focuses on the structure and processes of care, considering the optimal membership of interprofessional teams, the focus on the patient and family as the unit of care, and the locations and models of care delivery. In relation to research, the second domain focuses on the physical aspects of care, including symptom management and disease progression in patients with multiple comorbid conditions, as well as the physical care of patients in special populations. The third domain involves psychological and psychiatric care, with a particular focus on the needs of individuals with serious mental illness (Hospice and Palliative Care Nurses Association, 2012). Other funding agencies are interested in ways of promoting interprofessional education, the value of professional specialty certification, the integration of PC concepts into standard care across health communities, the value of concurrent curative care with PC, and the use of research findings to shape health policy (Hospice and Palliative Care Nurses Association, 2012).

All nurses have the opportunity to participate in research by identifying clinical problems specific to palliative and hospice care, participating in data collection, and critiquing research findings to determine the application of findings, particularly in the development of clinical standards of care and the development of policies (Lunney, 2011). Nurse researchers, as principal investigators, often lead the interprofessional research team. In collaboration with other nurses who are doctors of nursing practice (DNP), and other health practitioners and scientists, nurse



researchers develop new knowledge related to the specialty and facilitate the translation of this PC and hospice knowledge into clinical practice.

Another key role in the advancement of PC nursing is that of educator. In the academic setting, PC nurses advance the specialty through curriculum development and the inclusion of PC content within the curriculum. Through programs such as the Education for Physicians on End of Life Care (ELNEC) Train-the-Trainer, there is further dissemination of knowledge related to PC as it is integrated within undergraduate and graduate nursing curriculum both domestically and abroad (Paice, Ferrell, Coyle, Coyne, & Callaway, 2007). At the graduate level, PC is either offered as a component of the adult nurse practitioner curriculum or as a post-master's certification.

As health educators in clinical settings, palliative nurses integrate PC concepts into the generalist setting where most EOL care occurs. These include promoting optimal patient and family well-being by teaching them about pain and symptom management, self-care, and other interventions. As members of an interprofessional team, PC nurses further mentor and teach other members of the team regarding evidence-based approaches in PC.

PC nurses also serve in the role of public health advocates. By virtue of their numbers, experience, education, time spent at the bedside, and insight into the lived experiences of patients and families, nurses play a prominent role as public health advocates for PC at the local, national, and global levels (Payne, Ingleton, Sargeant, & Seymour, 2009). With shifts in population, disease demographics, and the aging of the population, particularly given the health needs of the "baby boom" generation, nurses lead much needed health care reform to ensure quality care across generations (Gott & Ingleton, 2011). As advocates, nurses inform key decision and policy makers about the importance and effectiveness of quality, accessible, and equitable PC, as well as its outcomes and cost effectiveness (Morrison et al., 2008; Penrod et al., 2010).

In their advocacy role, PC and hospice nurses focus on the following:

- Coordinating and ensuring continuity of care across settings and caregivers
- Educating patients, families, and providers
- Promoting and upholding PC as a basic human right
- Establishing networks of providers
- Increasing equity and access to palliative and EOL care in developed countries, and particularly in underdeveloped or resource-poor countries
- Developing and enhancing PC delivery models
- Increasing access to opioids and other symptom management modalities

- Increasing public and political awareness
- Developing integrated care pathways
- Actively participating in public policy development, engagement, and social/political activism levels (Payne, Ingleton, Sargeant, & Seymour, 2009)

In their multiple roles regarding PC, nurses strive to influence the societal changes occurring at international, national, regional, and local levels, which promote health and well-being across the life continuum. Nurses are a valuable resource in national efforts to improve care and QOL for patients and their families living with advanced, life-limiting illness. It is through collaborative efforts that the roles of hospice and PC and hospice nurses will be fully actualized. Professional organizations in nursing, medicine, hospice, and palliative care are called upon to engage in dialogue about the role of advanced practice nurses, and opportunities and strategies to enhance and empower the role.

## ■ CONCLUSION

"PC ensures that the person is viewed in his or her entirety, not as a collection of organs and medical problems" (National Palliative Care Research Center, 2011, p. 12). PC reduces high levels of suffering and distress of patients with serious illness at any age and at any stage of disease; improves communication; addresses the needs of family caregivers; reduces unwanted, unnecessary, and painful interventions; and improves patient, family, and staff satisfaction, while also improving survival (National Palliative Care Research Center, 2011). PC is also an economic imperative in reducing the cost of health care. But, even more importantly, PC is a humanistic imperative to ensure that QOL is promoted during all phases of the illness experience for both patients and their family caregivers (Sherman & Cheon, 2012). PC nurses advance the science and the art of PC through clinical practice, administration, research, education, and advocacy. With a focus on ensuring quality care within the context of a changing health care environment, palliative and hospice care nurses promote the awareness of palliative and hospice care, acknowledge its value to patients and families and the health care community, and find ways of promoting access to care and actions to ensure the integration of PC into the health care system. As leaders of health care, PC nurses have the knowledge and skills to bring together patients, families, communities, health institutions and practitioners, legislators, payers, and insurers to move our world ahead by advancing local, national, and global palliative care initiatives. PC is responsive to health care reform in the United States and PC nurses play a leading role in ensuring QOL for patients and families across the illness trajectory.

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# Ethical Aspects of Palliative Care

CHAPTER

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## KEY POINTS

- Ethics involves decisions about right and wrong, which are influenced by our values.
  - *Nursing ethics* involves clarifying *moral uncertainty*, resolving *moral dilemmas*, and coping with *moral distress*.
  - Two major approaches to theoretical ethical analysis are deontological (duty-based) and teleological (consequence-based) systems of ethics.
  - The major ethical principles of significance to nurses are respect for persons and autonomy, beneficence, nonmaleficence, and justice.
  - Decision-making capacity is task-specific, and differs from the concept of mental competence.
  - Surrogate decision makers should strive to make a “substituted judgment” of what an incapacitated patient would have wanted. A “best interest” standard is used if it is unknown what the patient would have wanted.
  - Advance directives may be helpful in identifying what a patient would have wanted when he or she no longer has decision-making capacity.
  - Minors have rights to be included in end-of-life decision making, depending on their decision-making capacity and maturity.
  - Parents or legal guardians of minors must make decisions within the medical standard of care.
  - There is no moral distinction between withholding or withdrawing life-sustaining treatment.
  - Decisions to withhold or withdraw life-prolonging interventions such as ventilators or artificial nutrition and hydration are not considered forms of assisted suicide.
  - Nurses should identify resources available to them to support ethical decision making, including decision-making frameworks, ethics committees, the Nurses Code of Ethics, and expert colleagues.
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## CASE STUDY

Mrs. Selano is a 78-year-old woman who has resided in a nursing home for the past 5 years. Due to end-stage dementia, she is totally dependent on the nursing home staff for all activities of daily living, is noncommunicative, and receives nutrition through a feeding tube. She has no family, but has received consistent visits from Mrs. Jenkins, a close friend and former neighbor. Mrs. Selano has a living will stipulating that if she were terminally ill, she should be kept comfortable rather than be treated with aggressive life-prolonging medical technology. However, Mrs. Selano checked off on her living will that she would want artificial nutrition through tube feedings to keep her alive. Mrs. Jenkins served as a witness when Mrs. Selano signed the living will document. Mrs. Jenkins tells the nurse that Mrs. Selano would never have wanted to be kept alive in the state she is currently in—contracted into a fetal position, unable to meaningfully interact with others. She says that the lawyer did not fully explain what getting nutrition through a feeding tube might entail for someone with end-stage dementia. Instead, the lawyer presented this as something that might be implemented if Mrs. Selano was “hungry and couldn’t eat.” Mrs. Jenkins asks if the tube feedings could be stopped and Mrs. Selano allowed to die in peace.

Some decisions nurses make when providing end-of-life (EOL) care seem particularly difficult; even experienced nurses may feel uncertain about whether they made the “right” decision. When the issue is what, all things considered, is the *right* thing to do, a moral or ethical question is asked. It is often exquisitely difficult to determine what the right response is when, for example, a terminally ill and suffering patient pleads with you to help speed her dying; you feel unable to help without causing her harm. An ethically hard case is one in which the good that you want to bring about can only be realized if the harm you seek to avoid is also brought about, that is, when benefiting the patient cannot be disentangled from harming (Cavanaugh, 1996).

Advances in scientific knowledge and developments in medical technology far exceed any social consensus about the circumstances for their appropriate use. The process of dying can now be prolonged almost indefinitely; this technological imperative (*can do* implies *ought to*) has given rise to an unprecedented array of professional, moral, and legal questions within health care. Many Americans fear the possibility of dying a painful, protracted, or undignified death, in an institutional setting, absent personal control or meaning (Schwarz, 2004a). Studies indicate that nurses also have concerns about how best to provide care for dying patients. Beckstrand, Wood, Callister, Luthy, and Heaston (2012) identified emergency department (ED) nurses’ perceptions of ways to improve EOL care in the ED. These included increasing the time ED nurses are given to care for dying patients, allowing family presence during resuscitation, providing comfortable patient rooms that preserve privacy, and

providing family grief rooms. Aslakson et al. (2012) conducted focus groups with surgical ICU nurses, and identified 34 barriers to optimal communication regarding prognosis, summarized into the following four domains: logistics, clinician discomfort with discussing prognosis, inadequate skill and training, and fear of conflict. Focus group analysis revealed 24 barriers to optimal EOL care, summarized into four domains as well: logistics, inability to acknowledge an EOL situation, inadequate skill and training, and cultural differences relating to EOL care.

Ethical aspects of EOL decision making pose compelling challenges for nurses because they frequently involve conflicts among values, principles, and priorities of care; such conflicts require reasoned deliberation for their resolution. This chapter provides practicing nurses with the tools needed to identify and address the ethical issues in EOL care. In order to identify ethically relevant aspects of complex cases, nurses are encouraged to engage in values clarification and personal reflection. To address the ethical issues in EOL care effectively, nurses should use a decision-making framework that incorporates ethical theories, clearly defined moral concepts, and an understanding of the *Code for Nurses* (American Nurses Association [ANA], 2001).

Ethical and legal issues often seem intertwined in many EOL decisions. For example, the selection of who is permitted to speak for a person who is decisionally incapable is a legally determined question, but which treatment the decision maker chooses is often a moral issue. Often the most difficult clinical conflicts occur at the junction of law and ethics, where an act that is illegal may seem morally required, or one

that is legally required may seem morally inappropriate. Many of these cases resist satisfactory solutions. Although ethics and law function similarly in society, in that they both sanction and guide behavior, they also differ in important ways. This chapter focuses on ethical issues in nursing care for patients approaching death.

## ■ ETHICS AND ETHICAL THEORY

Ethics is a branch of philosophy that considers and examines the moral life. The word ethics comes from the Greek *ethos*, and originally meant character or conduct; the word moral comes from the Latin *mores*, which means customs or habit (Davis, Aroskar, Liaschenko, & Drought, 1997). *Ethics* and *morals* are frequently used interchangeably in nursing ethics to refer to conduct, character, and motivations involved in moral acts, although distinctions are sometimes made between these terms.

The concept of morality is often used to refer to personally embraced concepts of duty, obligation, and principles of conduct. *Morals* is frequently used interchangeably with *values*, and refers in particular to values or principles of conduct to which one is personally and actually committed (Jameton, 1984). Use of the word *ethics* is distinguished by reflective thinking and practical reasoning, and often includes overarching, publicly stated sets of rules or principles, such as those found in professional ethics codes. Stanley and Zoloth-Dorfman (2001) note that ethics seeks to logically justify choices for right behavior and rules—particularly in situations that challenge established norms of behavior, or in those that require a new paradigm for judging behavior. These authors add that ethical inquiry—which seeks to interpret acts and to answer such questions as “What is the right thing to do?”—traditionally includes an evaluation of (a) the moral agent and his or her character, (b) the motive for the act itself, and (c) the effect of the action on others. *Normative* ethics seeks ways to answer questions about right and wrong, or good or bad in situations that call for a moral decision. Nursing ethics is both normative and practical, in that it makes use of ethical theory and analysis to examine and resolve what *ought to be done* in situations involving moral conflict in nursing practice. *Bioethics* refers to the application of ethics and ethical analysis to moral and practical problems in biological sciences, medicine, and health care.

## Values and Value Clarification

Values have been called the cornerstone of nursing’s moral art (Uustal, 1987). Few aspects of our personal

or professional lives are value-free. Values are ubiquitous, although often unspoken and frequently unexamined; they determine the nature of our moral choices. **Values are foundational to our notions of good and bad, and inform our understanding of what constitutes benefit and harm; thus they are instrumental to the ethical decisions we make.** Because our values influence the choices we make, they may also bias our judgments about the worth of our own view and negatively influence our judgments about the merits of others’ choices; hence the need for values clarification. In the absence of reflection, we may simply assume that others believe and would (should) do as we do.

Bill Peace is a paraplegic (he prefers the term “cripple”) who writes a blog about disability rights ([badcripple.blogspot.com/](http://badcripple.blogspot.com/)). In an essay, he wrote about a botched attempt by a hospitalist to speak with him about his EOL preferences. Peace had a wound that had become infected with antibiotic-resistant bacteria. The hospitalist explained the seriousness of the situation and offered him the option of foregoing antibiotics and other life-sustaining interventions and switching to comfort care. Peace declined the offer, and described the fear he felt during his long recovery:

My fear was based on the knowledge that my existence as a person with a disability was not valued. Many people—the physician I met that fateful night included—assume disability is a fate worse than death. Paralysis does not merely prevent someone from walking but robs a person of his or her dignity. In a visceral and potentially lethal way, that night made me realize I was not a human being but rather a tragic figure. Out of the kindness of the physician’s heart, I was being given a chance to end my life.

Perhaps, if the hospitalist had reflected on his own values, beliefs, and attitudes and how these influenced his recommendations for Mr. Peace, he might have approached this patient differently. The topic of death (the clinician’s, his or her loved ones, and his or her patients) can emotionally trigger clinicians in many ways. Clinicians’ unexamined emotional triggers thwart effective communication about EOL care. This can bias their recommendations for patients, or cause them to avoid such conversations altogether, which fails both the patients and the loved ones who will grieve for them.

**Values clarification is a process of self-reflection that helps individuals identify, consider, and articulate the belief, purposes, and attitudes they prize and that drive their actions.** Beliefs about death and what makes life worth living, our conclusions about the



nature and significance of truth, or the meaning of paths not chosen are all moral values. Fowler (1987) states that the purpose of values clarification is to assist individuals to identify those personal and professional values that influence their behavior and moral decision making. It is recognized that the essence of ethical conflict is the clash of values, principles, legal rules, and personal perspectives (Dubler & Liebman, 2011). The need for values clarification is an essential first step in moral decision making.

Every nursing act that intervenes in the life of a patient has at least the possibility of enhancing or transgressing some value cherished by that patient. In situations of moral uncertainty or ethical dilemmas, questions of value will always be foundational. *Moral uncertainty* occurs when nurses are uncertain if a moral problem exists, are unsure about its nature, and are unclear which values conflict and which principles might facilitate clarification. These situations often occur in nursing practice. Moral uncertainty may occur when a patient seems to be suffering unnecessarily, is refusing pain medication, but is unwilling or unable to explain the reason for refusing your efforts to help.

*Moral dilemmas* occur less frequently and are understood as a situation in which two or more clear moral or ethical principles apply that support mutually inconsistent courses of action. Each alternative course of action can be justified by a moral rule or principle, but one can choose or satisfy only one course of action at the expense of *not* satisfying the other. The nurse who believes he or she is duty-bound both to preserve life and reduce suffering may experience a dilemma when preserving life causes intense suffering or when suffering can only be reduced by interventions that may shorten life. There is no satisfying right answer to an ethical dilemma, but one should utilize reasoned (principled) thinking to provide a rationale for the decision reached.

The third type of moral problem is the experience of *moral distress*, an emotion that occurs when nurses have identified and know what right response is called for, but institutional or other constraints make it almost impossible to pursue the right course of action (Jameton, 1984). Hamric (2012) found that moral distress can emerge from factors present in unit cultures, in institutions, and in the larger health care environment, as well as from factors internal to the individual and specific to a given clinical situation. Nurses surveyed by Varcoe, Pauly, Storch, Newton, and Makaroff (2012) identified a variety of situations they found morally distressing, including witnessing unnecessary suffering and being forced to provide care that compromised values. Kayser, Nault, and Ostiguy (2012) describe how nurses resolved moral distress when caring for patients who continued to smoke

while using home oxygen therapy. Nurses who experience moral distress from institutional constraints on their ability to practice as morally autonomous clinicians should seek support from colleagues and from other institutional and professional resources such as institutional and nursing ethics committees and state nursing associations.

Resources to assist the nurse in managing moral problems effectively are included in subsequent sections of this chapter. However, whatever the conflict, knowing one's own values and being sensitive to the values of others is an essential first step in ethical nursing practice.

## ■ ETHICAL THEORIES

Moral theories are methods of determining what counts when a decision must be made, and offer a method for weighing or ranking considerations identified as morally relevant to that decision. More succinctly, an ethical theory provides a framework of principles within which an agent can determine morally appropriate actions (Beauchamp & Childress, 2012).

It should be noted that nurses regularly explore and resolve ethical questions in their practices without recourse to ethical theories and without a formal consideration of the nature of their foundational moral values. Yet people hold different foundational views, which sometimes can heighten moral conflict and diminish the options for resolution. The following scenario by Benjamin and Curtis (1992) illustrates the role that ethical theories can play in facilitating or hampering decision making. The case involves the question of whether everything should be done to prolong the life of an elderly gentleman in a nursing home who lacks decision-making capacity. The staff must make the decision because there are no friends or family and no prior indication of his wishes. Person A argues that he should be treated because not to do so would violate the duty to protect and preserve life. Person B agrees that the man should be treated, but for a different reason. B argues that he should be treated because he is not in any pain, and although he is significantly cognitively impaired, he seems fairly content. In B's view, what one ought to do above all is to maximize happiness, and therefore the man's life should be prolonged. As presented, the question about whether to continue treatment can be answered without agreement about the nature of basic ethical values and with dissimilar ethical theories.

Suppose the facts are changed a little, so that the gentleman is experiencing intractable pain and distress. In this case, with her foundational commitment to maximizing happiness, B would revise her judgment

and conclude that they should no longer strenuously attempt to extend the man's life. But this change in facts would be irrelevant to A, and her judgment that the patient's life should be prolonged would remain the same. This conflict is not likely to be resolved without further questions about the nature and justification of ethical principles that are the foundation to approaches of making ethical decisions.

Within bioethics, there are two major approaches to theoretical considerations—deontological and teleological systems of ethics. The deontological (from *deon*, Greek for duty), or Kantian, approach to ethics focuses on duties and obligations. Teleological theories (from *telos*, Greek for end) base the determination of whether an action is right or wrong on the action's consequences. These two ethical theories have been subject to criticism for their overreliance on unrelated and often conflicting principles in dealing with moral problems in health care (Clouser & Gert, 1990), and by feminist moral theorists for their indifference to the particularity of relationships (Gadow, 1996). These theories continue to dominate the ethical arguments used to resolve moral problems in health care, and nurses must recognize them and be familiar with their use in decision making. These two theories are described and contrasted to a decisional theory based on caring.

### Deontological Moral Theory

A deontological, or Kantian, approach to decision making focuses on duty and obligations. Kantian deontology is attributed to the 18th-century moral philosopher Immanuel Kant. Deontologists maintain that whether an act is right or wrong depends upon the nature of the act itself when considered in terms of its inherent moral worth. Kant argued further that consequences can never make an action right or wrong. **Duty-based theories hold particular duties to be fundamental and make use of principles or their derivative rules to guide decision making.** Examples of duty-based theories include natural law, which identifies a duty to obey God's will and requires that one not kill; and the rules of traditional medical morality derived from the Hippocratic tradition, which maintain that above all we should do no harm.

A deontological position requires commitment to the principle of universalizability, which means that **once a moral decision is made, that same decision must be made in all similar situations.** The essence of this position is that morality requires that **we cannot make exceptions for ourselves.** Thus, if the proposed action is one that would be wrong if done generally, then the particular action is also wrong—even when the specific action has no harmful consequences. Such rules as “it is always wrong to directly take innocent

human life” are considered valid when they meet certain conditions, identified by Kant as categorical imperatives. Proposed by Kant as a means to resolve conflicts between rules and principles, this imperative means that for a rule to be valid it must be applicable to everyone universally. This principle can be illustrated as follows: If it is morally acceptable for me to act as I do for my patient (e.g., not charging for services, stealing medications for her use, skipping home visits, etc.), so must it also be acceptable for every other nurse to act similarly for his or her patients.

Another form of this categorical imperative requires that persons should always be treated (and valued) as ends in themselves, and never solely as means. Thus, nurses are required to respect individuals and their beliefs regardless of consequences and they are similarly obliged to respect persons' autonomous choices. Kant identified these categorical imperatives as unconditional commands that are morally required and obligatory under any circumstances (Davis et al., 1997). Within this theoretical perspective, it is simply one's duty to obey categorical imperatives without any exceptions, without reference to the consequences of the act, and in the absence of external or guiding authority. The moral standard includes keeping promises, avoiding or preventing harm, and respecting persons; these are principles that are morally required and are consistent with the rules provided in our professional code of ethics. Fiester (2007) cautions that the trend to approach ethical decision making using a “four principles” approach (i.e., weighing obligations toward beneficence, nonmaleficence, respect for persons, and justice) predisposes clinicians to overlook other ethical obligations toward patients (e.g., the obligation to acknowledge another's suffering, and to apologize and make amends when clinicians make mistakes).

### Teleological Moral Theories

**Teleological theories determine an action to be right or wrong based on the consequences of the action.** The most important teleological theory for contemporary health care is utilitarian ethics (Steinbock, Arras, & London, 2012). Utilitarianism is best understood as a moral theory, which asserts that there is only one basic principle in ethics, the principle of utility, which declares that we ought always to produce the greatest possible balance of value over disvalue for the greatest number of persons (Beauchamp & Childress, 2012). This position assumes that one can weigh and measure harms and benefits and arrive at the greatest possible balance of good over evil for the most people (Davis et al., 1997).

Utilitarians are disinterested in considerations of the agent's intentions, feelings, or convictions; all are viewed as irrelevant to the question of “What is the



right thing to do?” In the same fashion, utilitarians regard the question of whether a proposed action conforms to established social norms or ethical codes as relevant only to the extent that conforming (or not) has a bearing on the production of happiness or value over unhappiness (Steinbock, Arras, & London, 2012). At least in principle, utilitarians are able to provide definite answers to specific questions about how one ought to act. The question of whether it is ever morally permissible to be untruthful depends upon context and circumstances—in those situations where telling a lie would produce, overall, more happiness or value than unhappiness, then telling a lie would be morally justified.

As with deontological theories, there are two versions of this theory: an act-utilitarian is primarily concerned with the consequences of particular acts, whereas a rule-utilitarian is more concerned about the consequences of general policies. To illustrate the difference between these versions, imagine that a nurse is trying to decide if it would be morally right to help a terminally ill patient die. An act-utilitarian would try to determine which alternative in this particular situation would maximize happiness or minimize suffering, or both. The considerations included in making that determination would be the nature of the disease and the certainty of prognosis, the presence of a treatable depression, whether the patient really wanted to die or needed better palliative care (PC), the impact on the patient’s family, and the professional repercussions for the nurse.

In contrast, a rule-utilitarian uses the principle of utility to formulate and justify moral rules, viewing the correct moral rules as those that promote the greatest happiness for the greatest number (Steinbock, Arras, & London, 2012). In this particular case, the nurse would ask whether a general rule permitting assisted suicide would maximize happiness. Important considerations of this approach include questions about whether such a practice would put us on a slippery slope and threaten the lives of other terminally ill patients who do not really want to die but might feel obliged or are susceptible to being coerced. Thus, a rule-utilitarian might agree that although helping this particular patient to die might maximize happiness (or minimize suffering) for the individual, it would still be wrong because of the larger negative consequences of a general policy permitting assisted suicide (Steinbock, Arras, & London, 2012).

How would a Kantian resolve this nurse’s problem? Steinbock, Arras, and London (2012) suggest that the categorical imperative gives less guidance—it functions only to tell us what *cannot* be done, and not what *should* be done. The principle of universalizability is just one value in Kantian ethics; the other mandate is respect for persons. The question would

then be reframed: Does a policy of assisted suicide promote respect for persons, or would such a policy lead to the devaluing of human life and to nonvoluntary killing of the weak, the vulnerable, and the poor? Each of these theories has strengths and limitations, but neither ethical theories nor principles alone will provide a formula for resolving specific ethical questions. What they do provide is a framework for trying to reach workable solutions to complex and difficult questions (Steinbock, Arras, & London, 2012).

## Focus on Caring

An ethic of caring that focuses on relationships and responsibility is one aspect of the broader field of feminist ethics. This ethic stems in part from a criticism of traditional ethical theories as being biased in their representation of the experiences of men rather than women. Another dimension of feminist ethics is the analysis of oppression and dominance within relationships and social institutions. It is certain that power differentials among nurses (who are more often women), physicians, patients, administrators, and payers illustrate just some of the relational inequalities that exist in most health care organizations (Davis et al., 1997). *Caring*, within the context of an *ethics of care*, refers to “care for, emotional commitment to, and willingness to act on behalf of persons with whom one has a significant relationship. Noticeably downplayed are Kantian universal rules, impartial utilitarian calculations, and individual rights” (Beauchamp & Childress, 2008, p. 369).

The idea of an ethic of caring is particularly appealing to nurses because caring is considered to be the very foundation of their practice. Sara Fry, a nurse philosopher, proposed caring as a fundamental value for the development of a theory of nursing ethics (Fry, 1989). Care for others is a core notion in an ethic of care, and is evident in the ANA *Code for Nurses* (2001), which mandates respectful care of the individual as its core tenet. Wright and Brajtman (2011, p. 26) acknowledge that “nursing is unique in how it cares; what is unique about nursing is the nature of the work that nurses do.” They describe the importance of maintaining relationships in health care encounters by acknowledging the power of narrative and “embodied knowing,” writing: “Nurses’ moral identities are dialogical, narrative, relational, and contextual, where moral responsibility in nursing involves striving to do good in situations that are never the same twice” (p. 26).

Fry, Killen, and Robinson (1996) maintain that:

the actions and judgments made using care-based reasoning must be measured against what it means to be “caring” within the context of the



responsibilities the decision maker has to others... [C]are-based reasoning does not involve the application of abstract ethical principles to the situation or impartiality on the part of the decision maker. (p. 42)

Critics of the ethics of care posit that it is not clearly defined and distinguished from other approaches (Edwards, 2009). Thus, an ethic of care is not yet adequately developed to function as a conceptual theory for identifying “right” actions in morally troubling situations.

## ■ ETHICAL PRINCIPLES AND CONCEPTS

The major ethical principles of significance to nurses are respect for persons and autonomy, beneficence, nonmaleficence, and justice. The duties of veracity, fidelity, and confidentiality are moral rules derived from these principles that further guide and direct nursing actions. These moral rules are embedded in the provisions of the *Code of Ethics for Nurses* (ANA, 2001). One particular rule that resonates for nurses who care for patients at the EOL is the proscription that “nurses may not act with the sole intent of ending a patient’s life even though such action may be motivated by compassion, respect for patient autonomy, and quality of life considerations” (p. 8).

There may be occasions when moral agents feel obliged to question these rules and their appropriateness in particular circumstances, and they may wish to “appeal” to a higher level of moral authority (Veatch & Fry, 1995). Perhaps, a nurse may question whether it is *always* wrong to “act with the sole intent of ending a patient’s life” and to ask whether other duties, such as mercy and compassion, might sometimes prevail. This higher level of authority within a moral framework consists of ethical principles.

### Respect for Persons and the Principle of Autonomy

The most fundamental ethical principle within nursing practice is the principle of respect for persons. The first provision in the *Code for Nurses* (ANA, 2001) calls for nurses to “Practice with compassion and respect for the inherent dignity, worth, and uniqueness of every individual, unrestricted by considerations of social or economic status, personal attributes, or the nature of health problems” (p. 7).

The principle of respect for persons is broader and more abstract than the principle that addresses individual autonomy and self-determination. Respect for persons requires that each individual be treated as unique and entitled to treatment that is respectful of

their human dignity. It is this principle of respect for persons that requires particular justification before we are permitted to interfere with the plans, privacy, or behavior of autonomous adult persons, and specifically constrains *paternalistic* decisions made by health professionals for patients with decision-making capacity.

The concept of autonomy is multidimensional and in its broadest sense incorporates the following: having a minimum of relevant information; self-determined choice; freedom to act on the basis of one’s choices; and self-governance (Yeo, Moorhouse, & Dalziel, 1996). Autonomous (or decisionally capable) persons determine their own course of action in accordance with a plan chosen by themselves. An autonomous action is understood as one done intentionally, with understanding and without controlling influences that determine the action (Beauchamp & Childress, 2012).

How are nurses to understand and apply this principle? This principle guides nursing actions in that nurses are duty-bound to respect patients’ autonomous choices in all situations unless this principle is overridden by another moral principle of greater weight or standing (Fry, 1987). Such would be the case when questions are raised about whether the choice is truly autonomous, whether the choice is perceived as harmful to the individual or others, and in other situations where autonomous choice is not possible. In these situations, the nurse’s obligation to prevent harm to others or to benefit the patient may be determined to have greater moral weight. The example of intervening to prevent a suicide is not a good example of such a situation, because the rationale for preventing suicide is that the individual is not acting rationally (i.e., autonomously). Consider, instead, that a patient writes an advance directive (AD) stipulating that he not be fed—either artificially or by spoon feeding—in the event that he develops dementia and does not recognize family and friends. Imagine that he develops Alzheimer’s disease that is in an advanced stage. The staff members at the nursing home where he is living may argue that to withhold freely accepted oral feedings from this patient would cause a greater harm to him than overriding his prior wishes that he not be fed, and may be construed as negligence on their part.

It is the principle of respect for persons and autonomy that is the foundation of informed consent. According to this rule, persons must be given sufficient, accurate, and complete information necessary to make informed decisions about treatment choices. This includes decisions to accept, refuse, or terminate treatments, whether or not these treatments are necessary for sustaining or prolonging life.

## Limiting Autonomy

Nurses who care for patients at the EOL may sometimes wonder whether they ought to intervene to prevent harm that they fear may result from a patient's decision. Put another way, are clinicians ever justified in limiting or interfering with a person's autonomy? The two most frequently occurring ways that health care professionals infringe upon patient autonomy are through control of information (e.g., withholding, deceiving, or equivocating), or through preventing a patient from acting upon his or her choice (e.g., refusing to comply or assist, constraining, or forcing treatment; Yeo, Moorhouse, & Dalziel, 1996). This type of interference, known as *paternalism* or *parentalism*, occurs often in health care and is done with the best of intentions; indeed, by definition it is understood as an intervention that is imposed for the patient's good or benefit.

In fact, paternalistic actions such as deception, breaking promises, or interfering with adult choices are violations of moral rules that are never morally permitted unless an adequate reason is provided. To justify such violations, philosophers Culver and Gert (1982) argue that we must determine whether we would publicly advocate this kind of violation in all similar situations. "If all rational persons would agree that the evil prevented by universally allowing this violation would be greater than the evil caused by universally allowing it, the violation is strongly justified" (p. 149). This would be a difficult standard to meet for those who presume that justification exists for telling a lie based solely on the belief that doing so would benefit another. On the other hand, a classic example given to justify lying is the case of a Dutchman who hid a Jewish family during World War II and lied to a Nazi officer to protect the Jewish family. In considering circumstances when limitations on autonomy may be justified, "weak" paternalism is sometimes accepted to prevent persons from causing themselves serious harm. In this view, one would be justified in interfering to prevent a significant harm from occurring, but only when the person's conduct is substantially non-voluntary or nonautonomous (Yeo, Moorhouse, & Dalziel, 1996)—for example, stopping a patient about to jump out of a hospital window. To justify this type of interference, one would have to demonstrate that the presumption of autonomy or self-determination is no longer held, and that the person's choices were in fact no longer autonomous or freely chosen.

"Strong" paternalism, in contrast, involves limiting or interfering with the self-determination of someone whose autonomy is not in question (i.e., an adult capable of rational decision making), and thus is very rarely justified. For example, a decisionally capable person who at the end of her life makes a thoughtful

and considered decision to stop eating and drinking would be seriously wronged or harmed if a clinician were to override her decision and insert a feeding tube or intravenous line to prolong her life. Paternalistic behavior, regardless of how good the motives or the size of the benefit gained or the harm avoided, violates the right of an adult to be treated as a person. To disregard a person's life plans and values in such a fashion is to show contempt for them as persons, or in Kant's terms, it is to treat them as mere means to an end, rather than as an end in themselves.

Before an act of paternalism can be considered justified, each of the following conditions must be present (Benjamin & Curtis, 1992):

1. The patient's capacity for rational reflection must be significantly impaired. This (*autonomy* condition) must be clinically determined and substantiated.
2. The patient is likely to be significantly harmed unless interfered with (the *harm* condition).
3. It is reasonable to assume that the patient will, at a later time, with recovery of capacity for rational reflection, ratify or agree to the decision made to interfere (the *ratification* condition).

## Questions About Capacity for Autonomous Choice

Patients should be assumed to have the capacity to make decisions for themselves unless there is clear evidence to the contrary (Beauchamp & Childress, 2012). Clinical judgments about a person's decision-making capacity play a gatekeeping role in health care by distinguishing those whose decisions should be solicited and honored from persons whose decisions need not or should not be solicited or accepted (Beauchamp & Childress, 2012). Patient capacity is often neither completely present nor totally absent, as is particularly the case in some elderly persons who may evidence a level of capacity that waxes and wanes. When capacity waxes and wanes, caregivers should take advantage of opportunities to engage the patient in decision making and advance-care planning when the patient's capacities are at their best (Lynn et al., 1999). Capacity is best understood as task-specific, in that a higher level of capacity is required for decisions associated with serious consequences (i.e., agreeing to a proposed surgical intervention) compared to decisions about choosing meals or where to eat them (Mezey, Mitty, & Ramsey, 1997). A capacity determination is a clinical judgment made by caregivers who know the patient best. When the stakes of a capacity determination are particularly high or the determination is contentious, clinicians may wish to seek a psychiatric consultation to assist in the capacity determination. In these instances, it is important to distinguish between



a decision-making capacity assessment, which is situation-specific, and a mental competency assessment, which is global. For example, individuals may lack the decision-making capacity to complete a living will while retaining the decision-making capacity to appoint a health care agent.

There are occasions when nurses may question whether a treatment choice reflects what the patient truly wants or whether the patient's decision was informed and autonomous. Nurses may want to know whether the patient is capable of making an informed and autonomous choice and whether they should comply with a decision that seems inconsistent with previously stated wishes or values.

### Assessing Decision-Making Capacity

A decisionally capable person is able to understand a proposed intervention (or its termination), deliberate regarding major risks and benefits, make a decision in light of that deliberation, and communicate the choice to others. The following is information that decisionally capable patients should understand:

- His or her condition for which the intervention is recommended
- The nature of the recommended intervention
- The risks and benefits of the recommended intervention, of alternative interventions, including no intervention or treatment

Caregivers should determine the following:

- The patient acknowledges that treatment is recommended
- The patient understands how the proposed treatment or lack of treatment can affect his or her quality of life (QOL)
- The patient's decision is not substantially based on a delusional belief (Yeo, Moorhouse, & Dalziel, 1996, pp. 99–100)

These criteria are intended to establish whether the patient is capable of making a rational choice, not whether the choice being made is right or wrong in itself.

### Deciding for Others

If a patient lacks the capacity to make informed choices, other means must be identified for surrogate decision making. There are three standards for surrogate decision making: written ADs (e.g., living wills), substituted judgment, and best interest. These three standards are ordered so that ADs have priority over the other two, and substituted judgment has priority

over the best-interest standard (Lynn et al., 1999). The best of all situations is a thoughtfully drafted AD applied by a surrogate decision maker who knows the patient's values and wishes well.

The substituted judgment is a subjective standard that is ideally based on knowledge of the patient's wishes, values, views about particular interventions, and QOL determinations. If a patient has completed an AD, this should inform the surrogate's substituted judgment assessments. Realistically, a surrogate's knowledge about the patient's goals and values is typically not entirely clear and decisive regarding a particular choice of treatment (Lynn et al., 1999). These authors state that "in practice, surrogate decision making for incompetent patients often has to draw on all three standards for decisions about an incompetent patient's care" (p. 273). The best-interests standard is used when the patient's treatment wishes, or values, are unknown. Under these circumstances, the decision maker must objectively weigh the expected benefits and burdens associated with the treatment recommended by the health care team and determine what would be best for this patient.

Nurses have an important role to play in surrogate decision making; the surrogate must be encouraged to focus on what the now noncommunicative patient would want if he or she were able to communicate. It is often difficult for grieving family members to put aside their own distress about the implications of honoring patient preference, especially when the decision involves withholding or withdrawing life-sustaining treatments (LSTs). While the patient retains capacity, he or she should be encouraged and guided by nurses to discuss EOL choices with family members or other potential surrogate decision makers. Nurses are well positioned to describe to patients and their loved ones the actual risks and benefits that are known to be associated with the use of interventions such as cardiopulmonary resuscitation (CPR), tube feedings, and mechanical ventilation. As Perrin (1997) notes, "advance directives are unlikely to have an effect on care if a health care provider, proxy, or family member does not support and advocate for following the person's wishes" (p. 25). Yet, even when patients complete ADs, clinicians observe that the ADs often are unavailable or not applicable in many of the clinical situations faced by seriously ill adults (Fagerlin & Schneider, 2004).

■ **Use of Advance Directives.** Researchers investigating how ADs actually function in various clinical settings have explored whether the presence of an AD ensures compliance with patients' EOL wishes. A number of commentators agree that there are persistent difficulties associated with use of *written* directives; these include incomplete information, the inability to anticipate future medical conditions,

and uncertainty regarding the meaning and intent of written instructions (Fagerlin & Schneider, 2004). These problems of interpretation require clinicians to seek information from others in their attempt to determine what the patient “really meant” (Tonelli, 1996). Tonelli and others conclude that because of the limitations associated with use of written instructive directives, proxy or appointment directives are the preferred form of AD (Dexter, Wolinsky, Gramelspacher, Eckert, & Tierney, 2003; Perkins, 2000; Tonelli, 1996). Yet, surrogates also have difficulties accurately predicting the EOL treatment preferences of their spouses. Shalowitz, Garrett-Mayer, and Wendler (2006) reviewed 16 studies on surrogate accuracy published between 1966 and 2005 and found that, overall, surrogates are inaccurate 32% of the time (Shalowitz, Garrett-Mayer, & Wendler, 2006). Perkins (2007) argues that ADs promise more control over future care and EOL decisions than is possible to achieve. He concludes that “advance care planning must refocus from completing ADs to preparing patients and families for the uncertainties and difficult decisions of future medical crises” (p. 51). Clearly, there is a need for further research to explore whether ADs facilitate good EOL care, and nurses are ideally situated to direct and participate in furthering the understanding of the practical use of these documents.

In the absence of a thoughtful discussion that includes general EOL values and specific preferences about use of interventions such as artificial nutrition and hydration (ANH), the legally appointed surrogate may be poorly prepared to identify or implement treatment decisions that conform with the patient’s actual EOL preferences. In addition, family stress associated with decisions to withdraw LSTs from decisionally incapacitated patients has been found to be high in the absence of a completed AD (Tilden, Tolle, Nelson, & Fields, 2001).

Some have advocated for better methods of approaching EOL care planning. Waldrop and Meeker (2012, p. 367) identify types of advance care planning and barriers to effective communication about EOL preferences, including lack of physician education; inadequate methods for providing information; lack of protocols for such communication; reluctance to discuss death; difficulty discussing the unknown; and inadequate shared understanding about values and implications among the patient, family, and care provider. The Respecting Choices model ([respectingchoices.org/](http://respectingchoices.org/)) has been shown to achieve higher AD completion rates, based reportedly on better staff training in discussing EOL care planning. Bomba, Kemp, and Black (2012) posit that a state-based “physician orders for life-sustaining treatment” (POLST) form (out-of-hospital

order form for LST) may be an improvement over traditional ADs.

## Beneficence and Nonmaleficence

*Beneficence*, known generically as doing good, is often hard to separate from *nonmaleficence*, or the duty not to inflict harm. Some philosophers argue that the principle of beneficence includes four rules (Frankena, 1973):

1. One ought not to inflict evil or harm (what is bad).
2. One ought to prevent evil or harm.
3. One ought to remove evil.
4. One ought to do good or promote good.

These rules are prioritized in that the first takes precedence over the second, which is in turn more compelling than the third, which takes moral precedence over the fourth, all things being equal (Frankena, 1973). Although it can seem difficult in clinical practice to distinguish preventing harm from providing benefit, Benjamin and Curtis (1992) believe that it is easier to get agreement on what constitutes harm than on what constitutes a benefit. When the duty not to inflict harm conflicts with the duty to provide benefit, there is agreement that, all things being equal, there is a greater obligation not to injure others than to benefit them (Beauchamp & Childress, 2012).

In health care, the principle of nonmaleficence is understood as requiring clinicians to avoid intentionally causing patients unnecessary harm or pain, whether psychological or physical. Neither the principle of nonmaleficence nor any of its derived moral rules are absolute. We often do harm to patients in order to benefit them or to prevent a greater harm from occurring—administering chemotherapy to treat cancer is an obvious example. What is morally relevant is whether causing the harm is morally justified. Under most circumstances, death is considered a major harm; the question of whether causing death is ever justified is an issue of significance to nurses who provide care at the EOL.

Patients at the end of their lives may be particularly vulnerable to harm. They are harmed when they receive unwanted or unnecessary interventions, are overtreated with burdensome technological interventions that serve only to prolong dying, and also when treatments are unjustifiably withdrawn without their consent or agreement. Most certainly, they are harmed when their pain is not managed adequately due to the nurse’s fear that the patient’s death might be hastened as a result of pain management with high-dose opiates. The *Code of Ethics* (ANA, 2001) not only stipulates that nurses should “not act with



the sole intent of ending a patient's life," but also requires that "the nurse should provide interventions to relieve pain and other symptoms in the dying client even when those interventions entail risks of hastening death" (p. 8).

### Balancing Good and Evil: The Principle of Double Effect

Any discussion that includes attempts to distinguish between harming and benefiting patients often includes the principle of double effect. Developed by Roman Catholic moral theologians in the Middle Ages, this principle is applied to situations in which it is impossible to avoid all harmful action and a decision must be made about whether one potentially harmful action is preferable to another (Quill, Dresser, & Brock, 1997). This principle is used to justify claims that the results of an act that would be morally wrong if caused intentionally are permissible if foreseen but unintended. The principle is often cited to explain why certain forms of care at the EOL that result in death are morally permissible and others are not (Coyle, 1992; Latimer, 1991; Quill, Lo, & Brock, 1997; Schwarz, 2004b; Truog et al., 2008).

The traditional formulation of this principle stipulates that the following four conditions be met before an act with both good and bad consequences may be morally justified (Schwarz, 2004b):

1. The action itself must be good or at least morally indifferent.
2. The individual must sincerely intend only the good effect and not the evil.
3. The evil effect cannot be the means to the good effect.
4. There must be a proportionately valid reason for permitting the evil effect, that is, there must be a favorable balance between the good and the evil effects of the action.

The first condition determines whether the potential action is ever permissible, whereas the second and third conditions are used to determine whether the potential harm is intentional or unintentional, either as a means or as an end in itself. The fourth condition requires the agent to compare the net good and bad effects of the potential act to determine which course produces an effect of proportionally greater good (Quill et al., 1997).

Nurses may appeal to this principle in morally difficult situations where it is not possible to benefit a patient by an action without at the same time causing harm. An example is that of a dying patient on a ventilator, for whom a decision is made to withdraw

the ventilator, and death is expected. Medications like morphine sulfate given to avoid respiratory distress during the process of stopping the ventilator might also hasten the patient's death. The nurse has a moral duty to prevent and remove evil (respiratory distress) that appears to conflict with the duty to benefit patients (protect and preserve life). The answer to the question of whether the nurse may administer the morphine is clearly yes. Applying the criteria of double effect illustrates why this is so (Schwarz, 2004b):

1. The action of giving an injection of morphine is itself morally indifferent.
2. The intended effect is to relieve respiratory distress, not to depress the respirations.
3. Respiratory depression is not the means by which the respiratory distress is palliated.
4. The relief of respiratory distress and the related reduction of suffering combine to provide a sufficiently important reason, or proportionately greater good than the harm that is incurred—respiratory depression and likely death.

Although this moral analysis is consistent with the position found within the *Code of Ethics* (ANA, 2001), some question the clinical usefulness of this principle as a guide to ethical decision making (Beauchamp & Childress, 2012). In particular, some clinical experts in PC challenge the purported "double effect" of opiate use in terminally ill patients, and describe the likelihood of a secondarily associated hastened death as an "overblown myth" (Manfredi, Morrison, & Meier, 1998, p. 139). Indeed, some studies have shown that opioids do not hasten death in terminally ill patients, particularly in patients who are not opioid naïve, because individuals develop a tolerance to an opioid's respiratory depressant effect (Bakker, Jansen, Lima, & Kompanje, 2008; Portenoy et al., 2006). Macauley (2012) found that some ethics educators mistakenly believe that opioids are likely to cause significant respiratory depression that could hasten death in terminally ill patients, and others who do not believe this still rely on the principle of double effect to justify this possibility, which may contribute to clinical misperceptions and underuse of opioids at the EOL.

Experienced PC nurses recognize that death sometimes occurs secondarily as an unintended, though foreseen, side effect of medications used to manage refractory symptoms in dying patients. Despite the clear legal and moral consensus supporting the appropriateness of such interventions, when a patient dies immediately after a nurse provides analgesia, it can *feel* to the nurse that he or she is causing the patient's death. However, ethics is based on providing

well-reasoned justifications to support a given action, rather than relying on feelings alone. Nurses must be well versed in the ethical justification supporting actions to reduce patients' suffering at the EOL, even if such actions hasten a patient's death. Nurses are encouraged to also consult the ANA (1994) position statement on active euthanasia, which states that "risking the hastening of death through treatments aimed at alleviating suffering and/or controlling symptoms [is] ethically acceptable and [does] not constitute active euthanasia."

## Justice

The last principle that may facilitate nurses' decisions about EOL care is justice, which is understood broadly as fairness. Justice involves the determination of what someone or some group is owed, merits, deserves, or otherwise is entitled to (Yeo, Moorhouse, & Donner, 1996). At the societal (macro) level of resource allocation, the concept of justice includes questions of how scarce resources ought to be distributed and what should "count" as morally relevant differences between individuals in order to justify differences in treatment. Microallocation issues involve determining which particular person will receive a specific and limited resource. A number of criteria for making such selections include likelihood of medical benefit, random selection criteria, and present and future quality-of-life criteria (Yeo, Moorhouse, & Donner, 1996). It is generally agreed that if a medical intervention will not benefit a patient, it is considered futile, and as such its use is morally and professionally unwarranted. Medically futile interventions should not be proposed or offered to patients or families. As an illustration of how questions of futility have been clinically addressed, Choi and Billings (2002) describe a Texas law cited by Fine and Mayo that attempts to remedy a situation that can occur when clinicians feel forced to provide medically inappropriate or futile care to terminally ill patients whose families insist that "everything be done" to avoid death. Under this Texas law, a detailed process of negotiation includes consultation with an ethics or medical committee; the option of family participation in the committee deliberations; and if the committee concludes that treatment is medically inappropriate, giving the family 10 days to transfer the patient, appeal to the courts, or accept that life support will be withdrawn. The concept of "medically inappropriate" treatment is broader than the concept of "medically futile" treatment. Both, however, involve analyzing probabilities of achieving a desired goal, and weighing proposed benefits against imposed burdens. For example,

when considering whether CPR attempts would be medically futile, Westphal (2008) reported survival data to hospital discharge for patients with advanced cancer in the 6%–7% range. This rate does not meet the criterion of medical futility that Schneiderman and Jecker (1995) proposed—that a treatment should be considered medically futile if it has not achieved its intended goal in the last 100 cases. Nevertheless, Varon and Marik (2007) argue that obtaining do-not-resuscitate (DNR) orders for patients with advanced cancer is *medically inappropriate*, whether or not it fits the definition for being *medically futile*. Still, others question whether we have become so reliant on medical technology that we should view CPR attempts as a kind of EOL ritual to assuage the grief of survivors (Mohammed & Peter, 2009).

At the bedside level, clinicians cite justice to support all individuals who are terminally ill receiving access to high-quality PC. In the current era of cost containment and social injustice, some fear that those who are already marginalized and disadvantaged by poverty, chronic or terminal illness, old age, cultural and racial status, or gender may feel a duty to die in order to spare families financial or emotional strain (Bergner, 2007). Individual nurses or other health care professionals will not resolve these complex issues at the bedside. However, many who advocate for U.S. health care reform agree that cost must be considered in the allocation of health care resources (Emanuel, 2008). How to do this fairly requires inter-professional understanding and cooperative effort among all affected parties within society (American College of Physicians, 2008; Scheunemann & White, 2011). Meanwhile, the *Code for Nurses* (ANA, 2001) stresses that the nurse's commitment is to particular patients, "unrestricted by considerations of social or economic status, personal attributes, or the nature of their health problem" (p. 7) and regardless of the cost of their care to society. The challenge for caregivers is to reach ethically supportable decisions that are fair to individual patients while using available resources responsibly, and to treat comparable cases alike.

## ■ ELEMENTS OF A DECISION-MAKING FRAMEWORK

When nurses must choose between alternative courses of action that seem equally unattractive, they experience an ethical dilemma. The decision will have significant implications for the well-being of the patient, involved family members, and others affected by the choice. The nurse's ability to provide an ethically defensible rationale for decisions is recognized as



foundational to professional practice and the integrity of individual nurses (Davis et al., 1997). Rushton and Reigle (1993) argue in support of a shared decision-making model that promotes patient well-being and self-determination. According to this model, the health care team offers expert knowledge, treatment recommendations, and advice about medically available and appropriate options to the patient (patient/family unit). The patient decides which option will best promote his or her life goals and values. The nurse is particularly well positioned to understand the values that inform patients' choices and to appreciate the context of a patient's whole life, including the patient/family unit; their cultural, religious, and spiritual affiliations; and other unique preferences. The nurse is a vitally important member of this decision-making team.

When a clinical problem is identified as ethical and conflicts in moral values or ethical principles are present, the following steps will assist the nurse to discuss, analyze, and successfully develop an ethically supportable decision:

1. Review the overall situation—identify what is going on in this case.
2. Gather all relevant facts about the patient and his or her contextual situation, including:
  - Significant medical and social history
  - Decision-making capacity
  - Existence of any advance treatment directives—written, appointed, or verbal, and any pertinent institutional policies
3. Identify the parties or stakeholders involved in the situation, including those who will be affected by the decision(s) made.
4. Identify relevant legal data, including both state and federal laws.
5. Identify specific conflicts of ethical principles or values. Identify and consider nursing guidelines and the profession's code and position statements.
6. Identify possible choices, their purpose, and their probable consequences to the welfare of the patient, who is the focus of primary concern. Identify and make use of interprofessional and institutional resources such as institutional and nursing ethics committees, ethicists, chaplains, social workers, and other experienced colleagues.
7. Identify practical constraints to decision making (e.g., institutional, legal, organizational, political, and economic).
8. Take action if you are the decision maker and implementer of the decision(s).
9. Review and evaluate the situation after action is taken in order to determine what was learned that will help in the resolution of similar situations in patient care and policy development (Cassells & Gaul, 1998; Davis et al., 1997).

## ■ CONCEPTUAL CONFUSION AND DIFFICULT DECISIONS IN END-OF-LIFE CARE

The final segment of this chapter explores issues of patient autonomy and decisions about EOL interventions that range from instances of allowing or permitting death to hastening or intentionally causing death, and how these decisions are understood by nurses.

### Autonomy and the Refusal of Life-Sustaining Treatment

If the concept of autonomy means anything at all, it means the right to accept or refuse medical treatments. Decisions about the use or withdrawal of LSTs are often complex and value laden, in part because such decisions may forestall or hasten the time of death. Decisions regarding use of LST may also influence the patient's experience of the final stage of life by determining where death occurs, who is present, and whether the patient is able to communicate with loved ones.

The concept of LSTs includes any medical or nursing intervention, procedure, or medication, no matter how simple or complex, that is necessary for continued life. In the past, some treatments were considered ordinary and morally required, while others were called extraordinary and considered optional. This distinction between ordinary and extraordinary treatments has a prominent history within the Roman Catholic tradition and was used to determine whether a patient's refusal of treatment should be classified as suicide. Within that faith tradition, refusal of ordinary means was considered by some to be an unacceptable decision that was morally equivalent to an act of suicide (Beauchamp & Childress, 2012).

*Optional or nonburdensome treatments* include all medications, treatments, and operations that offer a reasonable hope of benefit and can be obtained and used without excessive expense, pain, or other inconvenience from the patient's perspective. *Extraordinary* (or *burdensome*) treatments are those that are very costly, unusual, difficult or dangerous, or do not offer a reasonable hope of benefit to the patient (Davis et al., 1997). What should be of moral concern for nurses is not what the intervention is, but whether the benefits of its continued use outweigh its associated burdens, as determined by the patient or surrogate decision maker.

### Withholding and Withdrawing Life-Prolonging Treatments

Many health care professionals and family members are more comfortable not initiating LSTs than stopping them once begun. However, the question to be

answered is whether this psychological fact has any moral significance (Beauchamp & Childress, 2012). Some clinicians regard withdrawing LST as “letting die,” an act previously referred to as *passive euthanasia*, while others view withdrawing LST as an *act* that feels more like causing death, or killing. Withdrawing LSTs may be experienced as morally problematic for some nurses, particularly those who emphasize the “sanctity of life” and believe that continued life is an intrinsic good, regardless of burdens imposed by illness. However, nurses should be familiar with the legal and moral consensus that recognizes no moral distinction between withholding and withdrawing LSTs.

This consensus began to emerge in the early 1980s when a presidential commission was created to explore significant ethical issues in health care (President’s Commission, 1983). One of their reports, entitled “Deciding to Forego Life-Sustaining Treatment,” maintains that “neither criminal nor civil law—if properly interpreted and applied...forces patients to undergo procedures that will increase their suffering when they wish to avoid this by foregoing life-sustaining treatments” (p. 89). The commission further held that “the distinction between failing to initiate and stopping therapy—that is, withholding versus withdrawing treatment—is not in itself of moral (or legal) importance. A justification that is adequate for not commencing a treatment is also sufficient for ceasing it” (p. 61).

There is a clear ethical consensus that LSTs may be withheld or withdrawn under certain circumstances—in particular, when its use is against the patient’s wishes (provided the patient is fully informed and freely consenting), when it will or has begun to harm the patient, or when it does not or will not benefit the patient (Beauchamp & Childress, 2012). The ANA (1994b) position statement on assisted suicide similarly encourages nurses to honor the refusal of treatments that an informed patient does not want, either because they are deemed overly burdensome or because they will not benefit the patient. This position statement specifically notes that when nurses participate in decisions to forego LSTs or provide other interventions aimed at relieving suffering that have an associated risk of hastening death, these acts are ethically acceptable and do not constitute assisted suicide.

### Withdrawing Artificial Nutrition and Hydration

Often the most difficult decisions about withholding treatments are those that involve simple noninvasive therapies, such as the use of antibiotics, and those that are symbolically linked to caring and nurturing

interventions, such as providing food and fluids. “Artificial” or technologically provided nutrition and hydration must be distinguished from the oral provision of food and water. Although dying patients typically experience a decline in appetite as death nears, nurses should continue to offer fluids and food as long as patients indicate any interest or derive pleasure in eating or in drinking fluids. The administration of ANH is viewed differently. A moral and legal consensus concludes that ANH is a medical treatment that may be refused or withdrawn on the same grounds as any other medical intervention, that is, on an estimation of its expected benefit or burden to the patient (Beauchamp & Childress, 2012). Ethical difficulties arise when it is unclear whether continued provision of nutrition is more beneficial or harmful to the patient.

Evidence suggests that routine use of ANH in the care of terminally ill persons is unwarranted, and that providing ANH is unlikely to achieve the clinical outcomes for which it is most often employed, for example, to enhance comfort, prolong survival, and improve QOL (Choi & Billings, 2002; Ersek, 2003; Suter, Rogers, & Strack, 2008).

In cases where a patient is unable to make his or her wishes known, or is unable to evaluate the benefits or harms of refusing ANH, a surrogate decision maker should help inform the health care staff regarding the patient’s stated wishes or known values or beliefs relevant to a decision about whether to provide ANH based on a substituted judgment or best-interest standard. Nurses should know whether their state’s legislative policy restricts or limits surrogates’ rights to decide about the administration of ANH.

### From Letting Die to Assisted Dying

Nurses who regularly care for dying patients may experience requests for assistance in dying (AID) from patients or family members. Interest in clinician-provided assisted dying is thought, in part, to reflect an American public increasingly fearful of the process of dying, particularly the possibility of dying a painful, protracted, and undignified death that lacks personal control or meaning (Schwarz, 2004a). Gallup’s 2011 annual survey on values and beliefs found that 48% of Americans believe that “doctor-assisted suicide” is morally acceptable. More Americans believe doctors should be allowed by law to “end” a terminally ill patient’s life by some painless means if the patient and family request it. Support for euthanasia has always been higher than support for doctor-assisted suicide. Some suggest that the option of voluntarily stopping eating and drinking (VSED) may be a preferable alternative to physician-assisted dying when suffering patients seek information about hastening



death (Berry, 2009; Terman, 2007). Other PC clinicians consider VSED to be an option of last resort for those whose suffering is intractable (Quill & Byock, 2000). Schwarz (2008, citing 42 U.S.C. § 5106g(6)) argues that nurses ought to respond to dying patients' questions about EOL options that may permit them to control their own dying; VSED is one such option that patients may legally choose.

### The Oregon Death With Dignity Act

Since 1997, physician-assisted dying has been a legally available EOL option in Oregon for terminally ill, decisionally capable citizens who make repeated, documented, voluntary requests for such assistance. In Oregon, a physician may write a prescription for a lethal amount of medication following a 15-day waiting period, between the first and second oral requests for assistance and after receiving a written request by the patient. The physician also must determine that the patient is terminally ill, decisionally capable, and making an informed and voluntary request for assistance in dying, and that the patient has been informed about and referred to palliative and hospice care. A second consulting physician must confirm that the patient is in the terminal stage of disease and the absence of any impairment in judgment due to psychiatric or other psychological disorder like untreated depression.

Oregon physicians are required by law to explore and document the reasons for their patient's request for aid in dying, and to submit that and other demographic data to the Oregon Department of Human Services, which publishes those data annually ([egov.Oregon.gov/DHS/ph/pas/](http://egov.Oregon.gov/DHS/ph/pas/)). Thus, we know the following about those who used the law in 2012: Approximately 75% of patients were diagnosed with cancer, most were 65 years and older (median, 69 years), there were about equal numbers of men and women, nearly all patients died at home, and all were enrolled in hospice and had some form of health insurance.

During 2012, 115 prescriptions for lethal medication were written, and 78 patients ingested medication (67 from prescriptions written in 2012 and 11 from prescriptions written in previous years); 77 patients died after ingesting such medication (1 regained consciousness and died of underlying disease). Each year, approximately two thirds of those who receive prescriptions actually use them, which confirms the fact that only a small proportion of terminally ill Oregonians choose to hasten their deaths by using this law. Since the law was passed in 1997, a total of 1,050 patients have died using the Oregon Death with Dignity Act (ODWDA).

Oregon physicians report that, although their patients often have multiple reasons for their decision to hasten their death, the following three concerns are consistently reported: (a) loss of autonomy, (b) decreasing ability to participate in activities that make life meaningful, and (c) loss of dignity. Disability rights advocates point to this finding as cause for concern that the growing endorsement of aid-in-dying statutes may have an unintended consequence of unwittingly legitimizing a pervasive disability bias (Golden & Zoanni, 2010).

However, to date, data from Oregon show that terminally ill Oregonians who choose to hasten their death under the provisions of the Death with Dignity Act do so infrequently, and only after thoughtful consideration and careful planning. Such measured and considered steps, in a process that requires at least 2 weeks to complete, seems to many to be distinct from acts of suicide that are frequently accompanied by impulsive, irrational, and often violent behavior. Perhaps, in recognition of that distinction, in October 2006, the Oregon Department of Human Services adopted a policy to stop using the terms "suicide" or "physician-assisted suicide" when referring to the death of persons who use the ODWDA. That policy is consistent with the actual language in the law specifically stating that actions taken in accordance with the Act shall *not* constitute suicide, assisted-suicide, mercy killing, or homicide.

Increasingly, members of some professional organizations who work with dying patients have joined in the call for use of emotionally neutral language to describe the EOL choices made by decisionally capable, terminally ill persons who are considering hastening their deaths. In 2007, the American Academy of Hospice and Palliative Medicine (AAHPM) published a position statement on physician-assisted death (PAD) that explained the reasons for their preferred use of the term PAD, stating that PAD more accurately captures the essence of the process than the more "emotionally charged designation of physician-assisted suicide" ([www.aahpm.org/positions/suicide/html](http://www.aahpm.org/positions/suicide/html)). This organization also took a position of "studied neutrality" on the question of whether PAD should be legally regulated or prohibited. Also in 2007, the American Medical Woman's Association published a position statement supporting the right of physicians to provide a competent, terminally ill patient with—but not administer—a lethal dose of medication and/or medical knowledge, so that the patient can, without further assistance, hasten his or her own death. They call this practice Aid in Dying.

No nursing organizations have taken a similar position. Indeed, in 2006, the Hospice and Palliative Nurses Association reconfirmed their opposition to the legalization of assisted suicide, and the American

Nurses Association has yet to revise its 1994 position statement opposing nurse participation in assisted suicide that includes the frequently cited definition of such assistance as “making a means of suicide (e.g., providing pills or a weapon) available to a patient with knowledge of the patient’s intention.”

Nurses hold varied views about nurse participation in assisted dying and often justify their position by referring to their own clinical experience (Schwarz, 1999). Crucial to most who argue in support of assisting in dying are duties of beneficence, compassion for irremediable suffering, and the obligation to respect the autonomy of competent persons (Daly, Berry, Fitzpatrick, Drew, & Montgomery, 1997). Some experienced hospice nurses argue for those “very occasional” patients who, despite receiving skilled PC, prefer death to the life they are left with (Stephany, 1994). Most participants in the study by Schwarz (2003, 2004a) maintained that if patients were decisionally capable, had received good EOL PC, and made a voluntary and informed decision to end their own lives, they had the right to do that, but patients did not have the right to have a nurse’s assistance in dying (Schwarz, 2004a).

The professional nursing organization opposes nurse involvement in both active euthanasia and assisted suicide; participation in either action is considered a breach of the *Code for Nurses* (ANA, 2001) and the ethical traditions of the profession. The justification for opposing nurse participation in active euthanasia is based on the principle of respect for persons, and nursing’s historical commitment “to promote, preserve, and protect human life” (ANA, 1994a, p. 2). Opposition to assisted suicide is based on the nurse’s “obligation to provide comprehensive and compassionate EOL care, which includes the promotion of comfort and the relief of pain, and at times, foregoing life-sustaining treatments” (ANA, 1994b, p. 1). The rationale for opposing nurse participation in assisted dying refers to the profession’s central moral axiom—respect for persons—as well as the duty to “do no harm.” The ethic of care and the profession’s covenant with society that historically has been to promote, preserve, and protect human life (ANA, 1994b) are also factors.

## Ethical Issues in Gerontology

Medical research and technology have extended life spans, which, together with the aging baby boomer generation, have shifted the population age demographics toward the older adult. Indeed, the fastest-growing age demographic in the United States is persons 85 years and older. While on the one hand this is a marker of success, on the other hand, it forces

more complex decisions to be made about when, if ever, to place limits on the use of medical interventions for the older adult. Should the focus be on life prolongation regardless of QOL? How should decisions be made about allocating limited medical resources to older adults, who have less time to reap the benefits of expensive and potentially risky medical therapies? What obligations are owed to caregivers of the elderly, whose lives are often greatly affected by the choices elders make about their health and living situation? Although many embrace the *idea* of caring for their aging parents, the physical and emotional caregiving burden can be overwhelming, particularly when we consider the stressors experienced by the “sandwich generation”—those caring for both their own children and elder family members at the same time or in quick succession (Rogerson & Kim, 2005).

In discussing ethics at the EOL, *end of life* usually serves as a euphemism for the process of dying and death. The term is generally reserved for those who are expected to die within a given time frame (e.g., less than 6 months) from an incurable, progressive disease. By this definition, the EOL is not restricted to the older adult. Yet, as one ages and surpasses his or her estimated life expectancy, mortality looms closer regardless of health status, causing most to include the older adult in discussions of “ethics at the EOL.” This is likely what prompted a healthy 90-year-old woman to tell her health care providers she was 10 years younger than she was to ensure that they would not “give up too easily” in providing her medical care.

However, while some fear that doctors may “give up” too easily on their elderly patients, others suggest that the over reliance on procedural, high-tech medical diagnostics and interventions is creating more burden than benefit among the elderly. Such concerns, backed by research findings, have led to a movement known as “slow medicine,” in which physicians stop to consider less aggressive alternatives before implementing high-risk medical interventions that may reap limited rewards for the elderly. In the “slow medicine” approach, patients and families must be re-educated to resist the default option of emergency department visits and hospitalizations if they are not likely to achieve the desired goal of improving QOL (Gross, 2008). Lynn and Goldstein (2003) also point out that the face of fatal illness has changed. Patients with chronic lung or heart disease, dementia, or even cancer typically face many years of chronic illness and waxing and waning health before they die from the disease. Hence, Lynn and Goldstein use the term “chronic fatal illness” instead of “terminal illness.” They advocate adjusting our approach to caregiving



and EOL planning to accommodate this longer, less predictable dying trajectory.

The question of rationing is often raised when discussing high-tech, expensive medical interventions that produce limited benefit. Could one conclude that individuals of a certain age should not be candidates for certain therapies, because they cannot reap enough benefit in their remaining years of life? It has been pointed out that age-based rationing already occurs in the United States through the Medicare program. That is, elders are *avored* in that they, unlike children in this country and the nonworking people who do not qualify for Medicaid, are assured of health care coverage. Some suggest that age-based rationing that would limit certain medical interventions (e.g., no renal dialysis or organ transplants, and certain other life-extending therapies, to those over a certain age) would be justified based on egalitarian and utilitarian arguments. The egalitarian argument is that individuals receive a greater investment of resources when they are young to allow them to be well-functioning citizens, with the understanding that as they get older, they will receive fewer resources to ensure that the next generation is able to enjoy the same investment of resources in their youth (Daniels, 1985). The problem with that argument is the same as the caveat mentioned above: Not all citizens enjoy the same access to resources before they reach their senior years. Furthermore, Jecker (1991) argues that age-based rationing would unjustly disadvantage women, whose life opportunities may have been limited due to sex discrimination; who provide the bulk of child and family member caregiving; and who, because they comprise a greater percentage of older adults, would be subjected to age-based rationing more often than their male counterparts. Finally, there is evidence that age-based rationing already exists implicitly (Hurst et al., 2006; Ward, 2000), and would only further disadvantage older persons and erode their trust in the health care system (and further diminish the respect owed to them) if it were formalized through explicit rationing schemes.

A utilitarian argument for age-based rationing is based on poorer outcomes in older adults for certain medical interventions, based on available evidence such as “quality-adjusted life years” (QALY; Dolan, 2001). Critics of this approach argue that age alone is an insufficient predictor of health care outcomes, and that if rationing of medical interventions were to be based on outcomes, such decisions should be made based on overall health indicators rather than age alone.

Many have observed that the U.S. culture is youth oriented and does not afford the older adult the respect that other cultures bestow upon their elders. We are a death-denying culture that seeks to defy

individual mortality, and thus defy the aging process (Piers et al., 2012). Some argue that elders have a duty to accept the limits of their natural life span and avoid requests beyond that point for expensive life-extending medical technology (Callahan, 2000). However, most agree that the health care reforms needed in this country cannot be achieved through strict age-based rationing (what some refer to as “hard rationing”). Rather, instead of placing no limits on aggressive, life-extending medical technology while price-rationing the more effective, efficient, and humanistic primary care, we should re-envision our health care priorities to focus on quality, justice, and caring rather than life extension alone. As Churchill wrote:

Most patients would not bankrupt their family and deny their children a fair start in life by striving for a last, expensive extension of their own lives. Neither should we extend our lives at the margins if by so doing we deprive nameless and faceless others a decent provision of care. And such a gesture should not appear to us as a sacrifice, but as the ordinary virtue entailed by a just, social conscience. (Churchill, 1988, p. 647)

Clearly, decisions about withholding or withdrawing life-sustaining therapy at the EOL can weigh heavily on health care providers. However, the more seemingly mundane decisions about resource allocation for elders in the clinician’s office or clinic may be the more difficult ones on which to reach consensus about what is just. A step in the right direction would be to put health care decisions in the hands of health care professionals and the inevitable rationing decisions in public forums where they can be debated and approached rationally and compassionately. However, others argue that rationing is already happening at the bedside, and that clinicians must be part of the process rather than perpetuate the illusion that rationing is something that only happens at a macro-level (Strech & Danis, 2012).

### Ethical Issues in Pediatrics

A cornerstone of ethics in pediatrics is recognizing the patient’s and parent’s input into medical decision making throughout the developmental trajectory. From birth to the age of majority, pediatric patients’ involvement in their medical care evolves as they grow and mature. Likewise, parents must respond to different obligations that accompany parenting an infant, toddler, child, and adolescent.

In pediatrics, as in other subspecialties, many ethical issues and dilemmas are born out of the increasingly complex medical technology that has

evolved over recent decades. A growing number of neonates, for example, require the special services of a neonatal intensive care unit (NICU). This is partly due to higher-risk pregnancies of women who delay pregnancy until later in life, and the increased reliance on artificial reproductive technologies that result in multiple gestation pregnancies (Goldenberg, Culhane, Iams, & Romero, 2008). Such pregnancies are more likely to result in premature births that require NICU support. The ensuing dilemmas were poignantly described in the seminal book, *Playing God in the Nursery* (Lyon, 1985). Many point to the NICU babies who beat the survival odds as “miracle babies” whose survival provides proof that pushing the boundaries of neonatal viability is worth the money and resources. Others suggest that providing life-saving NICU technologies to some severely compromised, extremely low birth-weight premature babies is tantamount to human experimentation (Chervenak, McCullough, & Levene, 2007). Parents and health care providers must consider several important questions when considering whether to pursue life-saving technology for an impaired neonate. These include the following:

- Is there a reasonable chance that the infant will survive?
- If the infant survives, will he or she have an acceptable QOL?
- Will future required medical care entail a net benefit or harm to the child?
- When, if ever, is a life of severe physical and/or cognitive impairment worse than death?
- Are resources available to support the future medical needs of the child?

In addition, parents must consider their own beliefs and values, and how their decision will impact other family members. For example, some parents may feel that subjecting a severely impaired infant to aggressive medical therapy that may likely result in neurological devastation and dependence on intensive medical interventions throughout childhood not only imposes undue suffering on that child, but would also place an unacceptable burden on other children in the family, who would be deprived of parental attention. In contrast, other parents may believe that it is their obligation to prolong their child’s life no matter what the outcome. You can see here that the former example leans more toward *consequentialism*—deciding what to do based on outcomes, whereas the latter example leans more toward *deontology*—deciding what to do based on moral duty, regardless of outcomes.

In the unique setting of the NICU, and labor and delivery ward, parents do not have the final say about whether infants receive life-saving interventions.

In the early 1980s, a case gained national attention involving an infant born with Down syndrome and esophageal atresia. The parents refused a routine surgical procedure to correct the deformity, resulting in the infant’s otherwise preventable death. In response, the federal “Baby Doe” regulations were adopted by the Department of Health and Human Services to protect against discriminatory treatment toward babies and children with disabilities. The courts soon struck down the regulations, which hospitals protested as being overly restrictive. In 1984, Congress amended the Child Abuse Protection and Treatment Act (CAPTA) to help discourage disability bias from influencing life and death decisions, while also avoiding mandating high-tech treatment for dying infants (Schwartz, 2008). According to CAPTA, a life-prolonging therapy may be withheld or withdrawn from an infant if it is considered to:

- Merely prolong dying
- Not be effective in ameliorating or correcting all of the infant’s life-threatening conditions
- Be futile in terms of the infant’s survival

Because a baby’s prognosis for survival may not be known immediately at birth, depending on state law, if an infant is born breathing, the health care providers may be legally obligated to administer life-saving interventions. However, despite the restrictions on forgoing life support at birth, palliative comfort care should always be an option for any neonate whose prognosis for survival is poor (Catlin & Carter, 2002, Kain, 2006).

For the most part, the same process for ethical decision making applies to pediatric patients as to adults: consider the likely benefits and burdens of available choices, and act to minimize harm and maximize benefit. Children in general are considered to be “vulnerable persons” who must be protected. Generally, this involves a parent or legal guardian (“parent”) making medical decisions for the child, with assent from the child obtained if he or she is capable. Ethical concerns in pediatrics often involve differences of opinion between providers, parents, and patients about the patient’s course of treatment. Consider the case of Katie Wernecke. Katie was diagnosed with Hodgkin’s lymphoma when she was 13 years old. Her oncologist gave her an 80% chance of survival with chemotherapy followed by radiation. However, Katie’s parents wanted to forgo the radiation to pursue an alternative treatment of vitamin C infusions. How did the health care team respond? Children’s Protective Services was involved, and Katie was placed with foster parents while she continued with her radiation. Ultimately, a judge ruled that Katie should be allowed to return to her parents and pursue the alternative treatment, but



only after she finished the recommended course of radiation. Some might advocate for a less adversarial way to resolve this conflict, to maintain Katie's family integrity and harmony at a time when she most needed it. However, such decisions are difficult when lives are at stake. As you can see, neither Katie nor her parents had boundless autonomy rights. The state intervened to ensure that Katie received the medical standard of care, which provided a good chance of putting Katie's cancer into remission. This is different from how the state handles a competent adult who refuses life-saving therapy. In that case, forced treatment would be considered a form of battery.

The state recognizes a competent adult's right to refuse life-saving therapy, but usually considers the state's interest in preserving life to trump autonomy rights when a child's life is at stake. Therefore, if a parent's request falls outside an acceptable medical standard of care, health care providers may be obligated to override the parent's request. Whenever possible, this should be approached using open channels of communication between the parents and health care team to avoid the need to involve the courts.

Conflicts may also ensue when the wishes of the parent and child differ. Consider a 14-year-old child who has advanced cancer with no chance of cure, but whose life may be prolonged with another course of chemotherapy. The patient tells the nurse that she does not want the chemotherapy, is tired of fighting the cancer, and prefers to focus on being as comfortable as possible. The parents insist that the chemotherapy be started as soon as possible. In such a situation, the health care team has an ethical obligation to resolve this conflict and not proceed without the patient's assent to chemotherapy (Jacobs, 2005).

In rare cases, the rights of a "mature minor" to forego LST are recognized. For example, if a 15-year-old Jehovah's witness demonstrates a clear and consistent commitment to forego blood products, an ethical argument could be made that this young person's autonomous choice should be respected, even if the risk of death is high. However, in most situations where death is likely and reasonably avoidable, and where parents refuse life-saving interventions for their minor child, health care providers opt to petition the court to mandate life-saving treatments.

Pediatric staff should familiarize themselves with their state's law regarding "emancipated minors." These are persons recognized by the courts as able to make their own medical decisions, even though they have not reached the legal age of majority (18 years in most states). Criteria for emancipation vary from state to state, but typically include living independently from parents, having a child, and being on active duty in the armed forces. Minors are also allowed

to obtain medical treatment for certain conditions without parental permission (e.g., birth control and certain types of mental health care). The rationale for allowing these exceptions is that many teens may not seek needed medical intervention if they know a parent must be notified. Here, health care providers must continually weigh the dueling obligations that the principle of *respect for persons* demands—respecting a decisionally capable person's wishes, and protecting a vulnerable person from harm. Since a teenager's ability to make well-reasoned, mature decisions evolves over time, the degree to which his or her wishes and privacy should be respected is situation-specific. Regardless of who makes the final medical decision, children and adolescents should always be included in medical decision making to the extent that their developmental level allows.

### Barriers in the Practice Environment to Sound Ethical Practice

Nurses need to find ways to talk to each other and validate their experiences, tell their stories of despair or triumph, and share their experiences of moral uncertainty. Nurses may experience conflict between their own moral values and the values of the profession, and they have the right to remain true to their conscientious moral and religious beliefs. Although prohibited from compromising legitimate patient choices or imposing their values on others, nurses who are ethically opposed to certain patient interventions will find support for their position in the *Code for Nurses* (ANA, 2001). They have the right to withdraw from providing interventions that run counter to their core beliefs, assuming that arrangements can be made for the patient's safe transfer to the care of another.

It is undoubtedly true that some of the barriers that constrain nurses from participating in ethical decision making are situations over which the nurse has no control. For example, most nurses practice as employees in health care organizations whose goals are business oriented and whose focus is utilitarian (institutional values providing the greatest good for the greatest number). Nurses, by virtue of their education, experience, and moral commitment to caring, are focused on doing good for individual patients. Conflict inevitably arises between the nurses' roles as caregivers and patient advocates, institutional employees, and clinicians expected to implement physicians' orders (Epstein & Hamric, 2009; Hamric & Blackhall, 2007; Wiegand & Funk, 2012). The experience of being the nurse in the middle combined with the moral distress of being unable to do the right thing may result in nurses perceiving that they are unable

to act as morally autonomous agents. In such cases, nurses must learn how to address individual, interpersonal, and systemic issues that impede their moral agency and ability to advocate for ethically supportable patient care (Huffman & Rittenmeyer, 2012).

### Ethics Committees and Ethics Consultation Services

Ethical issues in clinical practice often involve life-or-death decisions, and such decisions give rise to a host of emotions and concerns. Just as physicians and patients turn to medical specialists and subspecialists for advice and consultations on questions of medicine, health care professionals and patients may need to consult an ethics committee to discuss today's perplexing ethical issues. The overall role of an ethics committee is threefold. First, the committee may educate itself, the hospital administration, and the hospital staff about ethical issues occurring in our current health care environment. Second, the committee may participate in policy development. Third, the committee provides ethics consultation. Ethics consultations are more timely, less adversarial, and more flexible than court proceedings as a way to resolve disputes. A recent survey found that 81% of U.S. hospitals (and all hospitals with more than 400 beds) have an ethics consultation service (Fox, Myers, & Pearlman, 2007). Ethics consultation is one mechanism by which a hospital may satisfy The Joint Commission's requirement to have a mechanism to address ethical issues that arise in patient care.

Different goals may be sought by ethics consultation. The American Society for Bioethics and Humanities (ASBH, 2011, p. 3) identifies the general goal of ethics consultation as improving "the quality of health care through the identification, analysis, and resolution of ethical questions or concerns." This is achieved through intermediary goals, such as helping staff to identify and understand the specific ethical issues the case raises; improving communication between the patient, family, and health care team; providing emotional support to the health team members involved in a difficult case; offering "ethically justifiable" recommendations for how to resolve an ethical question or dilemma; and improving patient care by preventing patient care decisions that run counter to ethical guidelines and standards. In addition, Dubler and Liebman (2011) focus on the goal of conflict resolution through ethics consultation.

Another goal of ethics consultation may be, as Margaret Urban Walker (1993) suggests, to "protect moral spaces" within the health care setting. According to this view, burgeoning high-tech, expensive medical technology—along with our fragmented health care system—has increased the complexity and

burden of medical decision making. Yet, health care providers have *less* time to grapple with this increasing complexity. Ethics consultations may provide one countermeasure to this trend toward fast-paced decision making by allowing patients, families, and health care providers to take a step back and reflect on the ethical issues involved before rushing to judgment about a particular case.

One issue of concern is that a majority of ethics committee members have been found to lack formal training in ethics (Fox et al., 2007). The American Society for Bioethics (2011, 2013) has identified core skills and knowledge competencies that ethics consultants (or consult services, collectively) should possess to effectively respond to consultation requests. Nurses should be knowledgeable about who serves on the ethics consultation service at their facility, how their competence is ensured, and how to access the service. Nurses should develop their own ethics knowledge and skills competencies to effectively advocate for their patients. This might involve collaborating with an institution's ethics committee to provide education and mentoring in ethics. The National Center for Ethics in Health Care's Integrated Ethics program through the Department of Veterans Affairs provides excellent resources (available to open access at [www.ethics.va.gov/integratedethics](http://www.ethics.va.gov/integratedethics)).

### Preventing Burnout

Nurses who care for dying patients often may find themselves in situations of ethical conflict; burnout is one potential consequence. To avoid the experience of burnout, nurses should seek support from peers, share experiences of uncertainty, and seek ethics advice and support for the development of skills in identifying and resolving ethical problems in clinical practice. It is most important for nurses to acknowledge their own suffering and sense of frustration in caring for patients at the EOL. For example, it can be very upsetting and discouraging to identify a treatment approach that appears to be in a patient's best interest but then be unable to implement it (perhaps due to disagreements among team members or family members about what is in the patient's best interests). Sometimes, with reflection, a morally acceptable compromise can be identified, one that preserves the underlying values of the concerned parties. Agreement to a trial of therapy and to reassess within a specified time can help resolve some of the uncertainty.

Hospitals and health care organizations that provide nurse support systems that encourage and facilitate moral growth and understanding will employ nurses who are less likely to succumb to moral passivity. Nurses should be encouraged to create their



own opportunities for support regarding EOL issues and may consider the following interventions:

1. Use of an ethics consultant can be a source of guidance and help nurses acquire the necessary skills for future application. When requesting an ethics consultation, nurses should clarify the role they would like the ethics consultant(s) to play. For example, are they looking to clarify information about ethical standards, or do they also want the ethics consultant(s) to be actively involved in mediating conflict and communicating with a patient and/or family members? It is important for nurses to remain engaged in ethical decision making when an ethics consultation is requested. This is an excellent way for nurses to improve their ethics knowledge, skills, and abilities.
2. Multidisciplinary and nursing ethics committees should be available to nurses for case consultation regarding ethical conflicts. Nurses should be members of these committees and should work in concert with professional colleagues. Multidisciplinary institutional ethics committees also develop institutional policies and guidelines and plan programs for the ethics education of staff members.
3. Interprofessional ethics rounds present an ideal opportunity for individuals working in different patient-care disciplines to discuss regularly troubling cases that may not require an immediate decision. Such meetings provide an opportunity for analysis, exploration, and sharing of different points of view. Thus, when ethical problems do occur, a foundation exists to provide guidance about the most effective way to respond. Wocial and colleagues' "unit-based ethics conversations" holds promise to improve nurses' ethics proficiency and encourage a workplace culture where moral distress does not thrive (Wocial, Hancock, Bledsoe, Chamness, & Helft, 2010).

## ■ CONCLUSION

Health care providers justifiably look for definitive answers when asking what the "right" thing to do is in a given situation. Sometimes, after sorting through the facts and stakeholder viewpoints of a troubling case, the right way to handle the uncertainty or conflict becomes apparent. But often, there is no one "right" answer. Sometimes more than one response can be ethically justified (as in the example of responding to a dying patient's request for assistance in hastening death). Other times, whatever course of action is taken requires compromising a core ethical principle, such as abiding by a patient's prior wish to be kept alive with aggressive medical technology, despite the pain and suffering it invokes with little apparent gain. Nurses should be encouraged to continue to provide compassionate care and a caring presence as they struggle, together with patients, family members, and professional colleagues, in the attempt to identify what, all things considered, ought to be done in situations of moral conflict. In doing so, we are reminded that "to the extent that care of the dying draws us into their lives, we experience the gifts and deprivations of their own deaths and painfully anticipate the death of our loved ones and even ourselves" (Dixon, 1997, p. 297).

Nurses should continually seek to improve their ethics knowledge base by looking for learning opportunities. At a minimum, they should be familiar with ethical theories of deontology (duty-based ethics) and teleology (consequence-based ethics), ethical principles, and the concepts of decision-making capacity, surrogate decision making, ADs, mature minors, consent versus assent, moral justifications for withholding and withdrawing LSTs, and responding to requests for a hastened death. Nurses should access resources to assist them in ethical decision making and in nurturing their moral agency, such as institutional ethics committees, colleagues, and the *Nurses Code of Ethics*.

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## CASE STUDY Conclusion

How does one start in addressing the question of whether Mrs. Selano's tube feedings should be continued? Cassells's and Gaul's "Ethical Assessment Framework" (1998) offers a guide. One of the first steps is to gather the relevant facts. What exactly does the living will document state? Was it properly witnessed and thereby legally valid? Why is it that Mrs. Jenkins thinks Mrs. Selano would benefit from having her tube feedings stopped at this time? Does she think that this has caused Mrs. Selano to suffer? One should involve other experts, as needed, to provide input in this fact-finding phase. In determining which options are ethically justifiable, one should consider how different ethical principles apply to the case. The two components of the principle of *respect for persons* are relevant—protecting vulnerable persons, and respecting the autonomy of competent adults. Regarding the latter, in considering whether Mrs. Selano's tube

feedings should be continued, the nursing home staff is obligated to provide medical care that is consistent with Mrs. Selano's prior stated wishes. Mrs. Jenkins has cast doubt on the validity of Mrs. Selano's living will as it relates to tube feedings. However, given that stopping Mrs. Selano's tube feedings would hasten her death, and assuming that the living will is legally valid, Mrs. Jenkins's request alone would be insufficient to warrant stopping the feedings. This exemplifies the obligation to protect Mrs. Selano as a vulnerable person. One would need a good justification for withdrawing a medical treatment that would result in hastening a patient's death. This does not mean that Mrs. Selano's tube feedings should be continued beyond the point where they are no longer achieving their intended goal. If the tube feedings are considered medically ineffective (for example, they are no longer providing nutrition as evidenced by continued weight loss and increased residual gastric content and fluid backup), it would be ethically justifiable for a physician to order them to be stopped based on this criterion, if in accordance with local laws and policies (Pope, 2011). The nurse should discuss with Mrs. Jenkins what is being done to maximize Mrs. Selano's comfort and dignity. Hospice could be involved to help manage Mrs. Selano's end-of-life care. Just because Mrs. Selano has a tube feeding, keeping her alive does not change the fact that she is dying from end-stage dementia, and deserves all the best that palliative care has to offer.

## Evidence-Based Practice

Gershengorn, H. B., Li, G., Kramer, A., & Wunsch, H. (2012). Survival and functional outcomes after cardiopulmonary resuscitation in the intensive care unit. *Journal of Critical Care*, 27(4), 421.e9–17.

### Methods

**Data sources.** MedLine database, using key words cardiopulmonary resuscitation (CPR), resuscitation, limiting to research in the past 3 years.

**Study selection and assessment.** Adults who underwent in-ICU CPR in the United States from 2001 to 2008.

**Outcomes.** Survival rates, functional status, and predictors of good outcomes after in-ICU CPR.

### Main Results

Researchers used the Project IMPACT (Cerner Corporation, Kansas City, MO) database to conduct a retrospective cohort study of adults who underwent in-ICU CPR in the United States from 2001 to 2008. Of 362,074 ICU admissions, 6,518 (1.8%) received in-ICU CPR with 15.7% ( $n = 1025$ ) surviving to hospital discharge. Survival decreased with age, more comorbidities, and for certain admitting diagnoses such as sepsis. Patients who survived incurred significant functional morbidity. Of survivors, 33.6% were discharged home, and 20.1% were functionally independent on hospital discharge. A total of 63.4% had a decrease in functional status compared with admission. Only 3.3% of all patients (21.7% of survivors) were both functionally independent and discharged home ("optimal" functional outcome). Among survivors, the risk-adjusted odds of having an optimal functional outcome decreased with age ( $p \leq .022$ ) and with failure of three or more organs during ICU stay ( $p = .006$ ).



## Conclusion

Only one of six adults receiving in-ICU CPR survives to hospital discharge, and less than 5% are discharged home with independent function. Among survivors, most show large decreases in functional status compared with hospital admission.

## Commentary

Originally promoted as a first aid technique for the public to learn, CPR techniques were introduced as a medical procedure in the early 1960s. The originators cautioned physicians that the procedure was not meant to be used for all patients; rather, it should be applied selectively to patients who were likely to benefit from it. However, their caution was not heeded (Santonocito, Ristagno, Gullo, & Weil, 2013). The implementation of CPR on all patients who suffer cardiopulmonary arrest (in the absence of a do-not-attempt-resuscitation [DNAR] order) has given way to efforts to reduce the indiscriminate use of CPR. For example, the Patient Self-Determination Act of 1990 and state out-of-hospital orders for life-sustaining treatment initiatives encouraged the use of advance directives and discussions about end-of-life (EOL) care planning between patients and physicians. The challenge health care providers face today is that survival rates *overall* for witnessed in-hospital cardiopulmonary arrest have improved, likely due to improved techniques. For example, studies that Reisfield et al. (2006) identified before 1990 showed that resuscitation to hospital discharge was unsuccessful for all patients with metastatic cancer but had improved to 7.8% after 1990 (although survival rates in the ICU [2.2%] were much lower than those in the wards [10.1%]). Although Gershengorn and colleagues' study found that 15.7% of resuscitated ICU patients survived to discharge, the authors do not report what percentage of these patients had advanced cancer. Statistics like these complicate the process of EOL decision making. Clinicians may be reluctant to definitively state that CPR attempts for a particular patient would be medically futile, since the success rates Gershengorn et al. report are above the futility threshold that was established of less than 1%. For patients facing death, a 15% or 7% or even a 2% chance of surviving to hospital discharge may be worth the associated burdens. What is harder to discern is whether surrogates making such decisions are accurately representing what the patient would have wanted or making decisions based on their own emotions (i.e., not wanting to let go or "give up"). Thus, some have argued that for subsets of patients for whom CPR is unlikely to achieve its intended goal, offering them (or their surrogate decision maker) the false choice of CPR attempts is disingenuous and overly burdensome. These clinicians may write DNR orders for patients based on medical futility criteria (Fritz & Fuld, 2010), or based on their recommendation and nondissent from the patient or surrogate (Kon, 2011).

Unfortunately, some clinicians interpret "communicating about EOL preferences" to mean "getting the patient to agree to a DNAR order." This puts the focus on what the team will *not* do for the patient, rather than on what the team *will* do, based on the patient's goals of care. Whether or not it is possible to extend a patient's life through CPR, clinicians should always "do everything" to ensure that dying patients receive compassionate care that is consistent with their wishes, if known, and within the scope of ethically acceptable health care practices. Nurses are in a good position to support such efforts.

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# Legal Aspects of End-of-Life Decision Making

CHAPTER

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## KEY POINTS

- An adult is presumed to have the ability to make his or her own health care decisions—including termination of life-sustaining technology—unless he or she is shown to be incapacitated by clinical examination or ruled incompetent by a court of law.
  - Advance care directives are legal vehicles used by people to provide guidance to their health care providers concerning the care they would desire in the event they become incapacitated and cannot make their own decisions.
  - Common forms of advance directives are living wills, do-not-resuscitate directives, and durable powers of attorney for health care purposes documents.
  - Problems with advance directives may arise when they do not seem to apply to the patient's situation, so that the health care team may be reluctant to follow them.
  - In general, courts are hesitant to enforce advance directives.
  - Conflicts among health care providers, patients, and/or families about a patient's end-of-life (EOL) care may be resolved by the development of consensus about goals for care through listening, thoughtful discussion, multidisciplinary rounds, and ethics consultation.
  - Many states now have intractable pain legislation either as part of their natural death acts or as separate legislation that affirms dying patients' rights to adequate pain management.
  - Nurses have essential roles in attaining ethically and legally appropriate EOL care. These roles include educating the patient and family about the patient's condition and legal EOL choices, identifying the patient's and family's wishes for EOL care, articulating the patient's and family's desires to other members of the health care team, and assisting the patient and family to obtain necessary and appropriate EOL care.
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## CASE STUDY

Harriet Billings, a 76-year-old retired nurse, developed endocarditis and mitral valve dysfunction from an infected pacemaker lead. Harriet's past history included a 3-month hospital stay following mitral valve surgery 7 years earlier. She was overweight and had long-standing chronic lung disease, but was precise in managing all her medications. Harriet had lived alone for the past year following the death of her husband. She had recently updated her advance directive and durable power of attorney for health care, reaffirming that she wanted to be intubated, have hemodialysis, and have cardiopulmonary resuscitation, if they were necessary. In addition, she gave her brother power to make health care decisions for her if she became incapacitated.

Harriet was awake and able to understand what was occurring to her when the cardiac surgeon at her local hospital explained that her chances of surviving a second operation on the valve while she had endocarditis were slim. He stated that the infection was not responding to antibiotics, so surgery was necessary but was more risky than could be performed locally. He informed her that she had two choices: recognize that she was not likely to recover and forego surgery or transfer to a teaching hospital and see if they were willing to operate. Harriet chose to transfer and have surgery.

Initially, the surgery went well; Harriet was extubated 5 days after surgery and transferred to a step-down unit. Then, Harriet had respiratory arrest, was resuscitated, and required re-intubation. Following her cardiac arrest, Harriet developed renal failure and was started on hemodialysis with her consent. When it became apparent that Harriet was not going to tolerate extubation, she was asked if she wanted a tracheostomy to which she immediately responded, "Yes." Harriet's brother and some of her friends asked the nurses, "Why are you still doing all this? She's been through it once already, isn't that enough?"

Lay and professional communities throughout the world are struggling with bioethical and legal dilemmas brought about by the proliferation of medical technology. A heightened sense of self-determination and the decision making associated with the use of available life-sustaining technology, termination of life-prolonging treatment, patient-requested euthanasia, and assisted suicide have engendered bioethical and legal dilemmas in end-of-life (EOL) care. Although these dilemmas have different ramifications for different people, a patient's well-being can best be served when health care professionals are able to collaborate with each other, the patient, and the family to set goals for patient care as the EOL approaches.

For nurses in particular, EOL decision making is a moral as well as legal issue. The moral question of what is "right" or "best" for the patient, what ought to be done, and who is the person best suited to do the "right" or "best" thing evokes strong personal sentiments when discussing EOL care. These questions have the potential to provoke conflict among those involved in patient care—physicians, nurses, social workers, and others—and the questions for each are clouded by the individual's personal and professional ethics.

EOL questions pose a different dilemma for the family. Many times, families are faced with discussions

regarding whether to stop treatment and allow the patient to die a natural death. Family members or patients may not understand that there are limits to how long and how well medical technology can sustain life. For example, most people do not realize how unlikely a person is to survive cardiopulmonary resuscitation (CPR). More importantly, family members may not be certain of what the patient would have wanted if she or he had been able to make the decision.

Knowledge of the patient's wishes is important, as legal and ethical scholars agree that decisions about care at the EOL ought to be made in accordance with an individual's wishes, preferences, beliefs, and values. No one should be subject to medical care against his or her wishes. For the past 20 years in the United States, autonomy and self-determination have been the foundation for such decisions.

Nursing faculty, nursing students, and practicing nurses address ethical and legal issues, including EOL care, with patients and family members daily in clinical practice. With increased medical technology and competing interests of dying patients, their families, and significant others, the wish of many to die with dignity is a concern for health care professionals. Nurses are in a key position to address the escalation of bioethical dilemmas that result in



wrenching situations for patients, families, providers, and the courts. Since the landmark cases of Karen Ann Quinlan (*In re Quinlan*, 1976) and Nancy Beth Cruzan (*Cruzan v. Director*, 1990), nurses, physicians, and other health care professionals have shaped public policy regarding patient and surrogate participation in EOL decision making even when the patient is incapacitated and unable to make decisions.

## ■ LAW AND ETHICS: SAME OR DIFFERENT?

*Law* and *ethics* are similar in that they have developed in the same historical, social, cultural, and philosophical soil (Davis, Aroskar, Liaschenko, & Drought, 1997). *Black's Law Dictionary* defines law as "that which is laid down, ordained, or established; a body of rules of action or conduct prescribed by controlling authority and having binding legal forces; and that which must be obeyed and followed by citizens subject to sanctions or legal consequences" (Garner, 2004, pp. 884–885). The law may be defined better as the sum total of rules and regulations by which a society is governed. Ethics, in contrast, is informal or formal standards that guide how individuals or groups of people believe they ought to behave.

Law and ethics may differ in what they allow or require a person to do. For example, some actions may be legal yet not ethical. A historical example is the legality of slavery in the United States until the Civil War. More recently, a nurse in Oregon might legally have assisted a patient to commit suicide, although the American Nurses Association (ANA) declared that such assistance was unethical. Other actions may be ethical but not legal. A historical example would be the development of the Underground Railroad to assist slaves fleeing to Canada. This dichotomy can occur because legal rights are grounded in the law and ethical rights are grounded in ethical principles and values. The law establishes rules that define a person's rights, obligations, and the appropriate penalty for those who violate it. Moreover, the law describes how the government will enforce the rules and penalties. There are many laws that affect the practice of nursing, and nurses must be able to differentiate between ethical claims that suggest how a nurse should act and legal requirements for the nurse to act in specific ways or potentially incur sanctions.

## ■ NURSING AND THE LAW

Legal and moral obligations are not new to nurses. The Nurse Practice Act, a legal statute regulating nursing, and the professional code of ethics are the

foundations of nursing practice. Similarly, nurses are confronted with complex moral and legal questions on a regular basis when caring for dying patients: When does death occur? Does an individual have a right to choose death? Is there a difference between letting a person die and taking measures to hasten death? Do you disclose a terminal diagnosis to a patient? These are just a few of the ethical and legal issues in contemporary nursing.

Decision making at the EOL has been at the heart of many ethical dilemma discussions and legal cases in bioethics in the past 25 years. Because nurses are legally responsible and accountable for the health care that patients and their families receive, nurses can no longer afford to view the questions of ethics and law as solely an academic exercise, nor should ethical and legal considerations of today's health care issues remain solely in the purview of the organization's ethics committee or risk management departments. Nurses must understand the basic concepts of ethical decision making and know the relevant laws that address the current controversies to ensure that individual and societal rights and values are protected.

## ■ INFORMED CONSENT

Informed consent is not only a legal requirement, but also a moral imperative. The legal requirement of informed consent is based on the value of patient autonomy and self-determination. Every human being of adult years and sound mind has a right to determine what shall be done with his or her own body (*Schloendorff v. Society of New York Hospital*, 1914). Accordingly, the fundamental goals of informed consent are patient autonomy and self-determination (*In re Farrell*, 1987). This goal is effectuated by allowing patients to make their own decisions about their health care based on their own values for as long as they are able.

A second goal of informed consent is to empower patients to exercise their right to autonomy rationally and intelligently (Meisel & Cerminara, 2001). There is no guarantee that providing patients relevant information about treatment will result in patients making intelligent decisions, nor does it guarantee that they will use the information provided; however, without such a requirement, the likelihood of rational decision making diminishes (Meisel & Cerminara, 2001). The patient's right to consent presumes that the patient has sufficient information to make a reasonable decision.

Consent to treatment is valid only when the patient has the capacity to consent (Meisel & Cerminara, 2001). *Competence* is not the same as *capacity*, yet they are frequently considered to be synonymous.

A competent individual is able to comprehend the nature of a potential action and understand its significance. The law presumes that all adults are competent and have the ability to make their own decisions, including those about health care, and that assumption is ordinarily correct (Meisel & Cerminara, 2001). Therefore, incompetence is determined only in a court of law. However, a patient need not be adjudicated incompetent to lack the capacity to consent to medical treatment (Meisel & Cerminara, 2001).

Capacity is determined not by the courts, but rather by clinicians who assess functional capabilities to determine whether the capacity to make a specific decision is lacking. Incapacity is not determined solely by a medical or psychiatric diagnosis. Rather, decisional capacity within health care is determined via clinical assessment and the ability of the patient to give valid consent (Cooney, Kennedy, Hawkins, Hurme, & Balch, 2004).

The basic elements of a valid consent—the determination that a patient has sufficient decisional capacity to consent or refuse treatment—are based on the observation of a specific set of abilities. In order to have decision-making capacity, the patient must be able to understand the relevant information, appreciate the situation and its consequences, reason about treatment options, and communicate a choice (Appelbaum, 2007). Appelbaum notes that the use of standardized questions can increase the reliability of raters determining a patient's capacity. He recommends the McArthur Competence Assessment Tool, which takes approximately 20 minutes to administer and score. However, he also suggests questions that are normally included when assessing each criterion to determine if a patient has the capacity to make a health care decision. Examples of the questions include the following:

- Would you please tell me in your own words what your doctor told you about your current problem and its treatment?
- What is the treatment likely to do for you?
- What makes this treatment a good choice for you? Why is it better than any other one?
- Please tell me what you have decided to do.

Not all health decisions require the same level of decision-making capacity in order to make a valid decision. Decision-making capacity is not an “on-off switch” (Mezey, Mitty, & Ramsey, 1997a), where a patient either has it or does not have it. Rather, capacity is usually viewed as task-specific; an individual may be able to perform some tasks adequately and may have the ability to make some decisions, but may still be unable to perform all tasks or make all decisions. The notion of “decision-specific capacity” assumes that an individual

has or lacks capacity for a particular decision at a particular time and under a particular set of circumstances (Mezey et al., 1997a; Mitty & Mezey, 2004).

### **Special Concerns With Children: Assent Rather Than Consent**

In contrast to adults, children younger than 18 years of age are not considered to be legally competent and usually are not considered to be capable of giving fully reasoned consent. Therefore, in most cases, parents and health care providers make health care decisions for children without the child's consent. Instead of giving consent, a child is asked to assent, which means to freely express an opinion in favor of a treatment. The child's assent about EOL care is deeply affected by the child's developmental and chronological age, because young children have limited understandings of illness and death.

Over the past 40 years, the thinking about children and medical decision making has evolved. Although at one time the decision was made for the child without explanation of the illness or consultation, now there is more likely to be a shared decision-making process, in which children have more autonomy as they develop greater cognitive maturity. This change in emphasis from making decisions for children to giving children a voice promotes their dignity and quality of life (QOL), but presents many challenges (Whitty-Rogers, Alex, MacDonald, Gallant, & Austin, 2009). Preschool children are usually considered too young to make clearly rational decisions, so their parents are asked to make decisions for them based on the best-interests standard. This can be problematic, because parents' emotional distress may prevent them from realizing what is in the child's best interests.

When children reach school age, they are usually provided with information about their condition in a manner that they can understand. Although school-age children may express a preference and assent to treatment, parents and health care providers usually continue to be the primary decision makers, because the child is not thought to have the capacity to make an informed decision yet. In contrast to this common belief and practice, a study by Hinds et al. (2005) found that children as young as 10 years dying from brain tumors could understand the potential treatment options and recognize that their death could be the consequence of their decision. Hinds et al. (2005) noted that these children usually based their decisions on their relationships with others and the risks that the treatment imposed on themselves and others.

Once a child enters adolescence, there is less controversy. Some cultures actually assume that adolescents will make their own decisions (Whitty-Rogers



et al., 2009), because they are expected to have the decision-making capacity of adults. Harrison, Kenny, Sidarous, and Rowell (1997) recommend that the decision-making capacity of adolescents be examined in the light of their

- Ability to understand and communicate relevant information
- Ability to think and choose with some independence
- Ability to assess the potential for benefit, risk, or harm, as well as to consider consequences and multiple options
- Achievement of a fairly stable set of values

### **Nurses' Roles in the Informed Consent Process**

Nurses can make a valuable contribution by ensuring that the informed consent process is accurately carried out (Virani & Sofer, 2003). Nurses must become proficient in assessing decisional capacity and take an active role when the multidisciplinary team is determining decisional capacity. When nurses and other health care professionals assess capacity objectively,

two types of mistakes can be avoided: first, mistakenly preventing persons who have the capacity to make health care decisions from directing the course of their treatment; and second, failing to protect incapacitated persons from the harmful effects of their decisions (President's Commission, 1982). It is easy when a patient is very ill to let someone take over decision making for the person. However, as long as an adult patient has the capacity to make the decision, it is her or his right to do so.

Nurses must be certain that their patients have the capacity to make an informed decision. In addition, nurses should be certain that their patients were offered appropriate and understandable information that would help them to make the decision. Finally, nurses should ensure that their patients are aware that they have a right to either refuse or accept treatments—that their patients were actually offered options and were not coerced into one decision over another (Sims, 2008). Sometimes, this can be ascertained by expanding Appelbaum's (2008) questions to include, "How did you reach your decision?" or "Who else had input into your decision?" Nurses should make efforts to meet their legal and ethical obligations so that patients retain their rights to make decisions for as long as they are able.

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### **CASE STUDY *Continued***

Harriet was aware of her surroundings, recognized that she would die if she were extubated, and had experienced 2 months of ventilation in the past. Although she was too weak to write and did not tolerate a speaking valve, she made her wishes clearly known. She wished to have a tracheostomy, and continue both ventilation and dialysis. She was not ready to die. Since all those involved in her care were convinced that Harriet was competent and had the capacity to make decisions for herself, neither her medical directive nor her durable power of attorney for health care came into effect. The care that she was receiving, although extensive, was believed to have the potential to benefit her and was not deemed to be futile. Thus, Harriet continued to make her own decisions about the amount and type of health care she desired.

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### **■ THE SUPPORT STUDY**

Although in the case study, Harriet Billings wanted to continue to receive life-sustaining therapy, in many instances patients wish to discontinue interventions. Unfortunately, even with the increased attention to EOL issues in lay and medical publications, physicians are often unaware of their patients' preferences concerning EOL care. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) and its companion study, the

Hospitalized Elderly Longitudinal Project (HELP), both studies of seriously ill hospitalized patients, documented the lack of communication between physicians and their very ill patients about EOL issues (Knaus et al., 1995; SUPPORT Principal Investigators, 1995). The original SUPPORT study (SUPPORT Principal Investigators, 1995) and its offshoots documented the ineffectiveness of advance directives (Teno et al., 1994; Teno et al., 1997a; Teno et al., 1997b), the effect of serious illness on patients and their families (Covinsky et al., 1994, 1996), the lack

of cost effectiveness of life-extending interventions at the EOL (Hamel et al., 1997), and the influence of patient age and race on decision making (Hamel et al., 1996, 1999; Phillips et al., 1996).

However, most importantly, the SUPPORT study (Support Principal Investigators, 1995) suggested that since physicians did not understand their patients' preferences about EOL care, they often continued aggressive, painful life-sustaining treatment beyond the time patients and their families believed was appropriate. Because of that, families indicated that patients spent a considerable amount of time during their last days and hours in pain. One of the reasons offered for such aggressive care at the EOL in the SUPPORT study was that it was not clear to the health care providers that patients were definitely dying until less than 48 hours before the patients' deaths. How, then, should a health care provider know when to counsel palliative care (PC)? How should a provider know when care is excessive for a patient?

## ■ NATURAL DEATH ACTS

Natural death acts sprang from the belief that medical technology had made possible the artificial prolongation of patients' lives beyond their natural limits. Another underlying assumption of the acts was that adults in the United States have the right to control decisions about how they live their lives as well as how they die. The California Natural Death Act was one of the first in the country. Originally enacted in 1975 and revised in 1992, it authorized people to sign a declaration directing that life-sustaining treatment be withheld or withdrawn if they become terminally ill or permanently unconscious if the administration of life-sustaining procedures would only prolong their dying process or unconscious condition.

Now, every state has a natural death act explicitly allowing patients to refuse excessive medical care at the EOL. In addition, the natural death acts in some states, such as Washington, specifically state that "physicians and nurses should not withhold or unreasonably diminish pain medication for patients in a terminal condition where the primary intent of providing such medication is to alleviate pain and maintain or increase the patient's comfort" (Washington Natural Death Act, 1992, ch. 98, § 1; 1979, ch. 112, § 2). Finally, most states also include in their natural death act a provision that a person's right to control his or her health care may be exercised by an authorized representative who validly holds the person's durable power of attorney for health care (DPAHC).

However, as shown by the SUPPORT study (SUPPORT Principal Investigators, 1995), the

presence of natural death acts did not ensure that patients and their families were able to obtain the EOL care they desired. Guido (2006) states that the case of Nancy Cruzan, a young woman who remained in a persistent vegetative state following an automobile accident and whose family maintained that she would never have desired such technologically driven care, motivated Congress to enact federal legislation that would require states to make patients aware of their rights to have advance directives and to decide about their own care (*Cruzan v. Director*, 1990).

## ■ THE PATIENT SELF-DETERMINATION ACT

The Patient Self-Determination Act (PSDA), which became effective on December 1, 1991, was the first federal law to focus on the rights of adults to refuse life-sustaining treatment. The act was motivated by concerns that in the absence of clear directives regarding their views on life-sustaining treatment, patients' views would not be respected when they became incapacitated. The PSDA requires that facilities participating in the Medicare and Medicaid program provide written information to individuals about their right to participate in medical decision making and formulate advance directives. The key provisions of the legislation are touched on here.

With regard to the PSDA, facilities must provide the following:

1. *Written information* to each adult individual concerning "an individual's rights under State law (whether statutory or as recognized by the courts of the State) to make decisions concerning such medical care, including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives."
2. *Written policies* of the provider or organization respecting the implementation of such advance directives.
3. *Inquiry* as to whether a person has an advance directive.
4. *Documentation* in the patient's medical records whether the individual has executed an advance directive.
5. *Nondiscrimination*, that is, not conditioning the provision of care or otherwise discriminating against an individual based on whether the individual has executed an advance directive.
6. *Compliance* with requirements of state laws respecting advance directives at facilities of the provider or organization.
7. *Education* for staff on issues concerning advance directives and provision for community education regarding advance directives.



## ■ PURPOSE AND TYPES OF ADVANCE DIRECTIVES

Since the PSDA was enacted, all states have passed natural death acts and/or advance directive legislation. However, the specific types of advance directives, the formalities for executing a directive, and the requirement to alleviate pain and promote comfort at the EOL sometimes included within the directive vary from state to state. Despite these state-to-state variations, advance directives have become an important tool to determine patients' desires for EOL care (Duke, Yarbrough, & Pang, 2009).

Advance directives have several major purposes (Meisel & Cerminara, 2001). The first and perhaps most important is that they are a mechanism by which individuals who are currently competent indicate the type of health care they would desire if they lack decision-making capacity at some time in the future must be made. Directives provide guidelines to health care providers and family about the kind of medical care the person would like to receive in advance of the need for that care. Advance directives generally are discussed in the context of the right to forgo life-sustaining treatments. However, they also may be used to direct the administration of specific treatments, as they were in the case of Harriet Billings. Advance directives pertain to decision making about any kind of health care and they may be executed by any adult as long as he or she possesses the requisite decision-making capacity.

The second purpose of advance directives is to provide guidance, especially to health care professionals, regarding how to proceed with decision making about life-sustaining treatment for a patient with diminished capacity. When patients lack decision-making capacity, a great deal of confusion can arise as to how health care decisions are to be made, who has the authority to make them, and what the treatment should be. Teno, Gruneir, Schwartz, Nanda, and Wetle (2007) found that bereaved family members of patients with advance directives did report fewer concerns with communication with health care providers about treatment decisions and believed that the directives had facilitated the process.

The third purpose of advance directives is that they provide immunity from civil and criminal liability to health care providers when they act in good faith and in accordance with state statutes respecting advance directives (Meisel & Cerminara, 2001). Most litigated right-to-die cases end up in court because of health care provider fear of liability. Statutory immunity provisions provide an impetus for clinical decision making by protecting health care professionals who comply with an advance directive. However, a health care provider who fails to comply with a directive or

a family member's interpretation of the directive may be subject to professional sanctions or civil litigation (Duke et al., 2009).

There are two broad types of advance directives. The first is the instructional directive, which has several subtypes, including the living will, the medical directive, and the do-not-resuscitate (DNR) order. Instructional directives usually give guidance about the type and amount of care the person desires if she or he becomes incapacitated. The second type of advance directive is the durable power of attorney for health care (DPAHC), also known as the health care proxy. DPAHC documents usually identify an agent to serve as a surrogate for decision making. This section discusses each of these, as well as other relevant issues pertaining to advance directives.

### Instructional Directives

■ **Living Wills.** Instructional directives identify the amount and type of care a patient would wish to receive if certain conditions are met. In the case of the living will, the patient affirms that if she or he is terminally ill, she or he does not wish to receive life-sustaining treatment(s). There are two major problems with the living will. First, it is not always clear when a person is dying. In the SUPPORT (1995) study of seriously ill patients, many of the patients were still predicted to have a 50% chance of surviving at least 2 months, 2 days before they died. Also, health care providers are reluctant to recognize that patients with some diagnoses, particularly heart failure, are dying (Forbes, 2001). Furthermore, the patient does not usually have the opportunity to refuse specific treatments. Despite these problems, older patients with living wills are more likely to have their desires for EOL care met. They are more likely to die in their place of residence than in a hospital (Degenholtz, Rhee, & Arnold, 2004). In addition, they are less likely to have aggressive treatment and more likely to have a priority placed on comfort care (Silveira, Kim, & Langa, 2010).

■ **Medical Directives.** Medical directives are more specific, and they allow patients to specify their desires for or refusals of specific treatments under certain circumstances if the patient becomes incapacitated. For example, patients might indicate that they do not wish to be resuscitated (DNR) or would not want to be intubated, be ventilated, receive nasogastric feedings, or be dialyzed under specific circumstances such as becoming comatose. The major problem with medical directives that are not specific to a patient's illness is that the patient's situation may not be similar enough to the circumstance described in the advance directive for anyone to determine how the patient would wish to be treated. Teno et al. (1997b) found that directives were

specific enough in only 3% of actual circumstances to guide decision making. Other problems with medical directives are that they do not allow for advances in medical treatment or for the patient to change his or her mind about one of the interventions or situations without changing or destroying the directive (Olick, 2012). The medical directive may only represent the patient's desires for treatment at the time the directive was completed, not at the time treatment is being planned.

■ **Do-Not-Resuscitate Directives.** In the United States, only about 20% to 30% of older adults have completed any type of advance directive, although in long-term care facilities three fourths or more of the residents may have a DNR order (Molloy et al., 2000). DNR orders represent the most common type of advance planning done for adults in this country (Eun-Shim & Resnick, 2001; Ghosn, Teasdale, & Jordan, 1997; Nolan & Bruder, 1997). They are also often viewed as a "practical place to start" (Smith, Desch, Hackney, & Shaw, 1997) and are often the first step in considering treatment limitation at the EOL. When a DNR order is written, the patient or proxy designate and health care providers concur that if the patient is dying, the health care team will not make any attempt to stop the process or bring the patient back to life.

Originally, CPR was established to be used with witnessed arrests, sudden death in the young, drowning, and predictable arrests, such as in anesthesia and cardioversion (Hall, 1996). In 1988, New York became the first state to enact DNR legislation requiring that consent to CPR be presumed; if physicians do not want to resuscitate patients, they must obtain the patient's consent before writing such an order (Swidler, 1989). Many other states have enacted DNR legislation since New York did. The American Medical Association (1991) mandates that patients and families be consulted before a DNR order is written. Since then, all patients who have a cardiopulmonary arrest—for any reason, of any age, or with any condition—will have CPR performed in almost all hospitals or nursing homes in the United States unless there is a specific order written to the contrary (the DNR decision). With a policy of automatic resuscitation, obtaining a DNR order is critical if the patient wishes to avoid this type of treatment.

Most health care providers believe that it is quite reasonable for people, especially older adults, to forego CPR because CPR is rarely successful when attempted on older adults. Buchanan (1998) estimated that two long-term-care residents out of every hundred who receive CPR survive to hospital discharge, and they both would most likely have significant neurological impairments. Murphy, Murray, Robinson, and Campton, in a 1989 study of older adults receiving CPR in hospital, rehabilitation, and long-term care settings, found that 22% of patients

survived the initial resuscitation attempt, but only 3.8% of the patients survived to hospital discharge. Banja and Bilsky (1993) had no patients survive to hospital discharge after resuscitation in a rehabilitation hospital. Survival rates after CPR for all age groups have stayed consistent for three decades at about 13% to as high as 18% (Schneider, Nelson, & Brown, 1993). Marik and Craft (1997) found that patients who survived to hospital discharge following CPR had one reversible condition, were otherwise healthy, and had suffered a sudden, unexpected dysrhythmia. Bishop, Brothers, Perry, and Ahmad (2010) argue that the widespread use of CPR has outlived its utility because it "obscures what is known to all: Resuscitation although able to stay death in a limited number of cases is a pseudo-option that will not resort in a satisfactory restoration of health" (p. 61). Thus, it seems very reasonable for adults with multiple chronic illnesses to forego CPR.

The majority of clearly competent elders living in community or long-term-care facilities would prefer not to be resuscitated if they were gravely ill and probably dying (Diamond, 1989; Eun-Shim & Resnick, 2001; Wagner, 1984). However, elders who have moderate to severe impairment in daily decision-making skills but are still alert and conversant may prefer CPR (O'Brien et al., 1995). Molloy et al. (1996) stated that there was no "gold standard" for determining when an older adult has the capacity to make decisions about EOL care and there is a lack of consensus about what tool ought to be used to measure capacity and who ought to administer the assessment. Eun-Shim and Resnick (2001) state that capacity must be clinically determined, because the person must be shown to be able to understand and appreciate the consequences of the EOL treatment plan. Bradley, Walker, Blechner, and Wetle (1997) found that 48% of decisionally competent nursing home residents did not receive information about EOL treatment choices and advance directives, whereas 34% of partially or totally confused patients did.

What nurses need to know about DNR directives is that patients have a right to refuse CPR and may request DNR orders, when they have the capacity to make the decision, after they have been informed of the risks and benefits involved. Moreover, nurses need to know which patients have a DNR directive, the institutional policy and law governing the use of directives, the patient's wishes regarding interventions to be withheld, and their own values regarding the decision to withhold treatment. The medical record should clearly indicate the terms of the directive and whether the terms accurately reflect the patient's current stated preferences.

Recently, a number of health care providers have begun advocating for changes in approaches to



DNR and CPR. Bishop et al. (2010) advocate that to the extent permissible by law, health care providers consider the term DNR obsolete and replace it with the term *do not attempt resuscitation* (DNAR). They believe that such a change in terms is the first step to acknowledging that resuscitation might not occur with CPR. Daly (2008) has called for nurses to be actively involved in advocating for the end of “automatic” CPR. Daly reviewed the likelihood of success of CPR (most recently an 18% survival with only 14% having a favorable neurological outcome) and noted the difficulties of explaining to a patient and/or family that they are being required to refuse a treatment that is still required even though it is not likely to be of benefit. She proposes that the use of CPR should be restricted to “those patients who provide adequate informed consent and for whom CPR has a reasonable chance of success” (p. 378). Both Bishop et al. and Daly agree that all patients should have their CPR status assessed on admission, and in the absence of informed consent and a physician’s order, CPR should not be attempted. Such a proposal would bring the use of CPR more clearly into the realm of other treatments and directives, and patients would be giving consent for treatment rather than nontreatment.

### Durable Power of Attorney for Health Care

The other broad category of advance directives are DPAHC documents. These documents permit individuals to designate another person to make health care decisions for them if they lose decision-making capacity. The person who is appointed by the patient to make decisions is called a health care proxy, health care agent, or surrogate, or (in some states) a DPOA. The language used varies from state to state and nurses should become familiar with their own state’s language.

Usually, these directives allow greater flexibility and more relevance to the patient’s specific situation than instructional directives, as a DPAHC does not require that an individual know in advance all the decisions that may be needed for every situation that might arise. In fact, a health care proxy can interpret the patient’s wishes as medical circumstances change and can make treatment decisions as the need arises. While competent, the person should be encouraged to provide his or her proxy with guidance concerning the type of treatment he or she would like to receive. The advocacy group Aging with Dignity (2011) has promoted the Five Wishes public information campaign so that individuals have a format to discuss their wishes related to EOL care. The organization maintains a Five Wishes Online secure site to guide people through completing the form.

The five wishes are as follows:

1. The person I want to make care decisions for me when I can’t
2. The kind of medical treatment I want or don’t want
3. How comfortable I want to be
4. How I want people to treat me
5. What I want my loved ones to know

Interactive e-planning advance directive tools such as the Five Wishes Online are assisting people to think about and articulate their wishes. The electronic format helps some people to convey their thoughts in a more systematic format than they would have been able to achieve verbally or on paper. Green and Levi (2012) believe that the electronic forms may actually help people to explore their values and articulate their wishes in ways that are more logically consistent than they would have otherwise.

However, some patients do not have the capacity to answer these questions, or envision EOL scenarios, no matter how much assistance they receive. An advantage of a DPAHC noted by Molloy et al. (1996) is that the capacity required to designate a proxy is considerably less than that needed to envision scenarios and complete a medical directive. Thus, proxy designations may be more appropriate for people who, although competent, are having difficulty understanding options and making decisions about EOL care.

However, there are disadvantages to a DPAHC. The proxy designate may not realize all the responsibility that being a health care proxy entails and may have difficulty making a decision. The proxy may also confound his or her interests with those of the patient and fail to act in the patient’s best interests (Perrin, 1997).

How should a proxy make an EOL decision for a patient? First and most importantly, the proxy should leave the decision to the patient until the appropriate time. Advance directives become effective only when it is determined that the individual is incompetent, lacks decision-making capacity, or requests that the proxy make the decisions for him or her. As long as the patient retains decision-making capacity and wishes to make the decision, his or her decisions govern. When the patient is deemed to lack decision-making capacity, the health care proxy is authorized to make treatment decisions on behalf of the patient. There are two ethically and legally acceptable ways by which a proxy might make a health care decision for an incapacitated patient: substituted judgment and the best-interests standard.

In *In re Quinlan* (1976), the courts recognized the use of substituted judgment for a family member declining the further use of mechanical ventilation for an incompetent patient. In such circumstances,

the proxy makes the decision that he or she believes the patient would have made for himself or herself if he or she had the ability to do so. Sometimes the decision is clear because the patient has discussed the matter with the proxy or commented about what she or he would want to do under those circumstances. Overall, studies show that even if flawed, patients' wishes and decisions expressed by health care proxies more closely approximate the patient's own treatment preferences than do decisions of physicians or others (Danis, Garrett, Harris, & Patrick, 1994; Emanuel, Emanuel, Stoeckle, Hummel, & Barry, 1994). However, the patient preferences as expressed by proxies are not always followed. When physicians are surveyed concerning how they make treatment decisions for their incompetent patients, 81% state that they consider patients' preferences as expressed by the proxy but only 29% of them consider it to be the most important factor in the decision about what care to provide (Torke, Moloney, Siegler, Abalos, & Alexander, 2010).

In situations where there is no clear and convincing evidence of what the person would have wanted or the patient has never been competent, the proxy will be called on to make decisions on the basis of what he or she believes to be in the best interests of the patient. Under this approach, it is impossible to analyze the proxy's decision based on the patient's right to self-determination. However, Pope (2012) has identified a number of factors that the responsible surrogate should take into account when deciding what is in the patient's best interest. These factors include the patient's (a) level of cognitive functioning, (b) QOL, (c) treatment options, (d) current level of pain and suffering, (e) likelihood of pain and suffering if treatment is continued versus withdrawn, and (f) benefits and burdens from treatment. Although these factors seem objective, surrogate decision makers often find the factors difficult to consider and the surrogates' intense emotions may make it difficult for them to deliberate carefully (White, 2011). The lived experiences of surrogates are described in the Evidence-Based Practice section.

## Intractable Pain Legislation

Some states, such as Washington, contain a mandate for patient comfort and alleviation of pain at the EOL in their natural death acts. Others have separate legislation regarding the management of pain at the EOL. Yet, all patients who suffer from pain, not just those who are dying, should be treated. The debate about patient-requested euthanasia and assisted suicide has drawn national and international attention to the fact that appropriate interventions can eliminate or drastically

reduce the pain and suffering that many people experience. The need for appropriate types and amounts of pain medications was made clear in the U.S. Supreme Court ruling in *Vacco v. Quill* (1997). There is a relationship between pain and symptom management and requests for assisted suicide (Foley, 1991).

Through the Federal Intractable Pain Regulation, the federal government in 1974 clarified the federal law that prohibits physicians from prescribing opioids to detoxify or maintain an opioid addiction. The regulation stated, in part, that the prohibitive regulations are "not intended to impose any limitation on a physician...to administer or dispense narcotic drugs to persons with intractable pain in which no relief or cure is possible or none has been found after reasonable effort" (Institute of Medicine [IOM], 1997). Similarly, some courts explicitly recognize that a patient's "right to be free from pain...is inseparable from their right to refuse medical treatment" (Meisel & Cerminara, 2001), and have granted immunity to health care providers who treat pain with strong doses of analgesic medications that inadvertently end the patient's life (*McKay v. Bergstedt*, 1990). Moreover, several states have enacted intractable pain statutes to encourage those who treat patients who are terminally ill and have intractable pain to manage the pain without threat of legal liability if the treatment results in the patient's death.

The IOM report *Approaching Death: Improving Care at End of Life* (1997), coupled with other PC literature, asserts that change must occur at many levels if we are to improve care for the dying. The development of intractable pain statutes is a good first step to the undertreatment of pain. However, they are imperfect. Problems associated with intractable pain statutes include the following:

1. They do not, in all cases, mark a clear area of medical practice in which physicians feel free to manage their patients' pain. The more specific laws—for example, those that set out detailed prescription practices—may actually afford physicians *less* leeway in the practice of medicine. In addition, by carving out an area of pain treatment that is immune from discipline, there may be an implication that other forms of pain treatment should be subject to disciplinary review. However, physicians did obtain some measure of comfort that they would not be prosecuted for appropriate prescription of pain medications by the *Gonzales v. Oregon* decision that limited the Drug Enforcement Agency's (DEA) jurisdiction to actions involving drug trafficking (Kollas & Boyer-Kollas, 2007).
2. Even the strongest intractable pain law is still limited by the term *intractable*. Many cases are



ambiguous, and physicians may believe that they must delay opioid treatment until pain is far enough along to be called intractable.

3. Finally, legal affirmations in these laws of the importance of pain control do not, in themselves, correct practice patterns or improve physician training. Laws could, however, encourage patients to expect diligence in pain relief, including use of generally effective medications. Medical boards could consider disciplining physicians who fail to apply proven methods of pain control (IOM, 1997). In addition, Kollas and Boyer-Kollas (2007) observed that case law may be strengthening the requirement to relieve a patient's pain by establishing a new tort, failure to adequately manage pain. Not only have judges and juries repeatedly viewed pain in the dying patient as a compensatable injury, but recently plaintiffs have been able to "argue the tort of failure to appropriately manage pain by applying reasoning from *James v. Philhaven* and *Gaddis v. U.S.*" (Kollas & Boyer-Kollas, 2007, p. 1399).

Thus, health care system changes are needed to improve access to care and to eliminate barriers to effective treatment. Nurses need to educate patients and families about their right to adequate PC. In states where there are intractable pain statutes, the PSDA requires all covered facilities to inform patients of their state law rights to adequate PC (Meisel & Cerminara, 2001). Health care providers need to "add the assessment of pain as the fifth vital sign" (Meisel & Cerminara, 2001), and national pain management standards ought to be followed (Joint Commission on Accreditation of Healthcare Organizations [JCAHO], 2000).

### Combination Directives

A number of states have a single advance directive statute that combines elements of an instructional directive, a DPAHC, and possibly a pain management directive into a single document. A combination document arguably avoids many of the pitfalls of each document alone. If the instructions are too general, the health care proxy has the authority to determine whether instructions should be applied under the specific circumstances. If the instructions are too specific and do not address the particular situation at hand, the health care proxy has the discretion to apply them or not. One element that is often included in a combination advance directive is instruction about what the patient desires if she or he is unable to take food or fluids by mouth near the EOL or in a persistent vegetative state. In some states (even if a designated surrogate is making

the decision), artificial hydration and nutrition may be withheld only if the patient has previously completed a medical directive statement authorizing forgoing of artificial feeding (Olick, 2012). In any case, a discussion between the patient and the health care proxy should occur regardless of whether there is a DPAHC or a combination directive. Communication is the most effective way to ensure that the patient's wishes are known and that the health care proxy is prepared to follow the patient's directives.

### Oral Advance Directives

Although a written advance directive is preferable, especially in the case of an emergency, courts view oral advance directives favorably, especially living wills. The courts either have enforced them *per se* or have heavily relied upon them in deciding whether to forego life-sustaining treatment. Although state statutes recognize written advance directives, oral directives have been found to be legally operative in a number of jurisdictions. The more specific the oral advance directive, the more likely it is to be enforced and have clinical and legal significance.

When made by individuals with full decision-making capacity, courts have considered patients' statements when making a decision to terminate life-prolonging treatments. Criteria for weighing these statements include the following (Furrow, Greaney, Johnson, Jost, & Schwartz, 2001):

- Whether the statements were made on serious occasions or were solemn pronouncements (were brought up when the parties were together)
- Whether they were consistently repeated
- Whether they were made by a mature person who understood the underlying issues
- Whether they were consistent with values demonstrated in other aspects of the patient's life (including the patient's religion)
- Whether they were made shortly before the need for the treatment decision
- Whether they addressed, with some specificity, the actual condition of the patient

Accordingly, such statements should be considered and documented by the health care providers when discussing advance directives with patients.

### Family Consent Laws

Many people are under the impression that their family members will be allowed to make the proper

decisions for them if the need arises and therefore see no need to execute a formal advance directive (Furrow et al., 2001). Traditionally, health care professionals and the courts have also relied on families to make health care decisions for family members throughout the years, despite their lack of any legal authority to do so. In 1982, the President's Commission concluded that given this practice, family decision making had gained and should be accorded legal acceptance. The commission pointed out five reasons why deference to family members is appropriate when done in consultation with the physician and other health care professionals:

1. The family is generally most concerned about the good of the patient.
2. The family usually is the most knowledgeable about the patient's goals, preferences, and values.
3. The family deserves recognition as an important social unit that, within limits, ought to be treated as a responsible decision maker in matters that intimately affect its members.
4. Especially in a society in which many other traditional forms of community have eroded, participation in a family often is an important dimension of personal fulfillment.
5. Because a protected sphere of privacy and autonomy is required for the flourishing of this interpersonal union, institutions and the state should be reluctant to intrude, particularly regarding matters that are personal and on which there is a wide range of opinion in society.

Motivated by concern over the formal legal status of family decision making in the 1980s, state legislatures recognized and began to regulate it by statute. In 1995, with the exception of New York and Missouri, the courts authorized family members and others close to the patient to make decisions (New York State Task Force on Life and the Law, 1995). In fact, the District of Columbia and 24 other states have statutes that explicitly grant family members and others close to the patient the right to make decisions for patients who lack capacity. Family consent statutes vary from state to state. Some have been added to state living-will statutes to provide an alternative mechanism for making life-sustaining treatment decisions for individuals who do not have an advance directive, whereas others are free-standing statutes that apply either to life-sustaining treatment or health care decisions generally.

#### ■ Preference of Elders for Family Decision Makers.

Elders are more likely to speak with a family member about EOL care than with a health care provider. This does not mean that they have completed a health care proxy or DPAHC purposes. Rather, most elders have

simply discussed their preferences for EOL care with at least one family member (High, 1993). When asked whom they believe knows them well enough and whom they would trust to make a health care decision for them, elders overwhelmingly (94%) choose family members, primarily spouses or adult children. Confidence and trust in family members to make any necessary decision for them may be a major reason older adults do not complete advance directives (High, 1994).

High (1994) believes that elders prefer family decision makers for a variety of significant and appropriate reasons. The family member has an inherent knowledge of the culture, values, and expectations of the patient and is usually concerned with the patient's welfare. In most instances, High believes family members choose appropriately based on the patient's values and best interests. High suggests that too much emphasis has been placed on disagreement and abuse within families and not enough on family empowerment and good faith decision making. He suggests that elders' preferences for family decision makers ought to be recognized and advance directives should only be encouraged for those who "have very specific or unusual preferences, do not want family to serve as substitute decision makers, or have disagreements with family or have no family" (High, 1994, p. S17).

Elders say that they have thought at least a "moderate amount" about who they would want to make health care decisions for them if they became incapacitated. Overwhelmingly, they would choose to have their families make such decisions without the benefit of a written directive (High, 1994; Nolan & Bruder, 1997). Although the elders in one study realized that having a written advance directive would help their families to know their wishes and possibly prevent guilt among family members over the decision, most elders still did not complete advance directives (Nolan & Bruder, 1997). These elders wanted their families to decide about EOL care based on their families' best judgments in the specific situation. Perhaps this is because these elders put their trust in their families and not in a piece of paper (High, 1993). Or it might be because elders believe that the family is the center of their lives (Blustein, 1999) and no individual can be completely autonomous; any decision made for one individual affects the entire family. In High's (1993) study, none of the elders stated that he or she always expected to make his or her own decisions. Most elders realize that their families will be profoundly affected by providing or paying for their health care. Thus, elders may believe their families ought to have a significant role in determining what the most appropriate EOL care is.

Martin, Emanuel, and Singer (2000) emphasize that making a decision about EOL care ought to be done in a family context. They believe discussion with patients about EOL care "helps a patient prepare for



death, is influenced by personal relationships, is a social process, and occurs within the context of family and loved ones" (p. 1672). They assert that the primary value of EOL care planning is to allow the patient and family to prepare for death and dying and to find ways to cope with the impending death. Thus, they believe one reason patients may communicate about EOL issues with families more often than with health care providers is that the discussion may help the family to resolve any outstanding issues and become ready for the patient's death.

### ■ PHYSICIAN INVOLVEMENT IN END-OF-LIFE DECISION MAKING

Although most adults have had discussions about EOL care preferences with at least one family member, few patients have had such discussions with their physicians (Emanuel, Barry, Stoeckle, Ettelson, & Emanuel, 1991; O'Brien et al., 1995). Although patients are willing and eager to engage in such a discussion, they believe that it is not their role to initiate the discussion (Emanuel et al., 1991). Thus, they wait for their physicians to start the conversation; unfortunately, the physician usually does not.

Reasons physicians may be reluctant to initiate such conversations include the following:

- Personal discomfort with discussing death and dying (Ventres, Nichter, Reed, & Frankel, 1992). If the physician believes that the patient is dying because the physician has failed and there is no more that she or he can do, the physician is less likely to discuss CPR preference with the patient.
- Lack of physician education and experience in conducting such a conversation (Tulsky, Chesney, & Lo, 1995). Resident physicians learn early in the course of their education that various attending and older residents have differing views on how and when EOL discussions should occur. Unfortunately, according to Tulsky et al., resident physicians receive very little education in how to conduct a discussion about EOL preferences, and consequently they "often did not provide essential information" (p. 436).
- Fear that the patient will believe the physician has "given up on and is abandoning the patient" (Cotton, 1993). Some doctors say that they have difficulty discussing EOL care without conveying a sense of hopelessness to the patient. Kohn and Menon (1988) state that physicians may be unwilling to bring up the issue until a crisis develops, because they are afraid of unnecessarily alarming the patient.
- The physician may feel legally or morally bound to treat until death is proximate (Hanson, Tulsky,

& Danis, 1997). About 10% of physicians believe that they must treat all patients with maximal interventions and that to limit treatment is morally and ethically unacceptable. Another larger group of physicians believes that it is inappropriate to discuss treatment limitation until the patient is certainly going to die. Unfortunately, if discussion waits until the patient is definitely dying, the patient frequently no longer has the capacity to participate in decision making about her or his EOL care.

- Concern about the amount of time such a conversation will require (Emanuel et al., 1991). Some physicians fear that having discussions about EOL care planning, which are not reimbursable, may be very time consuming. Studies indicate that it takes approximately 10 to 16 minutes of physician time discussing with a patient and/or family for a DNR decision to be reached; this is often the first in a series of the EOL decisions (Smith et al., 1997; Tulsky et al., 1995).

Although they do not tend to initiate EOL conversations with patients, most physicians (82%) believe that it is their responsibility to begin the discussion (Markson et al., 1997) and to write the appropriate orders. Some physicians (Reckling, 1997) report that they prefer nurses and other health care providers not to discuss these issues with patients. The result is that health care providers and patients and families talk among themselves about appropriate EOL care, but do not talk with each other (Kohn & Menon, 1988). Less than one tenth of patients have spoken with their physicians when planning an advance directive, and the majority of patients with advance directives have never been asked by or told their physicians that they have advance directives (Teno et al., 1997a). Thus, unfortunately, conversations about EOL care among physicians, patients, and families usually do not occur until a crisis develops.

Researchers have documented concerns with how physicians engage in EOL care discussions in crisis situations. In Tulsky and colleagues' 1995 study, conversations about resuscitation lasted about 10 minutes and the resident physicians dominated the speaking time. Researchers did not believe that the information the residents provided to patients/families was adequate for them to make decisions about CPR. For example, only 13% of physicians mentioned the futility of CPR and the chance of the patient surviving. In addition, residents did not allow patients or families many opportunities to ask questions and elicited information about the patient's values and goals in EOL care less than 10% of the time.

Hanson et al. (1997) reported similar findings. They noted that because physicians tended to focus on

treatment descriptions rather than listening to patient concerns, their understandings of patient preferences remained poor even after face-to-face discussions. They stated that physicians tended to be coercive in forcing their opinions. Markson et al. (1997) surveyed physicians who admitted that they would attempt to persuade patients to change decisions that they believed were not well informed (91%), medically reasonable (88%), or in the patient's best interest (88%). Ventres et al. (1992) concluded: "Physicians' presentation of opinions to patients are not neutral. Options are often presented in such a way as to influence DNR decision making" (p. 163) and communication strategies "may work to distance physicians from their patients at times when it is imperative for them to explore the values and wishes of the patient" (p. 165).

According to Ventres et al. (1992), there are three common prototypes physicians use to approach the discussion of DNR with patients and families. The first might be described as legalistic or technical. In this situation, the physician might ask, once the patient has become incapacitated, if the patient has an advance directive or has a health care proxy and if someone can produce the appropriate papers. In the second approach, the physician might admit that there were no further medical treatments that might lead to a cure and ask the patient or family what the patient would want for EOL care. In the third approach, the physician might mention that there were legal requirements that CPR be attempted at the EOL unless a DNR order was written. The physician would next ask the patient's and/or family's opinion about the appropriateness of administering a painful and probably useless treatment.

## ■ CONTROVERSIES IN END-OF-LIFE DECISION MAKING

When decision making involves withholding or withdrawing interventions that are prolonging a patient's life, it is not surprising that difficulties may arise. Some of the issues include the following:

- When is it certain that the patient is dying and further intervention is of limited benefit?
- Is the patient able to clearly identify what she would like done, either by speaking herself or by the presence of instructions in an advance directive?
- If the patient has not spoken, is it possible to identify who the patient would want to speak for her?
- Does the patient, or her proxy, desire interventions that members of the health team believe are futile?

As noted earlier, the first issue is quite problematic for the members of the health care team, patient, and family. It is usually not absolutely apparent that a patient is dying, even to experienced hospice nurses, until 24 to 48 hours before the patient's death. When the daughter of an elderly woman asked her mother's physician how much longer her mother might live, she was told, "Your mother is a determined woman. Any other person might only live 2 hours but she could live 2 hours, 2 days, 2 weeks, or 2 months." Three months later, the woman was still alive. It can be difficult to decide what care is most appropriate when time frames are so unclear.

It is also sometimes difficult to determine for certain what the patient really wants. Patients who are awake and aware, like Harriet in the case study, can be depressed, as she most likely was. The health care team was able to believe that she had the capacity to make an authentic decision by giving her a trial of an antidepressant. Sometimes there is not such an easy resolution, and family, patient, and health care team members disagree about treatment.

## Problems With Advance Directives

Advance directives were intended to clarify EOL decision making. However, there are a variety of problems with them. First, the public has not embraced the use of advance directives and most Americans do not have one even though surveys demonstrate strong support for them (Larson & Tobin, 2000). The low numbers of patients who complete advance directives is alarming and is one of the factors that prevents them from being used effectively to guide EOL decisions. The literature suggests that more patients would complete advance directives if they had more information and assistance in completing them (Emanuel et al., 1991; Mezey, Ramsey, Mitty, & Rappaport, 1997b). To that end, a number of educational interventions have been implemented to address these issues. Notwithstanding, few interventions increased advance directive completion by more than 18% (Hare & Nelson, 1991; Rubin, Strull, Fialkow, Weiss, & Lo, 1994; Sachs, Stocking, & Miles, 1992) and many did not increase completion at all (Robinson, DeHaven, & Koch, 1993; Stiller et al., 2001). Patients at higher risk of becoming decisionally incapable and who were more likely to understand the need for advance directives were also not more likely to complete advance directives.

Fears that an advance directive permits providers to withhold care or will lead to substandard care may be at the root of the rejection of advance directives by some patients. People may be concerned that once an advance directive is completed and it



contains a statement to withhold treatment, providers will devote less attention to their care and may withhold more treatment than was desired (Caralis, Davis, Wright, & Marcial, 1993; Patel, Sinuff, & Cook, 2004). In a study by Elder, Schneider, Zweig, Peters, and Ely (1992), some individuals feared that an advance directive might allow care to be withheld too soon and could result in a shirking of societal duties. One person commented that he would not want to hear, "Sorry, we don't have the time or money to treat you." This fear is not present among patients alone; nurses and other health care providers hold similar beliefs (Davidson, Hackler, Caradine, & McCord, 1989; Louw, 2004).

Socioeconomic and cultural factors substantially influence decisions to complete an advance directive. Studies are confirming that people with less education, lower income, or who are African American or Hispanic are less likely to formulate advance directives (High, 1993; Mezey, Leitman, Mitty, Bottrell, & Ramsey, 2000a; Phipps et al., 2003; Robinson et al., 1993). Several explanations are plausible. Individuals with these sociodemographic characteristics are less likely to have regular access to care. For them, limiting any medical care would seem unnecessary because they already have too little, not too much. They are also less likely to have exposure to the concept of advance directives (Mezey et al., 1997a).

The location and timing of when a patient receives information about advance directives is also important. It is well recognized that an acute episode or emergency admission is an inappropriate time to receive this information, yet this is the point at which most hospitals fulfill their responsibilities under the PSDA. Information may be better utilized during the preadmission period where patients can discuss advance directives in the comfort of their own homes. Alternatively, information can be presented as part of the discharge process when the impact of hospitalization is still new, but without the distraction of acute symptoms.

Even when a patient has completed an advance directive, the directive may not be utilized because the health care team has not been made aware of its existence. A study of recently discharged hospital patients with advance directives documented that fewer than 15% were asked about an existing advance directive during their hospitalization, 60% of patients did not disclose to the hospital staff that they had a directive, and only 35% informed their physician about their advance directives (Mezey et al., 1997b). Although failure to communicate this information might be attributed to the patient's presumption that the directive would not be relevant for the hospital stay, selective disclosure may reflect a patient's misunderstanding or fear about use of the advance directive.

There is increasing concern in the medical community that the problem with advance directives may not be the flawed implementation of a sound concept but rather that advance directives are a fundamentally flawed concept (Perkins, 2007). Although Perkins believes that there are some benefits of advance directives—primarily that people might consider what they would want at the EOL and that they remind physicians of the necessity of considering the patient's goals and desires at the EOL—he notes that there are a series of problems. First among them is how few people have completed them. In addition, he notes that health care providers such as Jacobson et al. (1994) have expressed concerns about the patient's understanding of treatment options and thus the validity of the treatment choices the patient makes in the directive. A third problem Perkins identifies is physician nonadherence. He notes that physicians may disregard directives because they conflict with hospital policy or family preferences, or because they do not appear to pertain to the current situation.

Most importantly, though, Perkins (2007) believes that the use of advance directives is flawed because the "outcomes have consistently frustrated expectations" (p. 54). He believes that most people do not have the experience to envision a wide variety of scenarios at the EOL and merely know that they would want a death with dignity. He also believes that advance directives promise a degree of control that is not possible when a patient is critically ill and it is not certain if the patient is dying. Decisions in such situations must be made quickly. Finally, he believes that advance directives may engender rather than limit disagreements between family members or family members and health care providers, as the directives may be unclear and the proxy may be unprepared.

### **An Alternative to Advance Directives in End-of-Life Care: Physician Orders for Life-Sustaining Treatment**

Since advocacy groups have spent considerable effort promoting advance directives without appreciable success, an alternative effort to ensure that EOL care is congruent with patient preferences has developed (Meier & Beresford, 2009). Physician orders for life-sustaining treatment (POLST) are *not* an advance directive; rather, they are a set of medical orders for a patient with a serious, life-threatening condition. The physician discusses predictable future events for a patient with a life-threatening condition (such as cardiac arrest in the patient with severe heart failure) and determines in conjunction with the patient or surrogate how the patient should be treated if/when the events arise. A document is created that

specifies the treatment the physician has prescribed. The document is usually brightly colored so that it is easy to identify, and it accompanies the patient across health care settings, ensuring continuity of care. It is designed to provide quick, clear guidance to health care providers about the care that the patient desires and the primary health care provider has prescribed.

The categories for choices on POLST forms vary from state to state. Physicians, after consultation with their patients or surrogates, prescribe either “attempt resuscitation” or DNAR at the start of the document. Other categories on the documents used in most states provide places for the physician to prescribe or to withhold a range of medical interventions from comfort measures only to full treatment, the use of antibiotics, and the administration of artificially administered nutrition.

Advocates for the use of POLST state that POLST allows greater individuation in the care of terminally ill patients and appears to be effective in preventing unwanted treatments (Hickman et al., 2009). In fact, Hickman et al. note that their study is remarkable for the extent to which the patients’ preferences were respected. No patient in their study received unwanted CPR, ventilation, ICU admission, or feeding tubes, far exceeding anything recorded in studies of advance directives and suggesting a distinct advantage to the use of POLST. In a study directly comparing the effectiveness of POLST with durable powers of attorney for health care advance directives, Hammes et al. (2012) found that POLST forms were consistent with treatment across a variety of settings 94% of the time. These studies suggest that POLST can be effective in guiding the care of patients with severe and life-threatening illnesses during the last days and months of their lives.

POLST has been available since 1991, when it was developed in Oregon, and is currently available in only 14 states. Hickman et al. believe that there may be legal barriers to its implementation in many states (Hickman, Sabatino, Moss, & Nester, 2008). The most problematic barriers include the detailed out-of-hospital DNR forms required in some states, the witnessing requirements for health care in some states, and limitations placed by some states on withholding some types of life-sustaining treatments. Despite these potential barriers, the POLST paradigm is gaining support and traction nation wide because it appears to offer severely ill people of any age a greater likelihood of having their desires for EOL care followed.

## Conflict in End-of-Life Decision Making

Although it is infrequent, there are times when the health care team, patient, and family are not able to come to agreement about how to care for the dying

patient and conflict develops (Luce, 2010). The patient, a member of the patient’s family, or a member of the health care team may want to continue some or all of the life-saving treatments even though the others involved in treatment decision making believe that the patient is dying and treatments should be withheld or withdrawn (Perrin & Matzo, 2009). Sometimes the family believes that the treatment a physician is proposing is inappropriate (Luce, 2010) or that the patient is being lost in a health care system that favors system-wide cost effectiveness over providing the care an individual patient needs (Bailey, 2011).

When health care professionals ensure careful communication, instill trust, and listen to the voices of the people involved in the decision, most of the time, when death is imminent, consensus can be reached about which life-sustaining interventions should be provided and which withheld, so that the patient is able to die with dignity. However, sometimes consensus cannot be reached and conflict develops. One reason why conflict may develop is that trust was not established among the members of the multidisciplinary health care team, patient, and family early in the hospitalization. If lack of trust is the primary reason the patient and family want to continue life-sustaining care, the health care team should act to reestablish trust before proceeding with a decision about EOL care. Disagreement about treatment may also result when decision makers do not share a common understanding of the patient’s prognosis. Sometimes the conflict may result from a family member or a health care provider experiencing guilt about the care of the patient; in other instances, there may be secondary gains for a family member from the patient remaining alive, or the patient may come from a religious tradition that does not permit the withdrawal of life-sustaining therapy. In such situations, it may not be possible to reach a consensus about limiting care (Perrin & Matzo, 2009).

## Futile Care

The situation becomes especially complex when the patient or a family member demands an intervention that the health care team considers to be futile. Futility can be exceedingly difficult to define. In fact, one health care provider is said to have stated, “I can’t define it but I know it when I see it.” One possible definition is any treatment that is without any benefit to the patient. Because most treatments have the potential to provide at least minimal benefit, futility is not always apparent to all members of the health care team, the family, and the patient (Pfeifer & Kennedy, 2006). Bailey (2011) argues that some patients and surrogates demand more care because



they feel so insecure about the quality of their health care. They fear that they are “stuck in a one-size-fits-all system” (p. 177) where their individual needs and preferences are not respected and they are not being treated fairly. Chwang (2009) argues that there is

disagreement about what futile care is because we cannot agree or are not clear on what the goal of the treatment or the anticipated outcome is. This was the situation with Harriet Billings, the patient in the case study.

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### CASE STUDY *Continued*

Harriet had a tracheostomy inserted and continued on dialysis. She began to improve, was gradually weaned from the ventilator, and no longer required dialysis. After a 3½-month hospitalization, she was transferred to a rehabilitation center near her home. Three days after her transfer, when the aide went to awaken her in the morning, she was unresponsive. The rehabilitation facility had a copy of her durable power of attorney and immediately contacted a neurologist, the medical center from which she had been referred, and her brother. Since her advance directive clearly indicated that she wanted everything done, they anticipated her immediate transfer back to the medical center where she had been hospitalized.

Instead, Harriet was transferred to her local hospital where she was examined by the neurologist. On examination, Harriet was unresponsive, decorticate on her right side, and flaccid on her left. Her blood pressure had increased to 200/120 mmHg and she was hyperventilating. A CT scan revealed a large cerebral bleed. When the neurologist consulted with the medical center, they decided that there was little that the center could do that would benefit Harriet and she would not be transferred. Harriet's brother arrived and wondered why she was not being transferred and whether she needed to be intubated since she was breathing erratically.

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### Ethics Consultation

When the health care team, patient, and family cannot reach a consensus about the continuation of life-sustaining treatment, the issue should be referred to the hospital's ethics committee. The Joint Commission requires hospitals to have an ethics committee for discussion and consultation to aid in the resolution of such difficult issues. The consultation may be with a member or member(s) of the ethics committee, or the case may be presented before the entire committee. The goal of case consultations by ethics committees is to suggest ways to resolve disagreements in difficult situations.

Bernard Lo (1995) identifies five goals of ethics case consultations. First, the ethics committees can help the health care team identify and understand the specific ethical issues the case raises: for example, cases that involve questions about advance directives, surrogate decision making, or disputes over life-sustaining treatments. Health care providers need to think carefully and critically through the ethical issues themselves before they try to resolve disagreements with the patient or family. Second, the ethics

committee can suggest how health care providers might improve communications with the patient and family. Poor communications and lack of communication among the health care providers and members of the team may be a problem that the ethics committee can identify and help resolve. Third, the committee may provide emotional support to the physician, nurses, and other health care team members in a case. Fourth, the committee may offer specific recommendations to help resolve the dilemma. Most committees or consultants help the health care team analyze the ethical issues and facilitate discussions with patients and families rather than offer specific recommendations for resolving the dilemmas. Finally, the committees or consultants have a role in improving patient care. Patient care decisions do not necessarily have to change after consultations, nor is there a mandate that they must change. However, by participating in consultation, health care providers, patients, and families may feel that their concerns have been addressed and they may better understand the rationale for the treatment decision that is being proposed.

Unfortunately, not all cases can be resolved with an ethics consultation. In fact, a situation such as

Harriet's, when an individual is requesting futile treatment, is one common reason why the health care team, family, and patient might not be able to come to consensus about goals for EOL care. Some states, such as Texas, have laws that delineate procedures that must be followed prior to, during, and after ethics committee deliberations about futile treatment. After reviewing the case, the ethics committee might recommend either supporting the continuation of life-sustaining therapy or limiting treatment. In Texas, if the ethics committee recommends discontinuation of life-sustaining treatment, the patient and proxy must receive written notification of a 10-day treatment limit with an option to request transfer to another facility. If they cannot find another facility to accept the patient, then the life-sustaining treatment is discontinued after the 10th day (Pfeifer & Kennedy, 2006). Jacobs (2009) reviewed the Texas model on its 10-year anniversary. He concluded that despite requiring some modification to correct flaws, it was a model that reduced the morally unjustifiable treatment of dying patients.

■ **Role of the Courts.** There are times when disagreements concerning life-sustaining treatments give rise to litigation. Then, the institution's lawyer is well suited to advise and educate the health care team about litigation and should be available to answer questions about the legal process that the staff may encounter during litigation or to avoid litigation. Discussions with the lawyer may ease some of the fears and dispel some of the misconceptions that health care providers have about the law and litigation in this area. In addition, discussion with the lawyer may address the potential liability for members of the committee and available immunities.

In general, the courts are hesitant to become involved in litigation surrounding EOL care, in part because they are reluctant to become involved in disputes about dying (Schneider, 2004). Schneider offers several reasons for this. First, the judicial process is not tailored to address issues with the speed required, and by the time a decision to litigate is reached, the patient may have already died. In addition, such cases are usually very complex medically and the judicial process may not be able to untangle the complexity. Finally, "a suit to enforce a living will is usually a sign that horrible and irreconcilable differences polluted efforts to make decisions for a patient" (Schneider, 2004, p. 11). Or, as he summarizes, "In love and death alike, not all wrongs can be righted, and yet fewer can be righted by the law" (p. 11). Thus, for the most part, the courts have allowed and occasionally encouraged the process in which health care providers, patients, and families work together to come to a consensus about what type of EOL care should be provided.

## ■ THE ROLE OF THE NURSE IN END-OF-LIFE DECISION MAKING

What, then, should be nurses' involvement in EOL decision making? According to the ANA, in a position statement revised in 1995, nurses have a responsibility to facilitate informed decision making about EOL care, including but not limited to the discussion of advance directives. The ANA also recognizes that nurses have roles as educators about EOL care and as patient advocates to ensure that appropriate EOL care is provided. Thus, nursing responsibilities in EOL decision making may predominate at two times: when a plan for EOL care is being developed and when a plan for EOL care is being implemented.

The nurse may be involved in assisting a patient or resident to consider or plan for EOL care when the patient is admitted to a hospital or long-term care facility. Alternatively, nurses, in their roles as educators, may encounter people in the community who wish to discuss EOL care planning. For example, some critical care nurses are actively promoting EOL planning through television programming, group discussions, and community meetings. Most patients agree that it is when they are relatively well, which most believe they are even on hospital admission, that they ought to be considering EOL care planning (Nolan & Bruder, 1997).

The ANA concurs that nurses need not focus on completion of an advance directive during such discussions but instead ought to provide education about possibilities at the EOL and explore patients' values, wishes, and preferences. Davison and Degner (1998) suggest that a logical place to begin the discussion is determining how much control the person wishes to exert over his or her EOL care. They utilize a card sort that establishes three categories of patient decision making. The three categories are as follows:

1. **Active.** The person might select "I prefer to make the final selection about which treatment I will receive." The patient might also choose to have the family make the final decision; a definitive choice for the family to decide is also seen as an active decision by the patient (p. 134).
2. **Collaborative.** The person would choose from the card sort: "I prefer that my doctor and I (or my family and my physician) share the responsibility for deciding which treatment is best for me."
3. **Passive.** The person would select a choice such as: "I prefer to leave all decisions concerning my treatment to my physicians." The person might suggest that the physician consult with the person or family for an opinion, but in this selection, the final decision is the physician's alone.



Davison and Degner (1998) suggest that once it has been determined what role the patient wishes to assume in decision making and whom the patient wishes to include in the decision making, then it is the nurse's role to initiate appropriate discussion and education among decision makers.

Since most patients desire that they and their families have at least some input into EOL decisions, Davison and Degner (1998) recommend that the nurse next focus on identifying the patient's and family's goals and values, as well as their understanding of the possibilities and results of the use of life-sustaining technologies at the EOL. The nurse might begin such a discussion by saying:

I want you to imagine that you were diagnosed as having a terminal illness. By that I mean you were dying from the illness and would not be likely to get better no matter what treatment your doctor prescribed. What would matter to you; how would you like to be cared for at that time?

This is the step that many physicians avoid. Although difficult, it is imperative that the health care provider listen actively to the patient's and family's concerns, questioning and clarifying what they desire without the health care provider imposing his or her own values and goals. What the nurse is attempting to learn is what this person and his or her family believe they will value as the EOL approaches. Most elders have a strong tendency to favor limitation of treatment when they are unlikely to return to their baseline functioning or are probably dying (Gillick & Mendes, 1996), but this is not always true and some elders wish to continue to live until specific events occur or goals are reached. This is the nurse's opportunity to learn what the elder and family believe will probably be important as the EOL approaches.

After the patients' and families' goals and values have been explored, the nurse should assess what they understand about the use of life-sustaining treatment. According to Silveira, DiPiero, Gerrity, and Feudtner (2000), a significant proportion of outpatients misunderstand options at the EOL. This is not particularly surprising since many Americans obtain their information about life-sustaining technology and EOL care from television. Diem, Lantos, and Tulskey (1996) documented that in reality-based television medical shows, nearly all patients survive CPR. While in fictional shows such as "ER," approximately 75% of patients survive CPR. This serious misinformation often has to be corrected and misperceptions dispelled before patients and families consider what types of life-sustaining interventions they would desire at the EOL.

According to the ANA, nurses have an important role in educating patients and their families about

their options at the EOL. This includes a discussion of the experience and outcomes of such treatments as CPR and ventilation. The description of CPR should be accurate and include all of the elements of resuscitation (aeration with intubation, chest compressions, defibrillation, etc.). However, it is important the nurse allow the patient and family to develop their own opinions and come to their own conclusions. Just as physicians can color their discussions to patients and families with their perspectives on life-sustaining interventions, so can nurses. Many nurses have very negative remembrances of CPR (Page & Meerabeau, 1996), and it is quite possible for nurses to convey these impressions to their patients and the families. Nurses might begin discussion of specific preferences for life-sustaining treatments in a manner similar to the way in which they began discussion of the patient's values and goals for EOL care, such as:

I want you to imagine that you are very close to dying and would not be likely to get better no matter what treatment your doctor prescribed. What type of medical interventions would you want us to try in an attempt to prolong your life and delay your death?

The final step in the development of an EOL plan should involve multidisciplinary development of a plan. The meeting (or preferably meetings) should involve at least the patient and physician, but also family and other health care providers as possible and appropriate. At the meetings, the patient and family can clarify any questions they might have about EOL care options and develop a plan, possibly a written directive. Hopefully, the final plan will include the extent to which the patient desires to be involved in the decision making, the role she or he wishes her or his family or physician to play, the patient's goals or values for EOL care, any specific desires the patient has for specific interventions to be utilized or withheld at EOL, and a choice of health care proxy, if appropriate. The more physicians and other health care providers are involved in developing a plan for EOL care for a patient, the more likely the plan is to be followed when the patient becomes ill and a decision needs to be made.

Once the person becomes ill and enters the health care system, the ANA recommends that the nurse assume the role of advocate for the patient's EOL care preferences. On admission to a health care institution, the patient and family must be asked if the patient has an advance directive and if a directive exists, whether they can produce a copy of the directive. Before assuming that the directive should come into effect, the nurse or another health care provider needs to inquire if the patient still wants the directive to take effect. As previously noted, many patients change their minds

about portions of their advance directive as they age and their health status changes. However, only one member of the health care team needs to inquire of the patient about the patient's current thoughts and feelings. The spouse of one patient who had declined all life-sustaining technologies recalled his wife being asked by 13 health care providers in 24 hours if she had changed her mind. Communication among health care providers about advance directives is essential.

Communication between health care institutions is also essential. One major problem with existing advance directives is that they are lost when the patient is transferred from one institution to another. If, as health care providers, we are asking people to complete advance directives prior to the development of an illness, we ought to be able to arrange for communication regarding the directive between facilities.

When directives exist, the nurse may use the directive to help families to understand and follow the choices laid out in the directive for a family member who has become gravely ill and is incapacitated. When a patient has stated in a directive that she or he wishes to have life-sustaining interventions such as CPR or intubation withheld, the family often feels relieved to know that they are not making the choice. Some families experience guilt over depriving a family member of even the smallest possibility of continued survival.

However even when a directive exists, it is much more likely when a patient becomes suddenly, gravely ill that the patient's choices will not be clearly related to the specific circumstances the patient is experiencing. Most likely of all is that no advance directive exists. When the patient is gravely ill, it is often the nurse who first notices that death is approaching. Clear communication to the family and physician is essential at this time because the family frequently has not considered death as an alternative (Caswell & Omery, 1990). Families need adequate, consistent information in terms that they can understand. Norton and Talerico (2000) caution that families need health care providers to use words such as death and dying; vague language makes families become confused. It is especially important, Norton and Talerico state, that health care providers not use terms like "better" when a patient's condition has temporarily stabilized but the overall prognosis is unchanged, because this leads to conflicting impressions among family members and family disagreement about treatment. Another term that confuses family members is "hope." Health care providers often use the term when there is hope for a good death or pain control; however, for family members, hope primarily means survival. Norton and Talerico (2000) recommend that nurses be specific in

identifying that they are hoping for a good death or pain control for the patient, not continued life.

If death appears imminent and there has been no decision about EOL expectations, nurses may introduce the discussion of withholding or withdrawing of life-sustaining interventions, such as CPR, intubation, and ventilation. There are two common ways that nurses begin a discussion of these interventions (Norton & Talerico, 2000). One of them is to inform the family that the state requires that all people receive CPR (even when it is unlikely to be of any benefit to the person) unless a DNR order is written. This is often an easier way to begin the discussion if the family has not completely acknowledged that the patient is probably dying. However, it may prevent the family from acknowledging and discussing the nearness of the patient's death. Another common approach is to acknowledge that the patient is gravely ill, probably dying, and ask the family which vision of the patient's death would be in the patient's best interests: one in which they were surrounded by family with the lights lowered and were receiving medication for pain and symptom relief, or one in which they were surrounded by health care personnel who were providing CPR. A discussion of the likelihood of survival following CPR should also be included.

Most patients and families want to discuss EOL care with their nurse, but they need to hear the same message from the patient's physician. Thus, the nurse must be in communication with the physician about the patient's prognosis and the patient and family's preferences about EOL care. Hanson et al. (1997) note that one reason for delays in the withdrawal of patient treatments is that although patient preferences are documented, they are not communicated to physicians so that the physicians actually appreciate the patient's wishes. When there are differences in expectations of patient outcome or confusion over the appropriateness of various therapies, multidisciplinary patient care conferences are very important.

The nurse can assist a surrogate or family member to understand her or his role in the multidisciplinary team and to help make the decision about the patient's EOL care. To begin with, White (2011) believes that the nurse must educate the person about what the role of the surrogate entails as well as how important it is. Next, the nurse should ensure that there is not just one meeting, but regular meetings between the surrogate or family member and the multidisciplinary team. The nurse should prepare the surrogate before each meeting so that she or he is ready with questions, support the surrogate during the meeting, and debrief the surrogate following the meeting to ensure that the surrogate has an accurate understanding of the discussion (White, 2011).



Discussion about EOL care with families or patients in crisis cannot come as a barrage of questions all at once from multiple health care providers. It is best if the patient or family has some time to consider EOL care. Thus, withholding CPR is often discussed first and gradually questions concerning withholding or withdrawal of other life-sustaining interventions are introduced.

As the ANA has stated in its position statement, it is the responsibility of nurses to facilitate informed decision making for patients at the EOL. This responsibility begins when the nurse has a patient consider what would be important to him or her at the EOL, continues with the nurse educating the person about EOL care options, and is completed when the nurse advocates for and delivers the type of care the patient desires at the end of her or his life. However, this process of communication about EOL care is not solely the responsibility of the patient and the nurse; it is an interprofessional process that includes at least the physician and family in addition to the patient and nurse.

## ■ CONCLUSION

Numerous factors make it likely that EOL decision making will continue to raise difficult issues for health care professionals, patients, and patients' families. The reasons that people do not complete advance directives and discuss EOL care, even after educational interventions, seem much more compelling

than the reasons for completing them. Health care providers often do not have enough regular ongoing contact with patients, so patients do not feel comfortable discussing EOL issues or completing advance directives.

Instead of focusing on the actual number of advance directives completed, we should look at whether our activities are encouraging discussions of EOL care with patients and families. The evidence to date indicates that simply providing information encourages patients to talk about their preferences with family members and friends, that is, the people who will be making decisions in the event the patient loses decision-making capacity. Anything that encourages such conversations enhances patient autonomy and self-determination.

Advance directives, DNR orders, court actions, and legislative actions are all important mechanisms for nurses to consider when seeking ways to resolve the dilemmas that exist when caring for patients at the EOL. Nurses must have opportunities to think critically and articulate their views and positions on the dilemmas they face as individuals and as professionals. Ethics rounds, grand rounds, ethics colloquia, courses in basic nursing education, continuing education offerings, and conferences all provide forums for nurses, students, faculty, and clinicians to enhance their ethical and legal awareness. The American Nurses Association Center for Ethics and Human Rights is one rich resource for nurses who seek consultation and ethics information.

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## CASE STUDY Conclusion

Harriet was admitted to the ICU of the local hospital. Her nurse remembered Harriet and her brother from Harriet's previous admissions. She recognized that the brother was unsure about what ought to be done for Harriet. She said to him, "Despite all that we have done for her, Harriet is dying now. There is nothing we can do to stop the dying process. However, we can keep her comfortable, and I think that she would realize we have tried very hard to follow her directions. She asked you to be her health care proxy because she trusted you to know when the time had come to say 'it is time to stop doing things that will not help her and time to keep her comfortable instead.'"

Harriet's brother agreed and she died peacefully an hour later.

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## Evidence-Based Practice

Wilson, D. (2011). Quality care at the end-of-life: The lived experience of surrogate decision makers. *Journal of Hospice and Palliative Nursing*, 13(4), 249–256.

Q: What factors were important to surrogates who decided whether to prolong or end treatments for a seriously ill family member?

### Methods

This study was descriptive phenomenological research.

### Data Sources

Data were collected during an in-depth interview where surrogates were encouraged to share their experiences.

### Study Selection and Assessment

A networking sampling technique was employed and participants were enrolled until the data were saturated. A total of 10 participants who had been extensively involved in making end-of-life (EOL) decisions for a family member provided demographic data and were interviewed for the study.

## OUTCOMES

### Main Results

Themes that emerged from this study included the following:

**Knowing EOL wishes.** When the participant or family had had a conversation with the patient about EOL, they were more confident about following the patient's wishes than if only an advance directive existed.

**Communication with health care providers.** Participants expressed a great deal of frustration trying to obtain accurate information about the patient's health status, and this was a barrier to decision making.

**Acceptance/acknowledgment of futility.** All participants discussed the need to believe and accept the fact that the end of the patient's life was approaching.

**Strengthening relationships with loved ones.** More than half of the participants stated that they were able to reconnect with the patient/or other family members and forgive old wrongs after accepting the impending death.

**Pain and symptom management.** All participants stated that they wanted good pain management for the patient, whether they designated the patient to have comfort measures only or aggressive treatment.

### Conclusion

"Treatment decisions were facilitated when the treatment preferences of the patient were known, when health care professionals provided accurate, consistent information about the patient's health status and when the patient's condition was clearly futile. Barriers to treatment included: lack of knowledge, poor communication with health care providers, and the cyclical nature of many health care conditions that fueled a sense of hope" (p. 255).



## COMMENTARY

This study demonstrated that surrogate decision makers found that having a conversation with the patient where the patient expressed preferences for EOL care was more important than the presence of an advance directive identifying patient desires. Pope (2012) notes that although such an instance is not common, the surrogate in such an event becomes a reporter of the decision rather than an actual decision maker and the process is usually easier for the surrogate. Braun, Naik, and McCullough (2009) concur, noting that the more certain the surrogate was of the patient's desires, the less burdensome she or he perceived the decision to be. In contrast, surrogates who had a high level of uncertainty about the patient's preference perceived making the decision as being very burdensome. Participants in a study by Buckey and Molina (2012) emphasized how emotionally difficult (even devastating) the decision was to make when they were unsure of the patient's preferences. Berger, DeRenzo, and Schwartz (2008) believe that surrogates struggle in part because of the number of additional factors that they usually consider when they do not know the patient's wishes. Nonmoral or medical factors that may affect such surrogates' decisions include family dynamics, the stress of being a surrogate, and a bias in favor of "status quo." It is apparent from these studies that surrogates need support from health care providers when making decisions for patients, particularly when the patient has not clearly expressed his or her wishes.

This study also portrayed surrogates as feeling frustrated by their inability to obtain consistent and clearly understandable information about the patient's health care status. Surrogates believed that they needed accurate information that supported the fact that the patient was dying (acknowledgment of futility) in order to make EOL decisions. White (2011) has identified structural/process of care barriers that are partly responsible for surrogates feeling unable to obtain the information they believe they need. These barriers include clinician turnover, time constraints, lack of convenient space for family meetings, and lack of regular/timely communication. He also identifies lack of communication skills by the clinical team as a separate barrier to effective surrogate functioning. White therefore argues that nursing involvement is essential to quality surrogate decision making. His recommendations for nurses working with surrogates are described in the main section of this chapter. However, he places the responsibility of ensuring that appropriate communication concerning the patient's condition and prognosis occurs with the nurse. He states that nurses should help the family's formulate questions for discussion during multidisciplinary rounds, elicit the family's or surrogate's understanding about prognosis, and facilitate the "crucial yet challenging" discussion of the possibility of death. If nurses consistently took such an approach, surrogates might not routinely encounter the frustration described in the study by Wilson.

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# Caring for the Whole Person in Palliative Care

## SECTION

Today, I admitted Candy Harris to our home care agency. Candy is a 42-year-old woman who, until a month ago, worked as a nurse for developmentally delayed children. She has been married to Ron for the past 20 years; a picture taken of them at their senior prom sits on a bookshelf. They have two children aged 5 and 8 years and live in a new neighborhood development. She seemed so sad when I arrived, but I would be, too, if I were in her situation. I find admissions like this so difficult; she is close to my age and we are so similar in other ways.

She tells me the history of her disease in a very matter-of-fact way. For the 9 months prior to her diagnosis, Candy had noticed increased flatus that had not gotten better, despite alterations in her diet. For the 2 months prior, she said that she had little appetite, but still had gained 5 pounds. She felt bloated all the time and the waistbands of her clothes were tight. Her mother started menopause in her early 40s and died at age 56 of breast/ovarian cancer. Candy thought that her symptoms were related to the early start of menopause and so decided to visit her nurse practitioner for a physical examination and Pap smear.

Given Candy's symptoms and her positive family history of cancer, the nurse practitioner ordered an abdominal CT scan in addition to a complete physical work-up. An ovarian mass was detected and Candy was scheduled for a laparotomy. Stage III ovarian cancer was diagnosed. The surgeon was able to use cytoreduction to decrease the tumor volume to less than 2 cm in diameter, and the oncologist suggested platinum-based combination chemotherapy. Candy was in shock that all this was happening to her so fast. The children were really too young to completely understand what was going on and her husband insisted that they were going to "fight this."

Candy had just finished her third cycle of chemotherapy. She is very weak and in need of home health care support. Candy was sitting in a chair in the living room when I arrived. Her hair had all fallen out and her eyes were red, as though she had been crying, and she was holding a rosary in her hand. One section of the wall was covered with get-well cards; she referred to this area as her "prayer wall." As I was assessing her, she burst into tears and told me that she thinks "God is punishing me for something" and that this is why she has cancer. This was not the first time that I have heard this from a patient. Believing in the importance of atoning for her sins, Candy has been attending Mass whenever she has the strength, praying the rosary regularly, and asking the church congregation to pray for her. She has gone to confession and received the Sacrament of the Sick. She also admitted that she wanted to

“cover all of her bases” and that she has turned to holistic interventions in addition to her chemotherapy so that her body, mind, and soul will also heal. After her initial diagnosis, she researched complementary interventions for cancer and started on a macrobiotic diet with additional B<sub>12</sub> and D vitamins.

Candy receives Reiki twice a week and is seeing a therapist weekly. She said that she and her husband use mental imagery and relaxation techniques to imagine her body defenses as a powerful source to annihilate the cancer cells. Candy said that she has so much to live for, that she has a lot of good friends, a loving husband, and great kids. She really does not know what she has “done wrong” but she asks for God’s forgiveness and hopes to get on with her life.

As a nurse, I marvel at her will to live and her determination to beat this disease. She seems to draw her strength from her religion and her relationships. Her strength is an inspiration to all who care for her.



# Culture and Spirituality as Domains of Quality Palliative Care

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## KEY POINTS

- Culture and spirituality structure human experience, values, and behaviors.
- Spirituality provides a sense of connection to self, others, nature, and God and is important in crisis and illness.
- Cultural competence involves knowledge of your own and other cultural groups.
- Cultural assessment has several areas to be addressed.
- Spirituality and religiosity help individuals to cope with serious illness and play a role in the dying process.
- Suffering is a part of the human condition and is experienced in physical, emotional, and spiritual ways.
- Suffering is reciprocal, involving not only the patient but also his or her family.
- Hope plays a role in promoting spiritual well-being.
- Health professionals must learn how to conduct a spiritual assessment and have conversations about spiritual and religious issues.
- Spiritual care discovers, reverences, and tends to the human spirit.
- Knowledge of cultural and spiritual perspectives on death informs care.
- Culturally and spiritually competent care requires self-reflection and self-care of health professionals.
- Palliative care addresses the cultural and spiritual needs of patients and families.

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## CASE STUDY

Mrs. Martinez is an 84-year-old Latino woman, who has progressive pain and weakness due to sensory neuropathy, secondary to diabetes and arthritis. During the course of her illness, she has maintained her independence and good spirits. Mrs. Martinez believes that her faith in God has enabled her to endure her chronic pain. She states, “Sometimes I pray when I am in deep, serious pain. I pray and all at once the pain gets

easy. I feel it has helped me more than the medication. I believe in God. He is my guide and protector.” Mrs. Martinez lives with her daughter, son-in-law, and grandchildren.

They are a source of comfort and support and are very concerned about her well-being. Unfortunately, Mrs. Martinez recently had a stroke, which resulted in left hemiplegia. After an initial hospital stay, her family insisted that they care for her at home. On a visit to their home, the health care professional observes a shrine of Mary in the front yard, as well as crucifixes and pictures of Jesus in every room. In addition to traditional medications prescribed by her physician, Mrs. Martinez takes herbal remedies in an attempt to restore her health. The health care professional acknowledges the cultural and spiritual values and beliefs of Mrs. Martinez as considerations in providing quality palliative care.

Culture and spirituality are among the most important factors that structure human experience, values, behaviors, and illness patterns. As a system of shared symbols and beliefs, culture supports a person’s sense of security, integrity, and belonging and provides a prescription for how to conduct life and approach death (End-of-Life Nursing Education Consortium [ELNEC], 2013). Every culture has a worldview or construct of reality that defines the individual within that reality. Patients’ cultural backgrounds are therefore fundamental in defining and creating their reality and determining their purpose in life (Ersek, Kagawa-Singer, Barnes, Blackhall, & Koenig, 1998). A transformation of identity begins when an individual is diagnosed with a fatal illness. Cultural rituals provide the sacred elements that support patients and families during times of illness and transition. Specific rituals assist individuals and families in coping with death, which is the final transition in life. The rituals of death change the identity of the patient from the living to the dead, and also the identity of the family member, for example, from spouse to widow or widower (Kagawa-Singer, 1998). Culture provides a framework of expectations about communication with others, including health professionals, and the role of family, and influences the dynamics of decision making regarding health issues and the dying process itself (Barclay, Blackhall, & Tulskey, 2007).

Spirituality plays a vital role in times of crisis and illness, as it provides a sense of connection to self, others, nature, and God, and is a means to cope with loss, grief, and death (Weaver, Flannelly, & Flannelly, 2001). Life-threatening illness is a crisis on many levels: physical, psychological, familial, social, and spiritual (Doka & Morgan, 1993). Given the uniqueness and individuality of each person, even people of the same culture and spirituality may have different backgrounds, experiences, needs, concerns, and interpretation of illness. In addition to the individuality of the person, the nature of the life-threatening illness may be different and the person may be at different points in adapting to the reality of the disease. Spiritual and

cultural concerns may permeate the illness experience or may arise at any point across the illness/dying trajectory. For patients and families who are experiencing life-threatening illness, the concerns may be of suffering that may take multiple forms relative to the mind–body–spirit. It is now recognized that the uncertain and long-term nature of many life-threatening illnesses poses the potential for pain, alterations in body image, and confrontation with death, which may lead to spiritual distress. The renewed focus on incorporating spiritual care into nursing practice is congruent with nursing’s commitment to holistic practice and the renewed valuing of human experiences that defy scientific description and explanation (O’Neill & Kenny, 1998). Within the past few years, research has shown that religious beliefs and spiritual practices affect the meaning of illness, physical and emotional well-being, coping with illness, and health care decisions, particularly for individuals facing life-threatening illness.

Spiritual and cultural competences are central tenets of palliative care (PC). As a philosophy of care, PC combines active and compassionate therapies to support and comfort individuals and families who are living with life-threatening illness. PC strives to meet the physical, psychological, social, and spiritual expectations and needs, while remaining sensitive to personal, cultural, and religious beliefs and practices (National Consensus Project, 2013). Undergraduate-prepared nurses and advanced practice nurses must become spiritually and culturally competent in the care they offer across the illness/dying trajectory. Such care is critical to enhancing the quality of life (QOL) and quality of dying, and to supporting the intrinsic dignity of patients and their families.

## ■ UNDERSTANDING CULTURE

*Culture* is defined as a way of life, which provides a worldview, fundamental in defining and creating a person’s reality, determining his or her meaning and



purpose in life, and providing guidelines for living (Ersek et al., 1998). As cultural perspectives evolve, changes are evident in the beliefs, values, and attitudes of a cultural group or its members. Cultures are not monolithic; rather there is a range of potential responses to each issue in every cultural group. Thus, there may be within-group variations, such as those attributed to acculturation differences, as well as to differences related to age, education, geographic location, and social context (Barclay et al., 2007; Kagawa-Singer & Blackhall, 2001). It is important to inquire whether an individual patient adheres to the beliefs and practices of his or her cultural group, rather than assuming that he or she holds the same values and beliefs (Crawley, Marshall, Lo, & Koenig, 2002).

Although culture is often identified with ethnicity, it is a far broader concept, which encompasses the components of gender, age, sexual orientation, differing abilities, educational level, employment, and place of residency (ELNEC, 2013). As examples, cultures may value male children more than female; the young more than the old; heterosexuals rather than homosexuals; the educated and employed more than the uneducated or unemployed; individuals with stable domiciles more than the homeless; and the healthy more than the physically, emotionally, or intellectually challenged. The diversity of the population with regard to many of these factors may increase their vulnerability in terms of perceived cultural status. Concepts of culture and ethnicity may be useful for making generalizations about populations; however, if they limit appreciation of the unique differences of people and are used to predict individual behavior, they may lead to stereotyping (Koenig, 2002).

Cultural background also relates to issues of power, decision making, language and communication, sources of support within the community, degree of fatalism or activism in accepting or controlling death, maintaining hope, and also views of the patient and family about death (Sherman, 2001). Cultural differences are further evident in terms of the relationship between the older adult and his or her family. In certain cultures, the older person is viewed as the patriarch or matriarch of the family who has the final word in personal and family matters. In other cultures, the older person defers decision making to members of the family, as interdependence among the family and community members is more valued than individual autonomy (Ersek et al., 1998). Depending on cultural expectations, families may believe that it is their duty to protect the patient from bad news, which is believed to burden the individual or cause emotional distress or harm. Therefore, full disclosure of diagnosis and prognosis to the patient may be considered harmful by families (Barclay et al., 2007). As the cultural diversity of patients and practitioners in

the United States continues to increase, there is a risk for cross-cultural misunderstanding surrounding care at the end of life (EOL). Cross-cultural understanding and communication techniques increase the likelihood that both the process and outcome of health care are satisfactory for all involved (Kagawa-Singer & Blackhall, 2001).

## ■ CULTURAL PERSPECTIVES IN HEALTH CARE

Understanding the cultural backgrounds of patients is fundamental to the development of a trusting and supportive relationship between patient, family, and health care professionals, and essential in developing a plan for health care that is consistent with their cultural expectations and health beliefs, as many health belief systems are culturally constructed (Herselman, 2004). Andrews and Boyle (1995) discussed three types of health belief systems: magico-religious, biomedical, and holistic. In the magico-religious paradigm, a person believes that God or supernatural forces control health and illness. In the biomedical paradigm, to which most Americans subscribe, it is believed that illness is caused by a disruption in physical or biochemical processes that can be manipulated by health care. In the holistic paradigm, health results from a balance or harmony among the elements of nature and illness is produced by disharmony. Examples of the magico-religious system is a Haitian patient who believes that his symptoms are caused by spirits, or the Mexican American who uses herbs, oils, incense, or religious figurines to drive away evil spirits or to relieve gastric pains. In the biomedical system, Americans or Europeans seek cure of illness through advanced medical technology and pharmacological management. Based on the holistic belief system, a Chinese woman may attribute her headache to a stagnation of qi, believing in the need for balance between yin and yang; a Native American patient may wear a bag of herbs blessed by the medicine man around his neck to maintain his strength (Grossman, 1996).

Recognition of these health beliefs systems is evident in the health care practices of many cultures. The health beliefs of the African American, Chinese, Asian Indian, Latino and Hispanic, and Native American are discussed on the basis of recent studies or cultural inquiries and provide a framework for offering culturally competent hospice and palliative care to members of these cultural groups. The only truly accurate way that one may know what individuals believe in or the effect that their culture or religion plays in their life is to ask them. The following information will guide the nurse regarding areas to be assessed.

## Cultural Perspectives of African Americans

Within the African American culture, there is a strong sense of community and of the importance of family, friends, and the church community as sources of support. The extended African American family consists of mother, father, children, grandparents, aunts, uncles, nieces, nephews, and cousins with a willingness to accept all relatives regardless of their circumstances (McDavis, Parker, & Parker, 1995). Older adults are prized in the African American family and they play key roles in the family, church, and community. Many grandparents accept the responsibility for rearing their grandchildren, while the parents of those children work or receive higher education. Children are taught to take care of their parents and to be devoted to them. In addition, older African American family members play a significant role in passing on cultural values, customs, and traditions to the children (McDavis et al., 1995).

African Americans are often distrustful of the health care system, given a history of oppression and mistreatment from slavery, racism, and even being subjected to medical experimentation in the United States, as seen in the infamous Tuskegee syphilis study conducted from 1932 to 1972 (Kennedy, Mathis, & Woods, 2007). Common themes of justice and respect have reinforced the importance of self-determination. In a study of attitudes, values, and questions of African Americans regarding participation in hospice programs, Taxis (2005) identified three main barriers: (a) a lack of information about hospice and inaccurate assumptions regarding hospice care; (b) cultural barriers resulting from an avoidance of discussions regarding EOL planning; and (c) institutional barriers resulting from a mistrust of the health care system. Bullock (2006) reported that even using a faith-based promotion model of advanced care planning, 75% of the 102 African American participants refused to complete advance directives. The participants' decisions were based on such factors as spirituality, view of suffering, dying and death, social support networks, and mistrust of the health care system. For African Americans, advance care planning conflicts with their beliefs and attitudes about fighting to the end, not giving up hope, and enduring suffering. In a study of 473 adults (220 Blacks and 253 Whites), Ludke and Smucker (2007) found that relative to Whites, Blacks were significantly less likely to consider hospice if they were near the EOL even if their doctor recommended its use. However, Blacks who had a prior exposure to hospice and who trusted their doctor were more willing to consider hospice.

Because family is central to the care of the dying, and with the assistance of and supportive relationships established with church members and neighbors, there is a decreased need for outside support (Sherman,

2001). Given strong family loyalty, there is reluctance to hospitalize family members. As a measure of respect and devotion, elder African Americans are placed in nursing homes only as a last resort (McDavis et al., 1995).

In the African American culture, death is integrated into the totality of life. Ancestor worship involves the communion with the living dead through memories, and the deceased are remembered by name. When living people no longer remember the deceased, they become part of the anonymous dead, but by this time, it is believed that their spirit has been reborn in a new child (Sherman, 2001).

To explore the meaning of death and the experience of grieving, Abrams (2000) conducted life history interviews of 9 church-going women, ranging in age from 19 to 82 years, from a small Black storefront Baptist church in the Pacific Northwest. The findings indicated that the women in the church had been taught to be strong in the face of death and to handle their grief "head on." The women believed that they would one day be reunited with their loved ones. The terminology of dying was through use of the words "passed on," "passed away," or "died." Participants described many spirit visits for the purpose of offering warnings or as direct messages. Belief in an afterlife was sustained by day-to-day experiences of visions or messages from another world. It was believed that God spoke to them in many ways through premonitions, perceived as the voice of God. There was strong perception of the journey of life in which there is a job to do on earth and a purpose to one's life. No life was in vain. Time was needed to prepare for death and to make peace with God as dying individuals. Participants also described the importance of hope, acceptance, and responsibility to comfort the dying and the bereaved. Abrams (2000) concluded that health professionals should learn to value the spiritual beliefs and grieving behaviors of members of other cultures, rather than viewing them as maladaptive. Supporting dying patients and their families in their beliefs is important in providing spiritual care. Verbal recognition of specific actions taken by families to support the dying person provided a sense of comfort and support to the family in their grief. The people in this storefront church were often comforted by the recognition that God sustained them in times of adversity and God would protect their loved ones. This acknowledgment of the family's belief system by health professionals can augment the healing process during times of loss and grief.

## Cultural Perspectives of the Chinese

In the Chinese culture, the primary theme related to social structure is the centrality of the family. From



the centrality of the family arises cultural expectations, such as: (a) duty to family manifested by respect and reverence for parents; (b) conformance to family and societal norms and especially not bringing shame to the family; (c) family recognition through achievement; (d) emotional self-control manifested through reserved and formal public verbal and nonverbal communications; (e) family disagreement, or demands, kept to a minimum; (f) collectivism evidenced by people keeping a focus on the family and community over self; and (g) humility manifested by a lack of striving for individual achievement but achievement that is related to the family (Kemp & Chang, 2002).

Given the traditionally hierarchical and patriarchal family structure of the Chinese, the oldest adult male is the primary decision maker. In family matters, there is significant influence of elders. Health decisions may be made by the family, and are based on what is best not only for the elder patient but also for the family (Kemp & Chang, 2002). In general, yes and no questions should be avoided, as yes is considered to be the polite answer and is nearly always given.

In China, the primary religion is Buddhism. The essence of Buddhism is the Four Noble Truths, specifically that: (a) all sentient beings suffer; (b) the cause of suffering is desire manifested by attachment to life, security, and others; (c) the way to end suffering is to cease to desire; and (d) the way to cease desire is to follow the Eightfold Path of: knowledge of the Four Noble Truths, right intent, right speech, right action, right endeavor, right mindfulness, right meditation, and right understanding. It is believed that following the Eightfold Path leads to emancipation from rebirth (Kemp & Chang, 2002).

In the Chinese culture, it is also important to understand the importance of balance of the yin and yang, which are complementary forces. A second important concept is that of traditional Chinese medicine (TCM), which is based on channel (meridian) systems, in which various body channels carry vital or life energy called *chi* or *qi*. Imbalance or disruption of channels leads to illness and the treatment goal of TCM is to restore balance. A third important concept in understanding Chinese approaches to health and illness is the use of allopathic medicine, as well as TCM.

Issues central to the care of the Chinese at the EOL center around family and communications (Kemp & Chang, 2002). Symptom management may be complicated by the patient's and family's reluctance to complain because of respect for others in positions of authority. Concerns also center around fears of addiction, desire to be a good patient, and fear of distracting the physician from treating the disease. In some cases, elders may even deny symptoms when asked directly; however, the use of the visual analog

scale and numeric rating scale can be used to assess pain. For example, patients may want to keep warm during illness by wearing sweaters or socks in bed and drinking warm liquids and avoiding cold drinks. As death nears, the family may wish to call monks or nuns for ritual prayers (Kemp & Chang, 2002). Communications at the EOL are also complicated by reluctance to discuss prognosis and diagnosis. Chinese families often withhold information from patients and may pretend that he or she does not know what is happening. Families believe that discussing EOL issues is like wishing death upon the elder, or may lead to hopelessness, especially as terminal illness is not socially accepted. As death approaches, it is believed that a person's final days should be characterized by calm and the patient should not be involved in decision making. The best way to handle the conspiracy of silence is to ask patients how much they want to know, and if they do not wish to know, then they should be asked to whom the information should be given and who should make decisions. Although a preference for nondisclosure of poor prognosis seems to have historically predominated in the Chinese culture, research with Chinese subjects is beginning to demonstrate a shift in attitudes with a preference for more direct and patient-centered disclosures of prognosis (Ahalt et al., 2012; Yu et al., 2007; Yun et al., 2010). Families often feel it is their cultural obligation to care for the person who is dying, and therefore hospice services are often refused (Kemp & Chang, 2002).

### Cultural Perspectives of (Asian) Indians

Among (Asian) Indians, extended families are prevalent and elders are highly respected. The husband's parents often move in with family after retirement, when the family decides to have children, or if there is illness. Elders are highly valued, as is their role as grandparents in raising children. Value is placed on independence and privacy in Indian culture, and family issues are discussed within the immediate family before outside help is sought (Bhungalia & Kemp, 2002). Health care decisions usually require family input.

Many Indians are of the Hindu faith. The goal of Hinduism is to free the soul from endless incarnation and suffering inherent in existence. The endless reincarnations of the soul are the result of karma or actions of the individual in this present life and the accumulation of actions from past lives.

The caste system is part of Hinduism. In this system, society is divided into four social classes: the highest class is the priest class, or Brahmins; and the lowest class is the laborer class, or Sudras. A person's class is inherited at birth based on his or her karma.

Hindu beliefs that may affect patient care include the following:

- Karma, or the consequences of one's actions or behaviors, influences the circumstances of life and may have caused an illness
- Meditation and prayer are important
- The practice of vegetarianism; many Hindus pray a specific prayer before eating to ask forgiveness for eating a plant or vegetable in which a soul may dwell

The Indian system of medicine is known as Ayurveda, which means knowledge of life. Indian medicine mixes religion and secular medicine, with more than 80% of people in India relying on herbal remedies to cure or prevent illness. In this system, the root of disease is not always inside the body, but may be related to the environment or other factors. In the Ayurveda system, the body comprises three primary forces, called *dosha*, specifically the vata, pitta, and kapha. Each represents characteristics derived from the five elements of space, air, fire, water, and earth; the balance between these forces is essential to health. Once there is imbalance between the forces, balance is sought using different therapies, which includes approximately 1,400 plants used in Ayurvedic medicine. Most Indians eat two to three meals a day, eating with the fingers of their right hand, and avoiding distractions while eating, such as watching television or excessive talking. Some foods are considered hot and others cold, and should not be eaten in combination, as it is believed to affect bodily functions.

With respect to EOL care, it is important for the ill individual to complete unfinished business and resolve relationships. Home is the preferred place of death, with many family members present. Symptoms may not be reported, as it is believed that suffering is inevitable and the result of karma. Many seek a conscious dying process without mental clouding from medications. As death approaches, the following rituals are valued:

- A lamp may be placed near the patient's head; turn the body to face east, toward Mecca; sacred ash may be applied to the forehead.
- A few drops of water from the sacred Ganges river may be placed in the dying person's mouth, while a mantra is softly chanted in the patient's right ear.
- Prayer and incense are part of the rituals of the dying process.

After death, family members should be the only ones to touch the body, and ideally a family member of the same sex should clean the body. After the body is cleansed, a cloth is tied under the chin and over

the top of the head, and the body is wrapped in red cloth. Embalming and organ donation are prohibited, and there is a preference for cremation. Following the death, religious pictures at home are turned toward the wall and mirrors may be covered. It is believed that for 12 days the soul wanders in the home, trying to let go of life and the material world. During this time, the family prays and chants, and on the 12th day, the soul is reincarnated (Bhungalia & Kemp, 2002).

## Cultural Perspectives of Latinos and Hispanics

The cultural group referred to as Latinos refers to individuals of Hispanic background. By conducting 10 focus groups and interviews with 17 gatekeepers in Latino communities, Sullivan (2001) identified Latino views regarding EOL care. The results indicated that many Latinos felt that they could not communicate effectively with health care providers due to language barriers, and were not able to understand informed consent even when interpreters were used. None of the Latino participants wanted to die in a nursing home, believing that it is the families' responsibility to care for their relative. Most participants were also not aware of hospice services or had false information. Although participants expressed diverse views, one third of participants were against the use of life support, particularly if it prolonged the suffering of the patient. Participants also believed that their religious beliefs, especially fatalism and reliance on God, were central to their decision making regarding EOL care. There was division among the participants regarding the extent to which they wanted to be informed about a fatal diagnosis, citing that being informed may accelerate the illness. Many Latinos also perceived racial discrimination and cultural insensitivity as barriers to quality care and healing (Sullivan, 2001).

In the Hispanic culture, there are several considerations that relate to quality care at the EOL (Sherman, 2001). It is recognized that in Hispanic culture, there is strong family support and a belief that the dying person should be protected from his or her prognosis. Women show extreme grief or hysteria, while men show little or no grief. Death is often confronted with a humorous sarcasm and is viewed as an equalizer (DeSpelder & Strickland, 1999). Mexican Americans, as well as other Hispanics, are likely to call a priest for the Sacrament of the Sick, and the bereaved may take shifts being with the deceased person. There is strong support of family as a unit. The funeral is the single most important family ceremony and goes on for several days, as there is the belief that it takes time



to grieve. Individuals are prohibited from speaking ill of the person who has died, and the bereaved visit the grave frequently. The Day of the Dead is celebrated in November and coincides with All Saints' Day, the feast of the commemoration of the dead. Although death is viewed as an adversity, references to dying and death are common in the culture, as children play with toys symbolizing death, and the funeral is an important family ceremony. It is a time of celebration with special foods, music, and the decoration of graves. It is believed that the dead return to the world of the living for this special celebration, and families are scorned if they neglect their responsibilities. The bereaved are discouraged from crying too many tears, as excessive grief may make the pathway traveled on by the dead slippery and burden them in the journey (DeSpelder & Strickland, 1999).

A clinical study of Latino immigrants at least 21 years old and in the United States for less than 10 years (Selsky et al., 2012) used validated Spanish language instruments to assess the hospice knowledge and intent of the 331 study subjects. Only 29% of the subjects had intent to choose hospice and an additional 6% would choose hospice once it was explained. Greater knowledge of hospice was correlated with a higher education level. Subjects who believed that prognosis should remain a secret were 19% less likely to choose hospice. Higher degrees of social acculturation were associated with greater intent to use hospice. The study suggests that knowledge helps to increase the intent to use hospice among recent Latino immigrants (less than 10 years); however, the importance of social networks and acculturation were highlighted by the findings (Selsky et al., 2012).

### Cultural Perspectives of Native Americans

For Native Americans, the focus of identity is on the tribe, rather than simply having Native American ancestry. This is important because values and beliefs vary among tribes and the different bands among the "First Nations." There may be similarities in nations originating in the same region, but there are also tribal distinctions (Brokenleg & Middleton, 1993). For many Native Americans, however, life and death are viewed as a natural part of the life cycle. Death is seen as a fundamental part of nature and human existence that requires "no manipulation or anticipation" (Hepburn & Reed, 1995). In Navajo culture, however, it is believed that talking about death may precipitate it, and the appropriateness of such discussions should be assessed, and if problematic, should be avoided. Time is considered as a recurring cycle rather than a linear process. Native Americans are concerned with how this cycle affects people in this

life, and death is viewed as a motivation to treat people kindly and lead a good life (Brokenleg & Middleton, 1993; Sherman, 2001).

From a cultural perspective, Native Americans avoid eye contact and are stoic regarding the expression of pain and suffering, and traditional tribal medicines are used (Sherman, 2001). Prayer is a medium through which one might accept the outcome of a situation, and it is not appropriate to question "why" something is happening, as there is an acceptance of the natural order of things (Brokenleg & Middleton, 1993). Death may be forecast by unusual spiritual or physical events. As examples, the sign of an owl may signify that someone close will soon die, and a blue light seen coming from the direction of a dead relative's home or room indicates death (Brokenleg & Middleton, 1993).

Given their reverence for the body in life and death, autopsies and cremation are not acceptable (Sherman, 2004a). Funerals are usually at home, with members of the community expected to stay with the mourners. A death song is sung that represents the summary of a person's life and acknowledgment of death. The dead are considered guardian spirits. After death, the spirit lingers near the site of the death for several days. Native Americans use a funeral pyre and adorn the corpse with flowers, feathers, and skins. For 6 months to 1 year, the name of the deceased is not called, in order to confirm their separation from the living. All material possessions of the deceased are given away so that the family can begin its new life without the presence of that person (Brokenleg & Middleton, 1993). In the Cocopa tribe, violent grief is expressed until cremation, when they invite the spirits to join them in celebration. In the Hopi tribe, death is kept at a distance because it threatens order and control. The expression of grief remains limited and funerals are attended by few and held privately. For Native Americans, hallucinations in which they see and converse with the dead are regarded as a part of mourning (DeSpelder & Strickland, 1999).

Based on focus groups representing many Native American tribes and conducted by Native American nurses, Lowe and Struthers (2001) identified seven themes representing core principles relevant to health care. These themes include: (a) caring, which embodies characteristics of health, relationships, holism, and knowledge, and is characterized as a "partnership in healing"; (b) traditions, which refers to valuing and connection with heritage; (c) respect, which includes characteristics of honor, identity, and strength and refers to the components of presence and compassion; (d) connection, which honors all people, the past, present, and future, harmony with nature, and explores differences and similarities; (e) holism, which includes balance and culture; (f) trust, which

is characterized through relationship, presence, and respect; and (g) spirituality, which includes unity, honor, balance, and healing and includes components of touching, learning, and utilizing traditions to recognize oneness and unity.

## ■ DEVELOPING CULTURAL COMPETENCE

A culturally competent health care system “acknowledges and incorporates at all levels the importance of culture, the assessment of cross-cultural relations, vigilance toward the dynamics that result from cultural differences, and the expansion of cultural knowledge, and adaptation of services to meet culturally unique needs” (Cort, 2004, p. 68). Achieving cultural competence is a dynamic state in which health professionals gain knowledge of their own cultural and social backgrounds and become aware of the history, traditions, and values of other groups, including understanding the history, food, and lifestyles of people from other countries (Cort, 2004). According to the Schim and Miller cultural competence model, there are four components of cultural competence:

1. Cultural diversity, which is reflected in every aspect of the health care system in the United States and recognizes diverse populations with unique values, beliefs, and customs
2. Cultural awareness, which implies knowledge and information exchange regarding health, beliefs, and practices specific to various communities, and cultural variations within groups
3. Cultural sensitivity, which requires the recognition of individual attitudes and beliefs and a refinement of communication skills related to active listening, use of silence and touch, conversational distance, language patterns, and the effective use of translators
4. Cultural competence, which is the ultimate goal and incorporates diversity (fact), awareness (knowledge), and sensitivity (attitude) into everyday practice and behaviors (Doorenbos & Schim, 2004)

Cultural diversity refers to differences between people based on treasured beliefs, shared teachings, norms, customs, language, and meaning that influence the individual’s and family’s response to illness, treatment, death, and bereavement (Ballard-Reisch, 2005). Cultural diversity is evident in the perception of pain, ways of coping with life-threatening illness, and the behavioral manifestations of grief, mourning, and funeral customs (DeSpelder & Strickland, 1999). The acknowledgment of such concepts and their relationships may provide a framework for cultural

assessment and an opportunity to provide quality care respectful of differences with regard to cultural expectations and needs. Failure to take culture seriously means that health professionals elevate their values above the values of others, which is culturally destructive rather than culturally skilled (Kagawa-Singer & Blackhall, 2001). Therefore, it is important to support trusting and effective patient and provider interactions through respect, and acknowledgment of cultural diversity and avoidance of misperceptions.

For those experiencing life-threatening illness, several issues are relevant with respect to cultural awareness. One such issue is patient autonomy, which emphasizes the rights of patients to be informed about their condition, its treatments, and the right to choose or refuse life-prolonging care. However, this reflects the American beliefs regarding independence and individual rights, which may not be shared by patients and families from other cultures (Kagawa-Singer & Blackhall, 2001). For example, those from Asian cultures may believe that the family as a whole should make decisions regarding an aged individual. This is an example of “family-centered” rather than “patient-centered” decision-making style (Barclay et al., 2007).

Another issue influenced by culture awareness is responses to inequities in care. When not addressed, this issue may lead to feelings of mistrust regarding the intentions of health care providers and a lack of cooperation and collaboration between the patient, family, and health care provider. Discussions of the cost of technology and the ineffectiveness of treatment may be perceived by the patient as a devaluation of his or her life (Crawley et al., 2002). As a result, there may be an increased desire for futile aggressive care at the EOL, and dissatisfaction with care. This issue is relevant to the care of African American patients and families who are more likely to want aggressive medical care at the EOL and less likely to have do-not-resuscitate (DNR) orders. To address this issue, practitioners can ask directly if the individual trusts someone who is not from his or her same background. Practitioners can work toward addressing inequities in care, or can attempt to understand and accommodate desires for more aggressive care (Kagawa-Singer & Blackhall, 2001).

Furthermore, communication or language barriers may lead to bidirectional misunderstanding and unnecessary physical, emotional, social, or spiritual suffering. It is therefore important to avoid medical jargon, make language simple, check for understanding, or hire a trained interpreter. The use of family or untrained interpreters should be avoided, as they may misinterpret phrases, censor sensitive or taboo topics, or filter and summarize discussions rather than translating them completely (Crawley et al., 2002; Flores, 2005).



There may also be differences in religion and spirituality, which may create a lack of trust between the patient and professional from different backgrounds. To create a sense of connection, health care professionals need to ask about religious or spiritual beliefs and practices, and how the patient could be supported in addressing religious or spiritual needs.

Another issue, which may have to be negotiated, is truth-telling. Individuals from certain cultures may develop mistrust or anger if the health care team insists on informing patients about their diagnosis or prognosis against the wishes of the family. Families often believe that such knowledge will result in a sense of hopelessness for the patient, which contributes to suffering. In this situation, it would be appropriate for the health care provider to ask whether the patient would want to know everything about his or her illness, and be cognizant of nonverbal communication when discussing serious information (Kagawa-Singer & Blackhall, 2001).

Consideration should also be given to the issue of family involvement in decision making. Disagreement and conflict between family and health care professionals may occur when the family insists on making decisions for patients who have decisional capacity. As health care professionals, it is important to identify the key members of the family and involve them in the discussions as desired by the patient. If the patient is capable of making decisions for himself or herself, yet the family requests that information be withheld from the patient and that they make the decisions, it is helpful to conduct a family meeting in which the patient, family members, and health care professionals are present. This may provide an opportunity to clarify issues, address conflicts, and provide clarity about the decisions and preferences of the patient.

At the EOL, cultural differences may also exist regarding the desire to enroll in hospice care. Health professionals need to understand the feelings and perceptions of patients and families from varying cultural perspectives, and emphasize that hospice is not a replacement for the family, but a way of providing resources to support the QOL for patients and families (Kagawa-Singer & Blackhall, 2001).

Although there may be diversity in terms of desires, preferences, and expectations across cultures, there are also similarities. In a study of the needs and experiences of non-English-speaking hospice patients and families in an English-speaking country, McGrath, Vun, and McLeod (2001) found, based on focus groups that included Indian, Filipino, Chinese, and Italian cultural groups and their caregivers, that participants from all groups expressed the same issues. These included the importance of support from families; the pressures on family members to care for relatives at the EOL; lack of knowledge about hospice

and palliative care services; lack of choice in how they wished to care for their family member; difficulty in talking about dying; and desire to care for a family member at home.

In providing quality PC for patients and their families, consideration should also be given to the following principles of culturally sensitive care (Council on Social Work Education [CSWE] Faculty Development Institute, 2010). The first principle is to *be knowledgeable about cultural values and attitudes*. Health care professionals should attend to a patient's needs in a sensitive, understanding, and nonjudgmental way, and respond with flexibility as much as possible. The second principle is for health care practitioners to *attend to diverse communication styles*, including spending time listening to the person's needs, views, and concerns. The third principle is to *ask the patient for his or her preferences for decision making* early in care. As a fourth principle, it is important to *recognize cultural differences and varying comfort levels* with regard to personal space, eye contact, touch, time orientation, learning styles, and conversation styles.

The fifth principle is to *use a cultural advisor from the patient's ethnic or religious background* to clarify cultural problems or concerns if communication with the patient or family is unclear. If necessary, ask the older adult to identify a family spokesperson and respect the appointment made by the patient, even if the person is not a family member or does not live nearby. If the elder's preference is for family involvement, family meetings are opportunities to identify family needs and concerns, and an opportunity for the family to understand the patient's goals of care and EOL wishes.

A sixth principle is to *get to know the community, its people, and resources* to identify the availability of social support and needed resources. Health care professionals may establish relationships with key community resources to assist the seriously ill older adult and his or her family.

As a seventh principle, health practitioners should *create a culturally friendly physical environment* by designing facilities with artwork or pictures valued by the cultural groups to whom care is most commonly provided. Written materials should be available in the language of patients to enhance their understanding of their disease and treatment options and provide their sense of partnership in making health care decisions.

As an eighth principle, it is appropriate for health professionals to *determine the acceptability of patients being physically examined by a practitioner of a different gender*. Patients should also be asked if they would want to have a family member present during the physical examination. Recognize that symptom recognition, as well as its reporting and meaning, may vary based on the patient's cultural background.

A ninth principle is for health professionals to advocate *for availability of services, accessibility in terms of cost and location, and acceptability of services* that are compatible with cultural values, and practices of the person.

Lastly, the tenth principle is for health professionals to *conduct a self-assessment of their own beliefs* about illness and death and how they influence one's attitudes; how significant culture and religion are in health professionals' personal attitudes toward death; what kind of death they would prefer; what efforts should be made to keep a seriously ill person alive and how their bodies should be disposed of; and what their experience of participating in rituals to remember the dead has been.

Having considered the importance of a comprehensive cultural assessment, it is also valuable for health professionals to have knowledge of the principles of culturally sensitive care. With this knowledge and understanding, health professionals are able to develop a culturally appropriate plan of care that addresses the cultural needs and expectations of patients and their families and supports their trust of health professionals and satisfaction with health care.

In providing culturally sensitive care, DeSpelder (1998) also suggests that health professionals listen for and mirror the language patterns based on an individual's culture. Small differences in language, such as saying "passed away" or "passed on," can indicate much about the speaker's experience. For example, "passed away" may describe the deceased from the survivor's perspective, whereas "passed on" may imply a belief in life after death. Nurses also can attend to the cultural needs of their patients by gathering information about distinctive rituals, practices, and beliefs, particularly an understanding of what is meaningful to the individual person. This assessment involves listening, observing, and asking about practices of patients and families that may be unfamiliar to the nurse. Furthermore, nurses can determine the strengths an individual draws on when encountering death, dying, or bereavement, such as internal resources provided by the individual's belief system or past experiences; and external resources, such as the comfort provided by cultural customs (DeSpelder & Strickland, 1999). As nurses interact with patients and families from diverse cultures, they have the experiential opportunity to learn about cultural values, expectations, and needs regarding illness, dying, and death. In caring for patients and families at the EOL, nurses can enhance the QOL and quality of dying by promoting a respectful and peaceful death through the recognition of their spiritual and cultural needs.

Cultural mistrust is a dynamic that has implications not only for individual health care providers

but also for administrators of health care systems (Cort, 2004). Measures carried out by hospices to overcome cultural mistrust may include (a) hiring competent African American staff and minority volunteers; (b) respecting differences in cultural preferences; (c) conducting public education campaigns, by television or community and local organizations, newsletters, and church presentations; (d) involving African American pastors in capacities that permit them to serve as bridges of trust between their communities and the health care system; and (e) avoiding perceptions of injustice and inequality by promising only the services that can be delivered (Cort, 2004).

Cultural competency is a set of academic and personal skills that allow practitioners to increase understanding and appreciation of cultural differences between groups (American Medical Student Association, 2001). Practitioners need to appreciate and accept cultural differences, to learn to culturally assess a patient to avoid stereotyping, and to explain an issue from another's cultural perspective. Areas of dissonance between patients and health care providers include historical distrust, varying interpretations regarding disability, the influence of family structure on decision making, and differences in willingness to treat diseases without symptoms, such as high cholesterol, or appreciating illness even when there are no observable manifestations.

Cultural competence entails listening with sympathy and understanding, acknowledging and discussing differences and similarities between perceptions of illness and its treatment, recommending treatments while remembering the patient's cultural perspectives, and negotiating and compromising when worldviews are in conflict (American Medical Student Association, 2001; Crawley et al., 2002). In improving the relationship between the health professional and the patient across cultures, it is important to maintain nonjudgmental attitudes toward unfamiliar beliefs and practices, and to determine what is appropriate and polite caring behavior. It is respectful to begin by being more formal with patients, addressing them by their surname, rather than by first name. Recognize that it may be a sign of disrespect to look directly into another's eye or to ask questions regarding treatment. Shaking of the hands as a form of introduction, although valued in American culture, may be inappropriate by a female when introducing herself to an Orthodox Jewish or Muslim male (Grossman, 1996). Furthermore, a firm handshake may be interpreted by members of Native American tribes as aggressive or rude.

Asian Americans may tend to have subtle and indirect communication styles that rely heavily on nonverbal cues, such as facial expression, body movements,



use of physical space, and tone of voice. For example, a patient may bow his head or may disengage from you if he is in disagreement with the plan of care (Grossman, 1996). Nodding of the head in Asian or Hispanic populations may be merely a social custom, showing politeness and respect for a person in authority rather than agreement. Given this possibility, the health care provider may then ask specific questions that require the patient to express his or her feelings and wishes (Crawley et al., 2002).

It is important to ask questions to explore the patients' beliefs about health, illness, and prevention. Accept the fact that many patients use complementary therapies as well as Western medicine, and do not discount the possible effects of the supernatural on health. As health professionals, it is important to have knowledge of the patient's family and kinship structure to help ascertain the values, differing gender roles, issues concerning authority and decision making within a household, and the value of involving the family in the treatment (Grossman, 1996). Discussion with patients and their families may also involve the importance of food and eating as potentially enhancing a sense of community and as a way of supporting customs and heritage. Such information can assist the health care team in providing appropriate dietary instructions. For examples, Islamic law forbids ingestion of alcohol or pork, or meat from animals that are not appropriately slaughtered. Jewish patients may observe the laws of *kashrut*, which prescribe specific ways of food preparation and prohibit the eating of pork, shellfish, and wild birds. Individuals from Cuban backgrounds may prefer a diet that is high in calories, starches, and saturated fats, and modification of such a diet may mean just adhering to a modest serving size (Grossman, 1996).

### Nurses' Cultural Self-Awareness and Development of Cultural Competency

By being aware of their own feelings, attitudes, preferences, and biases, nurses can be more in touch with themselves, acknowledging their right to their own beliefs, but not allowing those values and beliefs to take precedence over those expressed by patients and families. In order for nurses to care effectively for patients from diverse cultural groups, they also must be willing to learn about the cultures of their patients and presuppositions. The first step is to find educational sources that provide information about the various cultures, while recognizing that there are individual differences even within the same culture because of differences in social stratum, personal experiences with illness and death, and individual

preferences and values. By asking someone of a particular culture to help them understand the taboos and meanings of experiences and events, nurses can actively learn about other cultures. Nurses must also recognize that losses have different meanings from person to person and culture to culture and may be viewed as major or minor.

The key to accommodating cultural diversity is for nurses to understand their own values, beliefs, and customs related to the celebration of life, and coping with illness and death. Irish, Lundquist, and Nelsen (1993) suggest that health professionals assess the degree to which they are proactive in their attitudes and activities toward diversity by asking themselves the following questions:

- Have I actively sought information to enhance my own awareness and understanding of multicultural diversity?
- Have I consciously pondered my own attitudes and behaviors as they either enhance or hinder my relationships with others?
- Have I evaluated my use of terms or phrases that may be perceived by others as degrading or hurtful?
- Have I suggested or initiated workshops or discussions about multicultural diversity?
- Have I openly disagreed with racial, cultural, or religious jokes, comments, or slurs?
- Have I utilized in my work setting appropriate occasions to discuss the multicultural climate in the organizations with my colleagues and with institutional administration?
- Have I complained to the author when I see a broadcast, advertisement, or newspaper article that is racially, culturally, or religiously biased? (p. 45)

Furthermore, DeSpelder (1998) suggests that health care professionals develop EOL cultural competence when they reflect on their own attitudes, beliefs, and practices toward dying and death. Nurses may explore for themselves:

- Their own beliefs about death and what influenced these attitudes
- How significant religion is in their attitudes toward death
- What kind of death they would prefer
- If diagnosed with a terminal illness, whom they would want to tell
- What efforts should be made to keep a seriously ill person alive
- How they would want their bodies to be disposed
- What their experience is of participating in rituals to remember the dead

## Cultural Assessment

Developing cultural competency requires that nurses listen carefully and gather cultural information. The patient's background may provide clues about a person's beliefs; however, these are only assumptions unless validated by asking patients about their beliefs, needs, expectations, and wishes. Knowledge about a person's cultural group should serve only as a starting point or guideline in assessing individual beliefs and behaviors (Kagawa-Singer, 1998; Lipson, Dibble, & Minarik, 1996).

In conducting a cultural assessment, there are several areas to be addressed:

- Identify the birth place of the patient.
- Ask a patient about his or her immigration experience.
- Determine his or her level of ethnic identity.
- Evaluate the degree of acculturation as evidenced by his or her use of the English language, the length of time in the United States, and his or her adaptation.
- Determine his or her family structure.
- Identify the use of informal networks and sources of support within the community.
- Identify who makes decisions, such as the individual patient, the family, or another social unit.
- Assess his or her primary and secondary language.
- Determine the person's verbal and nonverbal communication patterns.
- Consider gender and power issues within relationships.
- Evaluate the patient's sense of self-esteem.
- Identify the influence of religion or spirituality on patients' and families' expectations and behaviors.
- Ascertain the patient's perceptions regarding discrimination or racism.
- Identify cooking and dining traditions and the meaning of food.
- Determine the patient's educational level and socioeconomic status.
- Assess attitudes, beliefs, and practices related to health, illness, suffering, and death.
- Determine patients' and families' preferences regarding location of death.
- Discuss expectations regarding health care.
- Determine the degree of fatalism or activism in accepting or controlling care and death.
- Evaluate the patient's knowledge and trust regarding the health care system.
- Assess the value and use of pharmacological, non-pharmacological, and complementary therapies.
- Discuss how hope is maintained (American Medical Student Association, 2001; ELNEC, 2013; Ersek et al., 1998).

## ■ UNDERSTANDING SPIRITUALITY

Spirituality and religiosity are often fundamental to the way patients face chronic illness, suffering, loss, dying, and death. Spirituality and religiosity are integral to holistic care and are important considerations, particularly since spirituality may be a dynamic in the patient's understanding of his or her disease and way of coping. Religious convictions may also affect health care decision making (Puchalski, 2001). Spiritual ideas are fundamental to PC because both are concerned with nonabandonment, value interpersonal relationships, and recognize the value of transcendent support (Purdy, 2002).

Although *spirituality* and *religion* are often used interchangeably in common conversations, spirituality is a broader concept than religiosity. Spirituality comes from the Latin word *spiritus*, which refers to breath, air, and wind. Carroll (2001) has described several conceptual models of spirituality found in the literature, which all reflect the whole person and their dimensions, but in different ways. Spirituality has been described as the energy in the deepest core of an individual representing his or her fundamental nature. It is an integrating and interconnecting life force that gives ultimate meaning and purpose in life, and may allow us to transcend our physical selves (Carroll, 1998). Spirituality represents the harmonious interconnectedness with self, others, nature, and God, and can also be communicated through art, music, and relationships with family or the community (Puchalski & Romer, 2000). Spirituality further involves a melding of the individual's past, present, and future (Hicks, 1999). Even individuals who have no specific religion or faith background are spiritual beings and can have spiritual needs.

Spirituality, as a concept, also includes references to the soul, as well as spiritual needs, perspectives, and spiritual well-being. Downey (1997) describes spirituality as the awareness that there are levels of reality not immediately apparent and that there is a quest for personal integration in the face of forces of fragmentation and depersonalization. Therefore, spirituality is that aspect of human beings that seeks to heal or be whole (Puchalski, 2001).

Moore (1992) has discussed the individual's spiritual quest, which is a process of "re-sacralization" of the self and the world in which we live. Individuals are embarking on spiritual journeys to discover the transcendent in daily life and in interpersonal relationships. The spiritual need is one of finding the mystery and sacredness of daily existence. Wink (1999) believes that individuals are searching for meaning outside of the confines of their religion. This is particularly important for individuals who are aging and who may be experiencing a chronic, debilitating, or



life-threatening illness and who are questioning the meaning of not only their lives but also of their suffering. Within this context, the spirit of the person seeks to transcend suffering through the virtues of love, hope, faith, courage, acceptance, and a sense of meaning in the encounter with death (Arnold, 1989). Puchalski and Ferrell (2010) believe that spirituality can help people to transcend suffering by helping them to “tap into their own inherent abilities to heal and cope, find meaning and purpose and hope, and do well with whatever life offers them” (p. 113).

Throughout a person’s lifetime, and particularly as people age, religion and spirituality assist them to confront their finitude and vulnerability; to uncover meaning, value, and dignity in illness and death; to establish connection with others and a higher life force; and to find hope, love, and forgiveness in the midst of fear and despair. As such, spirituality engenders serenity and transcendence, thereby buffering stress (Doka, 1993).

As a chaplain, Ryan (1997) emphasizes the five fundamental spiritual needs of all people: (a) finding meaning in life, particularly during adverse circumstances; (b) the need for a relationship with a higher life force or transcendent being; (c) the need to transcend the sources of suffering; (d) the need for hope no matter how difficult life can be; and (e) the need to have others who share our life journey and care for us. As one example, a 68-year-old woman with advanced breast cancer revealed her spiritual need when she stated, “I only wish there was one person in this world who could tell me that they love me.”

Religiosity is one means of expressing spirituality (Puchalski, 1998a). Religiosity refers to beliefs and practices of different faiths and an acceptance of their traditions, such as Catholicism, Eastern perspectives, Islam, Judaism, and Protestantism. For many people, religion forms a basis for meaning and purpose in life, and provides the moral codes by which to live. As illness can call into question the person’s purpose in life and work, spiritual and religious issues often arise. Seventy-eight percent of Americans indicate that they receive comfort and support through religious beliefs and have greater trust in health professionals who ask them about their spiritual or religious needs (Ehman, Ott, Short, Ciampa, & Hanson-Flaschen, 1999; Koenig, 2002).

### Spirituality and Palliative Care

Even as the physical body declines, healing, which means to make whole, can occur as spiritual needs are identified and spiritual care is given to restore a person to wholeness. Healing can be accomplished through the spiritual journey of remembering, assessing, searching for meaning, forgiving, reconciling, loving, and maintaining hope (Puchalski, 1998a). Holistic

care, including care of the soul or spirit, is important to quality PC, whose goal is to enhance a person’s QOL across the illness trajectory. People do want their spiritual needs addressed at the EOL and feel that health professionals should speak to patients about their spiritual concerns (Gallop, 1997). Furthermore, elder individuals who are dying express the need for companionship and spiritual support, particularly human contact, and to have the opportunity to pray alone or with others (Nathan Cummings Foundation, 1999).

When providing PC for patients and their families, it is important to remember the following principles (Doka & Morgan, 1993):

- Each person has a spiritual dimension.
- Illness and death can be opportunities for spiritual growth.
- Spiritual care may be different for each individual depending on his or her religious or cultural background.
- Spirituality is supported through formal and informal ways, such as religious practices, secular practices, symbols, rituals, art forms, prayer, and meditation.
- Care should be offered in settings that accommodate the needs of religious or spiritual practices and rituals, and promote spiritual work.

In addition to the above, a series of recommendations to enhance the quality of spiritual care as a dimension of PC was published in 2009 after an interprofessional consensus conference (Puchalski et al., 2009), as follows:

1. The domain of spiritual care should be included in all PC programs, quality improvement plans, and electronic medical records.
2. Spiritual care should be monitored and assessed with measurable quality and process outcomes and metrics. Assessment tools should be evaluated to determine which are most efficacious and clinically relevant and standardized across PC settings.
3. Quality improvement frameworks should be developed based on National Consensus Project Guidelines that relate to structure, process, and outcomes of spiritual care.
4. Quality improvement models specific to spiritual care should be tested.
5. Research should be conducted that contributes to improving spiritual care outcomes for PC patients. Recognizing the complex definition of spirituality and its difficulty in measurement, studies should use quantitative and qualitative methods.
6. Funding should be sought to evaluate the current state of the science, establish a research agenda, and facilitate research opportunities for spiritual care research.

## Spirituality and Health

Physicians, psychologists, and other professionals continue to research the role of spirituality in health care. Ongoing research indicates that spirituality is related to mortality, coping, and recovery, since people with regular spiritual practices tend to live longer, utilize health beliefs in coping with illness, pain, and life stress, and have enhanced recovery from illness and surgery (Puchalski, 2001). A systematic review of the literature during the 20th century revealed, based on 724 quantitative studies, a significant relationship between religious involvement and better mental health, greater social support, and less substance abuse (Koenig, Pargament, & Nielsen, 1998). In a study of religious coping in 850 hospitalized patients, a significant inverse correlation ( $p < .001$ ) was found between religious coping and depressive symptoms (Koenig et al., 1998).

In a study of religiosity, Bergan and McConatha (2000) reported that religious affiliation and private religious devotion increased with age across the life span. Based on a sample of 2,025 community-dwelling elder residents, it was found that religious attendance provided a persistent protective effect against mortality, even after controlling for the most potential confounders, such as social support, health status, and physical functioning.

Studies also indicate that those who are religious or spiritual have lower blood pressure, fewer cardiac events, better result following heart surgery, and longer survival in general (Koenig, 2002). Furthermore, spirituality counteracts stress-related physiological states that impair healing and facilitates coping with chronic pain, disability, and serious illness by enhancing a sense of control that interrupts the cycle of anxiety and depression (Koenig, 2002). Those who participate in religious services express less loneliness and isolation as they receive support from others and believe that God is with them.

Religion or spirituality also facilitates coping with chronic pain, disability, and serious illness by providing an indirect form of control that helps to interrupt the cycle of anxiety and depression. For some individuals, prayer provides a form of control by believing that through prayer they can influence their medical outcome; in contrast, others deliberately turn over to God their health situation (Koenig, 2002). The belief that God is with them provides relief from loneliness and isolation. Individuals who attend religious services also have an opportunity for socialization and support from others, while praying for others in need often provides a distraction from one's own pain (Koenig, 2002). These findings are supported by Sinclair, Pereira, and Raffin (2006), who provide a thematic review of the spirituality literature

regarding PC. Both articles provide comprehensive discussions related to differences between religion and spirituality, spiritual assessment, instruments to measure spirituality, correlates to health, and spiritual interventions.

In terms of health consequences, religious involvement has been associated with improved attendance at medical appointments, greater adherence to medical regimens, and improved medical outcomes. Furthermore, religious or spiritual practices are believed to influence sympathetic and parasympathetic nerve pathways connecting thoughts and emotions to circulatory and immune system changes, and counteracting stress-related physiological states that impair healing (Koenig, 2002).

Interested in religiosity and spirituality, Heintz and Baruss (2001) conducted a study based on a sample of 30 people whose mean age was 72.6 years. Although some religious behaviors, such as frequent religious practice, prayer, and church attendance were correlated with some dimensions of spirituality, many of the scores on the Expressions of Spirituality Inventory were independent of self-reported religious behaviors. These results reinforced the differences between the concepts of religiosity and spirituality.

In a qualitative study of 41 male and female residents aged 66 to 92 years, most of the older adults believed that a higher power was present in their lives, which supported them constantly, and was perceived as protecting, guiding, helping, teaching, and healing them (Mackenzie, Rajagopal, Meibohm, & Lavizzo-Mourey, 2000). God was perceived to work through the mundane world, such as through the work of physicians, loving friends, and helpful strangers. Many felt that their relationship with God formed the foundation of their psychological well-being. The authors concluded that the subjective experience of spiritual support may form the core of the spirituality–health connection for older adults.

## The Role of Religiosity and Spirituality in Coping With Serious Illness

As patients are faced with chronic or serious illness and eventually near death, they may experience despair, with spiritual and religious concerns intensified or awakened (Lo et al., 2002). The patient may struggle with the physical aspects of the disease, as well as the pain related to mental and spiritual suffering. They may ask “Why did this happen to me?” “Why is God allowing me to suffer?” “What will happen after I die?” “Will I be remembered or missed?” or “Will I be able to finish my life’s work?” (Puchalski, 2002). True healing requires an answer to these questions,



as healing can be experienced as acceptance of illness and peace with one's life (Puchalski, 2001).

It is through spirituality that people find meaning in illness and suffering and are liberated from their despair. Spiritual care changes chaos to order, and seeks to discern what if any blessings might be revealed in spite of and even through tragedy (Purdy, 2002). As people are dying, they want to be listened to, to have someone share their fears, to be forgiven by God or by others, and believe that they will live on in the hearts of others or through their good works (Puchalski, 2002).

In a study of 19 individuals with advanced cancer, Thomas and Retsas (1999) learned through in-depth interviews that people with cancer developed a spiritual perspective that strengthened their approach to life and death. As cancer progressed, participants described the transaction of self-preservation by discovering deeper levels of understanding self, which incorporates a higher level of spiritual growth, spiritual awareness, and spiritual experiences.

Individuals at the EOL also express spiritual needs. Based on a qualitative study of nine hospice patients, Hermann (2000) reported their need for religion, companionship, involvement, and control to finish business, experience nature, and the need for a positive outlook. Participants perceived spirituality as a broad concept that may or may not involve religion and that spiritual needs were closely linked to the purpose and meaning in life. In studying older patients approaching the EOL from advanced heart disease, it was found that 24% of the variance in their global QOL was predicted by their spirituality (Beery, Baas, Fowler, & Allen, 2002).

Taylor and Outlaw (2002) conducted a qualitative study to understand the use of prayer among persons with cancer ( $n = 30$ ) and recognized that individuals with cancer use prayer to cope with their illness. Participants viewed prayer as personal communication involving or allowing transcendence. The communication or prayer was initiative and receptive. The initiative aspect of praying was to talk to God, get in touch with God, or beseech God, while the receptive aspect of prayer was characterized by phrases like being quiet, being accessible, and listening to God. For these individuals, prayer meant being constantly conscious of God and coming into that higher intention in life. Participants' illness increased their awareness of the inadequacy of relying on self and the need to rely on a greater power. They described prayer as an active cognitive process, while others described prayer as a more passive process or as "prayer of the heart." Assistive strategies for praying included constructing a prayer, writing a prayer, relaxing, and reading religious material, and how one prayed depended on the purpose of the prayer. Some individuals prayed about

healing, or that "God's will be done." Many prayed for forgiveness or to be a better person. Most prayed for family and friends who needed peace and support, and also included thanks and praise in their prayers that they were given another day to live. Through the process of prayer, many individuals believed that they benefited, whether their prayer was answered or not. From prayer, they expected that the "best will happen," or that they will receive comfort, forgiveness, or salvation. As health professionals, the implications for prayer are that clinicians can help by fostering a condition and environment conducive to prayer and can facilitate patients' use of prayer, which is unique to individuals.

Through a qualitative study involving 28 African American and European American adult patients with cancer and their caregivers, Taylor (2003) examined participants' expectations of nurses in meeting their spiritual needs. Participants identified six approaches of nurses in addressing spiritual needs: (a) showing kindness and respect; (b) talking and listening; (c) prayer, such as offering verbal prayer or saying, "You are in my thoughts and prayers"; (d) connecting with authenticity and genuineness; (e) quality temporal nursing care, such as coming back to check on the patient; and (f) mobilizing religious or spiritual resources. The authors concluded that nurses need to consider their role in spiritual care and educate the public about their role as holistic health care providers.

The effects of spirituality on the well-being of people with lung cancer were studied by Meraviglia (2004). Based on a sample of 60 adults who were predominately Caucasian and women, it was found that higher meaning-in-life scores were associated with higher psychological well-being and lower symptom distress. Prayer was positively related to psychological well-being, explaining 10% of its variance. Regression analysis indicated that meaning in life mediated the relationship between functional status and physical responses to lung cancer and explained 9% of the variance in symptom distress. The author concluded that this study supported the importance of providing spiritual care for patients with cancer.

Lorenz et al. (2005) examined religiousness and spirituality among HIV-infected Americans. Based on a sample of 2,266 patients receiving care for HIV infection, 80% reported a religious affiliation and the majority indicated that they rely on religious or spiritual means when making a decision or confronting problems. Women, older patients, and non-Whites were more spiritual, but the clinical stage of the disease was not associated to religiosity or spirituality. It was concluded that religious or spiritual organizations should be used to support patients diagnosed with HIV infection.

Mako, Galek, and Poppito (2006) reported that of the 57 patients with advanced-stage cancer in a PC hospital, 96% reported spiritual pain due to intrapsychic conflict, interpersonal loss, or conflict in relation to the dying. Depression was correlated with the intensity of spiritual pain but not with physical pain or severity of illness. The authors conclude that unaddressed spiritual pain contributes to overall suffering.

Based on a study of 50 adult hospice patients, Prince-Paul (2008) also reported strong positive correlations among spiritual well-being, communicative acts, and quality of life at the end of life, when controlling for physical symptoms, explaining 53.5% of the variance. A multicenter, cross-sectional study of 580 chronic pain patients found that spirituality and religiosity went far beyond just a “fatalistic acceptance” of chronic pain, but was found to be an active, adaptive, and mitigating coping mechanism for patients (Büssing et al., 2009). In another study of 69 patients with advanced cancer receiving radiation therapy, 84% of the cross-sectional study participants indicated a reliance on religious and spiritual beliefs to cope with cancer. In multivariable analysis, patient spirituality and religious coping were associated with improved QOL ( $\beta = 10.57, p < .001$  and  $\beta = 1.28, p = .01$ , respectively). Most patients considered attention to spiritual concerns by their providers as an important part of their cancer care (Vallurupalli et al., 2012).

### **Spirituality or Religiosity During the Dying Process**

The attitudes an individual holds regarding the dying process and death are embedded in his or her cultural and religious values. Values affect the way individuals conceptualize death and behave in relation to death (Meagher & Bell, 1993). Many people return to the religious legacies of their childhood during the dying process since it may have been the first time that they heard about death and learned about Christian resurrection (Satterly, 2001). A study of 170 patients receiving PC at home showed a marginal increase in the strength of individual spiritual beliefs as patients approached death over the time of the study (King et al., 2013).

At this time, it would be important to explore guilt as central to a person’s religious pain, as well as the concept of forgiveness from his or her religious perspective. Religious rituals for cleansing or religious doctrine may allay feelings of remorse and guilt, providing for renewal of the soul and redemption. In supporting elders in spiritual pain, it may also be helpful to consider the concept of love. Most religious traditions provide a hopeful belief in the unconditional

love of God, as well as reinforcing how unconditional love can be allowed to self, especially when an individual may have previously engaged in self-criticism or self-hatred (Satterly, 2001).

As individuals approach death, Doka (1993) identified the spiritual need of individuals to die in a way that is consistent with their self-identity. For example, if a person’s approach to life has also been to remain in control and “not give up the fight,” then it would be expected that they may not want to forego aggressive therapies, even if the chances of cure or remission are low. Their spiritual need may be to continue to fight the disease. For those who are dying, Doka (1993) also emphasizes the spiritual task of finding hope that extends beyond the grave, as one seeks a sense of symbolic immortality. Individuals often need to feel that they are leaving a legacy, whether through having children or being remembered through their contributions to community, or through artwork, music, or their writings.

### **Suffering and Spirituality**

Suffering is a part of life and the human condition, with suffering either personally experienced in a physical, emotional, social, or spiritual way, or experienced when one is witness to another’s suffering. Suffering varies with the type of disease, type of personality, and the relationship between these factors. Cassell (1982) defined suffering as “the state of severe distress associated with events that threaten the intactness of a person” (p. 639). Suffering is usually psychological and represents an afflicted state “that happens to a particular person on whom has been [in]flicted unendurable pain or other symptoms, losses, enduring fear, hardship, injury, disaster, grief, sorrow or care and who has been changed as a result of the burden” (Cassell, 2004, p. 76). Cassell (1982) also believes that many aspects of a person can be sources of, or be affected by, suffering, such as personality, character, the past, relationships, life experiences, roles, one’s rights and responsibilities, family, and cultural background.

According to Kahn and Steeves (1996), suffering is a private-lived experience of a whole person, unique to each individual. As such, suffering cannot be assumed present or absent in any given clinical condition or situation because suffering is dependent on the meaning of the event or loss. The experience of suffering is also both intrapersonal and interpersonal because it involves the person’s own coping with suffering and the caring of others (Kahn & Steeves, 1996). “Meaningless suffering can lead to spiritual disintegration. However, the finding of transcendent meaning in the suffering experience can be a profound attenuator of how the suffering is experienced” (Emblen & Pesut,



2001, p. 42). Although we may not find answers about why we suffer, as a part of the human family we build relationships, communities, and society to reach out to one another to relieve suffering and sustain us in our struggle (McGann, 1997).

Millspaugh (2005a), as a chaplain, describes suffering as spiritual pain that involves an awareness of death, loss of relationships, loss of self, loss of purpose, and loss of control, which can be lessened by life-affirming and transcending purpose and internal sense of control. The loss of self involves fears about death, loss of independence, loss of body image, loss of a God who can be bribed, and loss of relationships to others. As spiritual pain is often marked by a sense of being alone, the task of the practitioner is to earn the person's trust and to walk with him or her by being present with the belief that a greater Spirit is at work—a joining of spirits, which provides the sufferer with a sense of being understood, and feeling a sense of control in the situation (Millspaugh, 2005b).

Although suffering and pain often are referred to interchangeably, they are not identical. In some cases, they are both present; at times, one exists without the other. The transition from pain to suffering can occur when pain is unrelieved and out of control or when the source of pain is unknown. The persistence of pain and uncertainty therefore can increase suffering exponentially. Yet, suffering can continue even when pain is controlled. Based on a sample of 177 end-stage cancer patients who had an expected life expectancy of less than 1 month to live in a hospice, Adunsky, Aminoff, Arad, and Bercovitch (2007) found, using the Mini-suffering State Examination, that there was a low level of suffering, despite maintaining a constant rate (68%) of the use of opioids at admission and the last week of life. The reduction of the level of suffering in EOL cancer patients, in the face of pain needs, may be attributed to the medical and nursing care offered through hospice care.

Health professionals may recognize spiritual pain as the person expresses sorrow or grief, verbalizes a sense of meaninglessness or emptiness to life, fear and avoidance of the future, sense of hopelessness and despair, anger toward God, as well as isolation of self and others (Matthews, 1999). It is important to realize that indications of spiritual pain can be both verbal and nonverbal, and that just as physical pain may change in nature and intensity over time, so too can spiritual pain change over time. As death approaches, new spiritual issues may arise, which may or may not be accompanied by spiritual pain (O'Connor, 1993). Furthermore, although health professionals may wish to alleviate spiritual pain, it is important to recognize the meaning and value of experiencing pain from the patient's perspective. Some individuals may believe

that pain will lead to salvation or act as a way of coming closer to God. Others may find the experience of losing a loved one to be a source of anger toward God and, as a result, feel distanced from the support that their personal relationship with God might bring for them at a time when they need it most. A survey of hospice patient family members found that 44% of the 134 participants reported some degree of anger toward God. Anger toward God was also found to have a positive correlation with self-reported depressive symptoms, which may have implication for family assessment, support, and referral (Exline, Prince-Paul, Root, & Peereboom, 2013).

At the EOL, suffering may also be exacerbated because of protracted or chronic illness, multiple simultaneous diseases and comorbid conditions, recurrent disease, and awareness of mortality. Because suffering has to do with a personal understanding of the physical, emotional, and spiritual self and their interrelationships, we learn about suffering only by the ways in which an individual expresses an awareness of the threats to his or her personal wholeness (Smith, 1996). Chochinov et al. (2006), in validating the Dignity Model, reported, based on 211 patients receiving PC, that “not being treated with respect or understanding” and “feeling a burden to others” were the issues most identified as having an influence on dignity. In a logistic regression model, “feeling life no longer had meaning or purpose” was the only variable that predicted overall sense of dignity. Addressing these issues is believed to be the cornerstone of dignity-conserving care.

Using heuristic research, Wayman and Gaydos (2005) explored the question, “what is the experience of self-transcending through suffering?” Four people were interviewed who self-identified themselves as self-transcending. The themes were presented linearly but participants were able to move freely between themes. Participants identified a *turning point* in their suffering when they turned from self-identification with their suffering, as it became a part of their lives but not who they were. This was a wake-up call and invitation to change. Then there was a *pause*, in which there was a forced pause in all activity due to treatment. This pause was followed by *confrontation* with their experience of suffering and their response, accepting their suffering for what it was. Participants *surrendered* to a new truth, which led to *extraordinary experiences* of peace and interconnectedness. These experiences became the *touchstones* of change as they reminded themselves of the lessons of suffering and the changes they had made. Participants were changed after transcending their suffering, valuing their lives more, and became more truly who they really were. Their transcending encouraged an unfolding of the hidden, with their inner selves becoming

more congruent with their outer selves. This led to the desire for meaningful work and a sense of gratitude for the experience. Their humility grew as they honestly assessed themselves. The experience of self-transcending is the patient's struggle and life journey, which can be supported when nurses facilitate opportunities for pause and reflection, and give reassurance and compassion, which facilitate a patient's sense of wholeness and well-being.

In a study of terminally ill patients ( $n = 96$ ) on PC units and hospice, Schroepfer (2007) identified four critical events as motivating individuals to consider hastening their death: specifically, perceived insensitive and uncaring communication of a terminal diagnosis, experiencing unbearable physical pain, unacknowledged feelings regarding treatment, and dying in a distressing environment. To address these issues, the authors recommended changes in policies and practices that promote time for communication by health professionals coupled with appropriate training in communication skills. It is further recommended that support be offered by members of the interprofessional team to reduce suffering and take a proactive rather than reactive approach to EOL care.

Inherent in the discussion of requests for a hastened death is the concept of refractory suffering. Although suffering continues to be explored from the perspective of patients and families, few studies have examined the effect that witnessing refractory suffering has on PC clinicians. A qualitative study of 17 Australian PC practitioners from medicine (5), nursing (10), social work (1), and pastoral care (1) identified four subthemes in clinicians' experiences with refractory suffering that have implications for practice improvement and health:

- The approach must be changed from "fixing" to "being with"
- Maintain perspective
- Negotiate and maintain boundaries
- Live the paradoxes (detachment and commitment, desensitization and compassion, accepting limits and trying to do everything; Breaden, Hegarty, Swetenham, & Grbich, 2012)

## Reciprocal Suffering of Patients and Family

Within the context of life-threatening illness, suffering, in the form of physical, emotional, social, and spiritual distress, often becomes an experience not only of the patient but also of the family caregivers, as the suffering of one amplifies the distress of the other (Foley, 1995). Family members, like patients themselves, are in transition from living with the disease to anticipating the death of their loved one from

the disease (Davies, Reimer, & Martens, 1994). They fear that death will occur in their absence, and may therefore refuse to leave the patient's side for even a moment. There is also a strong compulsion to attend to the patient's every need with disregard for their own needs. As the patient's illness progresses, the needs of the family also intensify and change, with both the patient and family caregivers potentially experiencing a significant compromise in the quality of their lives (Sherman, 1998).

Although family members may express the rewards of caring for terminally ill relatives, such care can have major psychosocial and physical effects, including heightened symptoms of depression, anxiety, psychosomatic symptoms, restrictions of roles and activities, strain in relationships, and poor physical health (Higginson, 1998). As witnesses to the patient's pain and suffering, family caregivers may also experience a sense of powerlessness, and are often frightened and confused by the dramatic physical and emotional changes they perceive in their loved one as the disease progresses (Loscalzo & Zabora, 1998).

Coyle (1995) gives examples of suffering, such as when patients experience despair, loneliness, and vulnerability; feel trapped by fear and bewilderment; experience loss and worry about treatment decisions; worry about being a burden; have financial concerns; experience abandonment; or fear dying yet are weary of life, and experience pain or the loss of hope. Families suffer as they assume the responsibilities of caregiving, watch the patient's deterioration, become exhausted, neglect their own needs, experience uncertainty about goals of care, and become anxious about the place of care. The suffering of family members also occurs because of fear of the dying process and the experience of the loss of life as it was, the person they knew, and of hope, as well as guilt in wanting death to come soon.

There are also many conflicting emotions and adjustment tasks, including conflict among feelings of loss, sadness, guilt, difficulty in knowing how to talk with the person who is dying, and worry about dying and death (Beeney, Butow, & Dunn, 1997). Furthermore, the family caregiver must adapt to changes in family roles and responsibilities, while attempting to meet the increased emotional needs of other family members and performing standard family functions (Doyle, 1994). Given that 25% of caregivers lose their job due to caregiver responsibilities and nearly one third of families lose their major source of income or their savings, families also experience significant financial burdens (Lederberg, 1998). This may lead to feelings of anger, jealousy, and an increase in the family caregiver's own needs because of heightened psychological distress. In addition, there is often a loss of social mobility, as well



as social abandonment by friends, which negatively affect the QOL of family caregivers (Lederberg, 1998).

From a spiritual perspective, family members may question the meaning of the illness and suffering. They often spend considerable time reviewing painful aspects of the past with feelings of regret for disagreements, conflicts, or failures and a wish that relationships with the patient and with each other were somehow different. Buck and McMillan's (2008) study of the unmet spiritual needs of caregivers of patients with advanced cancer emphasizes that, based on a sample of 110 caregivers of hospice home care patients, the highest spiritual needs of caregivers related to outlook such as seeing smiles, thinking happy thoughts, laughing, and being with family. Caregivers' unmet total needs were predicted by caregivers' outlook, caregivers' religion, and the patient's distress score. To reduce caregiver suffering, it was concluded that health care providers must be aware of the needs for positive thinking, reminiscing of happier times through story telling or the use of pictures, and that chaplains may offer comfort through the reading of religious texts and speaking with caregivers about spiritual issues.

With each family member's unique experience of the stress, families may find it difficult to come together to effectively cope with the imposed life changes (Sherman, 1998). In their search for meaning, patients and families affirm spiritual values, change life priorities, and examine how the experience of illness has contributed to their personal growth. Like their dying loved one, they live day to day to make the most of the present as they prepare for death on practical, cognitive, emotional, and spiritual levels (Davies et al., 1994). In a recent pilot study, family caregivers of patients with advanced pancreatic cancer often described the concept of reciprocity in both suffering and strengthening. Caregivers described a sense of being in sympathy with the "ups" and "downs" of the patient in terms of mood and functional status and being comforted by the strength of the patients themselves in dealing with their illness (Sherman, McGuire, Free, & Cheon, 2013).

The hope is that through palliative nursing care, both patients and family members can transcend their reciprocal suffering and experience growth as they face the challenges of life-threatening or terminal illness (Sherman, 1998).

### The Care of Those Who Are Suffering

Cassell (1982) believes that the ways to relieve suffering are, first, through the assignment of meaning to the injurious condition or event and, second, through

transcendence, which is the most powerful way of restoring an individual's personhood to wholeness. Watson (1986) proposes four generic meanings of suffering, which include *correction* in which an individual is being corrected of his or her wrongdoing; *affirmation* in which a person is affirmed of his or her "rightdoing" and the ability to be a role model for others; *naturalism* in which the individual is experiencing general human destiny; and *altruism* in which an individual's suffering will have benefit to others. In caring for those who are suffering, health professionals may help individuals come to a healthy, maintainable higher meaning to their suffering. From a theological perspective, Smith (1996) discusses the religious response to suffering and the possibility of transcendence of suffering through intellectual, ethical, and experiential dimensions of religion. The intellectual dimension involves the realization of some transcendent meaning, which connects the suffering person with some greater reality and delivers the individual from the threat of meaninglessness that is raised by illness and pain. The ethical dimension of religious life provides a perspective regarding how to interpret and respond to suffering. Suffering may be seen as a test of one's virtue or fidelity to God, a test of the worth of religious commitment, or as an opportunity of personal transformation. Within the experiential dimension of religion, the life of oneself and others and of the relationship of these lives to each other and to God are contemplated. The religious experience of suffering may therefore enable an individual to provide redemptive relationships with others, including God, and experience transcendence.

In caring for the suffering, Spross (1996) believes that the role of the nurse is one of coaching. "Coaching is an interpersonal intervention that requires the therapeutic use of the self, involving one's mind, past experience, words, heart, and hand to comfort those who suffer" (Spross, 1996, p. 201). In coaching, the nurse:

- Establishes a trusting partnership
- Assesses those who are at risk for suffering or who are vulnerable
- Reassures patients that although their suffering may not disappear, they will not be abandoned
- Identifies factors that may be eliminated or modified to alleviate suffering
- Intervenes to facilitate expression of feelings, find meaning in suffering, and help patients and families redefine the QOL

Spross (1996) states that the ability to alleviate suffering or find meaning in the experiences of suffering depends on the intrapersonal and interpersonal

qualities of the nurse. The nurse must be self-accepting, be secure in his or her own self-concept, and feel confident in strengthening others. As coach, the nurse values others and communicates that the individual's feelings, goals, and opinions are respected, while conveying that the person is trustworthy, responsible, capable of self-direction, and able to identify relevant goals and find meaning in life.

Watson (1986) believes that nurses and other health professionals can relieve suffering in six ways: first, by being a companion to sufferers by identifying the pain of their losses, and exploring the circumstance and extent of the loss; second, by listening for statements of meaning from a sufferer and allowing natural instincts and energy to surface the issue of higher meaning; third, by valuing any self-disclosure on meaning that a sufferer offers, by analyzing the meaning of the statements and learning what the statement reveals about the sufferer's view of himself or herself; fourth, by encouraging the sufferer's interpretation of his or her experience; fifth, by validating the sufferer's interpretation of his or her own experience while clarifying the meaning, seeking further definition of the meaning, and offering alternatives for reframing the meaning; and finally, by identifying supportive resources and hoping for the sufferer to extend his or her identity and meaning in the future.

In alleviating the suffering of others, Bird (1986) offers seven principles to be considered within the context of nursing practice:

1. Remember that institutions do not dehumanize patients; staff members do.
2. Assume responsibility for morale whenever you are in the chain of command.
3. Be a whole person yourself, with a healthy sense of humor and attitude.
4. Do not add clinical ineptitude to the further suffering of patients.
5. Be empathetic rather than sympathetic to patient's needs; otherwise, human suffering can emotionally devastate the nurse.
6. Offer holistic care and well-chosen words to allay suffering.
7. Determine to touch the life of at least one patient daily with some depth.

Halifax (1999) believes that health care providers, patients, and families can go to the root of their own suffering and transform the suffering into inherent wisdom. As a Buddhist, she reminds health professionals to come to the caregiving relationship with loving kindness, compassion by being in touch with one's own and others' suffering, joy in the well-being of others, and equanimity.

## The Role of Hope in Spiritual Well-Being

Cousins (1979) has said that death is not the ultimate tragedy of life; rather, that tragedy is being separated from our connection with others, and separated from a desire to experience the things that make life worth living, separated from hope. Spirituality may help people to cope with their dying, as it may offer hope. In early illness, the hope may be for cure of the disease by treatment, and later on for hope of prolongation of life. When cure is not possible, hope may be to see a loved one, to have a day without pain, to celebrate a certain life event, or have the time to travel or complete unfinished business. Eventually, hope may be for a peaceful death. It may be hope that allows seriously ill individuals to find courage and strength to transcend their suffering, and teach others how to die with dignity.

Mitchell (1997) offers a definition that hope is not a belief that something is going to go well, but rather a belief that whatever happens will make sense, no matter how it turns out. For patients who are dying, hope may be defined as "an inner life force that helps each dying person to live life until the moment of death" (Parker-Oliver, 2002). Indeed, hope may be defined as the positive expectation for meaning attached to an event, recognizing that individuals shape their hopes by finding new meanings for living (Parker-Oliver, 2002). Hope allows a sense of control and promotes an active rather than passive participation in life's events. Even in dying, people have the hope to discover new meanings.

The challenge for health care professionals is therefore to help individuals find hope as they search for meaning in their illness, suffering, and death. This can happen as professionals assist individuals to identify key relationships, facilitate caring relationships, and encourage the opportunity to heal relationships and complete unfinished business. Byock (1997) encourages the completion of relationships by saying "I forgive you," "Forgive me," "I love you," "Thank you," and "Goodbye." Through the encouragement of short-term, attainable goals, hope can also be promoted, as well as by recognizing and encouraging a sense of determination and courage in the face of adversity. Gum and Snyder (2002) conclude that hope can be maintained when health care providers provide clear information, control symptoms, and maintain functionality.

Hope can also found within the context of spirituality, as spiritual belief systems hold hope for happiness and a promise of an afterlife. Spirituality offers hope for living on in the world through a connection with others, traditions, and rituals and through establishing legacies. Hope can also be easily discovered by just asking patients what is meaningful to them



and what they want to do with the remainder of their lives. Based on a study of 69 participants, aged 65 or above, Theris (2001) reported a significant difference in hope based on the religion of participants. Based on a one-way ANOVA and Schaffer tests, Catholic participants expressed greater hope than those of the Jewish faith, and another significant difference existed between participants of the Protestant and Jewish faiths. There was also a significant, positive correlation between spirituality and level of hope ( $r = .73$ ,  $p = .000$ ). In a multiple regression analysis, which was used to test for the combined contribution of spirituality and connectedness with others to levels of hope, only spirituality emerged as a significant predictor of hope. The authors concluded that connection with oneself and connection with a higher being was especially important in the maintenance of hope in nursing home residents. Such results are consistent with the findings of Buchanan (1993), who reported, based on a sample of 160 older adults who were depressed or not depressed, that higher levels of spirituality, hope, health, and social support were positively correlated with meaning in life, and that there was an inverse relationship between meaning in life and depression.

Duggleby (2000) found that hope was a process of enduring suffering through a trust in a higher power and making meaning of one's life. Despite the stage of illness and a situation of poor prognosis, practitioners can provide hope and a positive outlook by discussing goals of care, offering symptom control, providing supportive resources, and promising the patient that they will not abandon her or him (Barclay et al., 2007).

For those who are dying, the focus of hope changes from a hope in the future or a redefinition of the future, to a hope on living day to day. The focus of hope for those with advanced disease is also hope for no more suffering, life after death, and that their families will not suffer when they are gone (Duggleby, 2001). At times, the most important way to provide hope is by listening attentively and being physically present, which convey a sense of value and affirmation of worth. Hope is then gained that the patient will not be abandoned and isolated (Duggleby, 2000). Hutchings (2007) conducted a qualitative study of eight people who were dying, guided by Parse's theory of human becoming. The interviews illustrated that persons at the EOL still envision hopes and possibilities despite declining function and decreased energy. Such findings help health professionals understand that dying patients co-create meaning day by day while emphasizing the importance of bearing witness to the struggles, joys, and hope of dying persons.

Rawdin, Evans, and Rabow (2013) studied association of hope, pain, distress, and spiritual well-being

in 78 oncology outpatients using the Hearth Hope Index (HHI). Like previous published studies on hope and pain, there was a negative correlation of hope with average pain intensity ( $p = .2$ ), worst pain intensity ( $p < .01$ ), and pain interference with function ( $p < .05$ ). However, this study demonstrated that the negative correlation is eliminated when depression and spiritual well-being are adjusted for in the multivariate linear regression model, suggesting that hope more strongly correlates to other psychospiritual factors than to pain.

### Learning About Spiritual Assessment and Caregiving

Health professionals need to be attuned not only to their own cultural beliefs but also to their own spirituality before participating in spiritual care. Personal preparation for spiritual caregiving includes the professional's self-evaluating personal spirituality; reviewing personal beliefs, opinions, and biases; understanding the meaning of spirituality; becoming aware of how one's own religious beliefs influence caregiving; and establishing a trusting patient-provider relationship (Hermann, 2000).

As in the care of all patients and families, health professionals caring for patients and their families must learn the specific techniques for addressing spirituality in clinical practice, including how to conduct a spiritual assessment. This also requires that the health professional be totally present and open by listening actively to spiritual issues (Hermann, 2000). Learning spiritual assessment and caregiving can also occur through a combination of teaching/learning strategies, including small group discussions, reflective writing, storytelling, use of poetry, case presentation and discussion, panel discussions with chaplains, patients, and health care practitioners, role playing with standardized patients, and attending lectures on the role of spirituality in health care (Puchalski, 2001).

In providing spiritual care, health care professionals must remember that religion is only one way of enhancing spiritual well-being. Conversations about life, love, hope, trust, and forgiveness may renew the spirit of both patients and health care providers. Although the perspectives of health professionals is of personal value in one's role as a health practitioner, it is important to be nonjudgmental, never imposing one's own beliefs and values on the patient or family and always remembering that it is the spiritual or religious perspective of the patient or family that is important. Indeed, the therapeutic value of the self will be recognized through listening, presence, and nonabandonment.

Millsbaugh (2005b) suggests that in providing spiritual care for individuals who are suffering, practitioners must be able to maintain boundaries, empathize, contain their own suffering, focus and attend to the sufferer's agenda, use theology as well as the social and behavioral sciences to inform assessments and interventions, and engender a sense of security and comfort.

### Conversations About Spiritual or Religious Issues

Conversation regarding spiritual needs often begins with the use of open-ended questions, such as "Do you have any thoughts about why this is happening to you?" Practitioners can also encourage the patient to say more by such statements as, "Tell me more about that." When exploring spiritual concerns, the practitioner should acknowledge and normalize the patient's concerns by comments, such as "Many patients ask the same question," and responding with emphatic comments, such as "That sounds like a painful situation" (Lo et al., 2002).

Pitfalls in discussions about spiritual or religious issues near the EOL often occur by trying to solve the patient's problems or resolve unanswerable questions; going beyond the practitioner's expertise or role in providing spiritual care; imposing one's beliefs on the patient; or providing premature reassurance, which may appear superficial or deter the disclosure of other important issues or emotions (Lo et al., 2002). When patients inquire about the religious background of the practitioner, they may be inquiring to determine whether it is safe to talk about spiritual or religious issues, or they may prefer to talk to someone who shares the same religious faith. However, practitioners may answer the question regarding their religious background, but need not explicate or expound on their religious or spiritual beliefs (Lo et al., 2002). If the patient asks for details, it is appropriate to re-focus the conversation back to the patient.

In addition to clarifying the patient's spiritual concerns and needs by following spiritual cues, and exploring emotions with emphatic support, health care professionals may also do the following:

- Make wish statements, such as "I also wish you were not ill."
- Identify common goals for care and reach agreement on clinical decisions.
- Mobilize support for the patient and family from family, church members, or the community (Lo et al., 2002).

In situations when the patient, or his or her family, is praying for a miracle even in medically futile

situations, the role of health professionals is to respect their beliefs and remain supportive by trying to understand their worldview and the role their beliefs have in coping. Criticism or confrontation will lead to distrust and close the dialogue between health care professionals and the patient. When older patients and their families feel that they can talk to health professionals about their religious or spiritual beliefs, there is greater chance that they will accept what the professional is saying. A response may be that, "Sometimes God answers our prayers for healing in interpersonal ways that may ultimately be more important than physical healing" (Koenig, 2002, p. 492).

### Conducting a Spiritual Assessment

Holistic care involves assessment not only of physical, emotional, and social needs, but also of spiritual needs and expectations. A *spiritual history* is a history about a person's values or beliefs that explicitly opens the door to conversations about the role of spirituality and religion in the person's life (Puchalski & Romer, 2000). A spiritual history is important not only to identify ways individuals may cope with adverse life circumstances, but also to examine potential negative effects in which religious beliefs are a source of distress and emotional turmoil (Koenig, 2002). Religious pain is a condition in which the patient feels guilty over the violation of the moral codes or values of his or her religious tradition. This may arise due to major transgressions such as abortion, adultery, overt cruelty, or from minor transgressions such as not seeking a second opinion or failing to take better care of one's self. As a result, the patient may feel that God is disappointed in his or her past or present behaviors, actions, or thoughts (Satterly, 2001). Feelings of guilt are often accompanied by a fear of punishment from God, that God does not love them, or that God has abandoned them in their time of need.

Although it is not the health professional's responsibility to solve spiritual problems or provide answers, health practitioners need to conduct a spiritual assessment to identify when a patient or family member is experiencing spiritual distress. It is important to create an environment that nurtures the patient's exploration of spiritual needs and concerns and supports the patient in his or her search for answers. A spiritual history or assessment should be completed with each new patient visit and on annual examinations, as a part of routine history taking (Puchalski, 2001). A spiritual history inquires about the role that religion or spirituality plays in the patient's ability to cope with illness. Affiliation with a religious or spiritual community is important for many individuals and often serves as an extended family for many adults,



especially those who live alone or have limited family support (Koenig, 2002).

In taking a spiritual history, Puchalski (1998b) suggests that the acronym FICA be used:

- “F” refers to faith as identified by the question, “What is your faith or beliefs and do you consider yourself religious or spiritual?”
- “I” refers to influence, which is assessed by the question, “How does your faith or spirituality influence your medical decisions?”
- “C” refers to community and is related to the question, “Are you a part of a spiritual or religious community?”
- “A” refers to addressing spiritual concerns as exemplified by the question, “Would you like someone to address your spiritual needs or concerns?”

As another approach, Highfield (2000) uses the letters from the word “SPIRIT” to remember questions appropriate to a spiritual interview, specifically:

- S—Spiritual belief system (religious affiliation)
- P—Personal spirituality (beliefs and practices of affiliation that the patient and family accepts)
- I—Integration with a spiritual community (role of the religious/spiritual group; individual’s role in the group)
- R—Ritualized practices and restrictions (beliefs that health care providers should remember during care)
- I—Implications for medical care
- T—Terminal events planning (impact of beliefs on advance directives; contacting the clergy)

A more recently developed spiritual assessment approach is known by the acronym FACT (LaRocca-Pitts, 2009), as follows:

- F—Faith/beliefs: What is your faith or belief? Do you consider yourself a spiritual person or person of faith? What things give your life meaning and purpose?
- A—Active (or Available, Accessible, Applicable): Are you currently active in a faith community? Are you part of a religious or spiritual community? Is support for your faith available to you? Do you have Access to what you need to apply your faith/beliefs? Is there a person or a group whose presence and support you value at a time like this?
- C—Coping (or Comfort); Conflicts (or Concerns): How are you coping with your medical situation? Is your faith (your beliefs) helping you cope? How is your faith (your beliefs) providing comfort in light of your diagnosis? Do any of your religious beliefs or spiritual practices conflict with medical

treatment? Are there any particular concerns you have for us as your medical team?

- T—Treatment plan: This step of the FACT model sets it apart from the previous spiritual history tools in that it asks the clinic to make an assessment of the patient’s spiritual needs and coping, and to develop a treatment plan that may involve referral and/or interventions that may take the form of prayer, counseling, or scriptural reading recommendations (LaRocca-Pitts, 2009).

Spiritual assessment further includes assessment of personal beliefs, sources of meaning and hope, values, belief in an afterlife, and sense of connection to self, others, nature, and God. Health practitioners begin to address spirituality by asking such questions as “How are your spirits?” “How do you define your spirit?” “What nourishes your spirit?” or “How have you relieved your spiritual pain in the past?” (O’Connor, 1993). For adults with life-limiting or life-threatening illness, valuable questions to explore include the following:

- Are you suffering in physical, emotional, social, or spiritual ways?
- What is the meaning of illness and suffering?
- Do you see purpose in your suffering?
- Are you able to transcend your suffering?
- Are you at peace, or feeling hope and despair?
- Do your personal beliefs help you to cope with anxiety about pain and death, and provide a way for achieving peace? (Puchalski & Larson, 1998)

Hermann (2000) further asks in a spiritual assessment such questions as “What gives your life meaning and purpose?” “Do you have goals you would still like to achieve?” “How has your diagnosis changed the meaning of your life?” “What kinds of things do you hope for?” and “To whom do you turn for help?” Practitioners should also observe for objective data such as signs of depression, flat affect or refusal of treatment, presence of religious, spiritual, or inspirational books or other literature, or jewelry (Hermann, 2000).

## Instruments to Measure Spirituality and Suffering

In the past several years, there has been a focus on the role of spirituality, as distinct from religion, in coping with illness. However, there remains a dearth of well-validated, psychometrically sound instruments to measure aspects of spirituality (Peterman, Fitchett, Brady, Hernandez, & Cella, 2002). One instrument that is a psychometrically sound measure of spiritual

well-being is the Functional Assessment of Chronic Illness Therapy—Spiritual Well-Being (FACIT—Sp). This instrument comprises two subscales, one measuring a sense of meaning and peace, and the other assessing the role of faith in illness. The FACIT—Sp has convergent validity with five other measures of spirituality and religion in samples of early-stage and metastatic cancer diagnoses, as well as documented reliability. A total score can be obtained.

A second spirituality assessment instrument with clinical utility is the Paloutzian and Ellison Spiritual Well-Being Scale, which has also been administered to 70 family members caring for a relative with life-limiting illness. This 20-item instrument yields three scores: a total score of spiritual well-being (overall score); an existential well-being score, which relates to feelings about meaning and purpose in life, feelings about the future, and sense of well-being; and a religious well-being score, which represents a sense of support and connection with God (Kirschling & Pittman, 1989).

Such instruments are of value in conducting research studies that explore the relationships of spirituality and QOL for patients on PC. By identifying a patient's or family member's sense of spiritual well-being or spiritual distress, spiritual interventions may be provided to maintain or improve spiritual well-being and, hopefully, the QOL and quality of dying as perceived by patients and family members.

A recent review identified 10 instruments specifically designed for the clinical assessment and research of suffering (Krikorian, Limonero, & Corey, 2012). Each instrument was assessed for ease of scoring, time to administer, and readability/comprehension, as well as for various psychometric properties including content and construct validity, internal consistency, test-retest reliability, responsiveness, interpretability, agreement, and floor-ceiling effects. Of the available tools, PRISM (Pictorial Representation of Illness and Self Measure) is a validated, self-administered tool that is regularly used, is widely accepted, and was found to have the strongest psychometric properties of all the instruments studied (Krikorian et al., 2012).

## Spiritual Caregiving

“Spiritual care is so much more than religious care. Spiritual care discovers, reverences, and tends the spirit—that is the energy or place of meaning and values—of another human being” (Driscoll, 2001, p. 334). In providing spiritual care, health professionals express the capacity to enter the world of others; to respond to fears, concerns, and feelings with compassion; and bear witness to the physical, emotional, social and spiritual dimensions of their suffering. As

adults age, health care professionals can provide an opportunity to find intrinsic dignity, which is the dignity that comes from being a human being with inherent value and worth. By reviewing past life experiences, health professionals can assist individuals to reflect on their life accomplishments, the value of their relationships with others, to forgive or be forgiven by others, and to say goodbye. Support can be given to patients to complete unfinished tasks or goals, and make peace with themselves or with God.

During hospitalizations, health professionals may ask if the person would like to speak with the clergy or chaplain or have the opportunity to attend a hospital worship service. Patients may also be asked if they would like someone to pray with or for them or have spiritual reading materials. Prayer has been identified as the most frequently reported alternative treatment modality of elders, with women and Blacks using prayer as a coping strategy significantly more than men and Whites (Dunn & Horgas, 2000). At times, if the patient is of the same faith background as the health professional, the patient may request prayer. However, prayer is appropriate only when the patient wants it and will be comforted by it (Koenig, 2002). Prayer should not be prescribed because the risk is that the intention is not patient-centered, but provider-centered, and in that context prayers offered by health professionals may be viewed as coercive (Koenig, 2002). The existing religious or spiritual beliefs of the patient should be supported and encouraged, yet the EOL is not the appropriate time to introduce new or unfamiliar spiritual beliefs or practices (Koenig, 2002). In a study of 30 individuals with cancer, Taylor, Outlaw, Bernardo, and Roy (1999) reported that several individuals described hesitations about petitionary prayers for particular things, cure, or for themselves, and described inner conflicts about releasing control to God.

If a person is not religious or does not want a health professional to address religious issues, spiritual conversations around hope, love, courage, and forgiveness can occur in the provider–patient relationship (Koenig, 2002). Patients and health professionals of different faith backgrounds can appreciate the commonalities of basic human needs, such as love and hope, and explore issues of coping and what it means to live with an illness. Although health professionals can assess spiritual needs and address uncomplicated spiritual issues, caring and listening is the intervention, not giving advice or trying to address spiritual problems (Koenig, 2002).

Addressing spiritual problems is often the role of the chaplain or clergy, as a member of the interprofessional team. The chaplain is a health care professional who has been trained to offer spiritual care to all people of any or no religious tradition and whose



primary focus is the spiritual needs of patients, families, and staff (Driscoll, 2001). Like other members of the PC team, chaplains are alert to the expressed needs of the patient. As counselors, they take time to listen, discern the significance of the words spoken, intuit the importance of what is unspoken, and affirm the value of shared silence (Purdy, 2002). Often, spiritual support consists of listening to rhetorical questions from patients wanting an honest hearing of the question, rather than an answer. Patients may want to explore with chaplains whether God exists, the meaning of mortality, what Heaven is like, who goes to Hell, the integrity of doubt, the possibility of a miracle, the need to forgive, or the loneliness of suffering (Purdy, 2002). Patients and their families experience spiritual support when interprofessional team members actively listen to their anxiety and allow discussion of the question, “Are we doing the right thing here?” (Purdy, 2002). Health professionals can also provide support by silent witnessing, and presencing, as well as serving as a liaison with other health professionals in addressing physical, emotional, and spiritual needs (Hicks, 1999).

A cross-sectional multihospice study of 66 hospice nurses found that the nurse participants deemed spiritual care to be highly important. Although generalist spiritual assessment and care is within the purview of nursing practice, participants acknowledged the importance of spiritual care performed by a chaplain or pastor (Tiew, Kwee, Creedy, & Chan, 2013).

Humor also has an effect on the spiritual aspect of healing, as many patients find humor “spiritually uplifting.” As an element of spirituality and a coping method for spiritual growth and healing, humor can be transcendent, momentarily removing one from an isolated state to join in surprise at ludicrous human situations (Johnson, 2002). In a study of nine women with breast cancer, participants stated that they looked for meaning in their lives through spirituality and humor, as humor helped them to laugh at themselves and life. For some, it appeared that God had a sense of humor and that finding humorous moments was a step to recovery, as humor heals and gives hope to survive the moment (Johnson, 2002).

Health professionals can also encourage patients to socialize with friends, family, and children, as well as encouraging them to help others, even if only by active listening. Supporting others often preserves a person’s meaning in life and sense of usefulness. Adults can also pass on their legacy to others by recording personal histories, telling stories, and reminiscing about the past. Conducting a life review by asking questions, such as tell me about tranquil times in your life, chaotic time, what was your childhood like, what obstacle you overcame, what have you achieved, and what are your fondest memories,

help individuals to recontextualize and reframe mistakes and failure, allow forgiveness of self and others, reclaim an un-lived life, and take advantage of current opportunities to participate in enjoyed activities (Jenko, Gonzalez, & Seymour, 2007). If the person is isolated, the health practitioner can suggest his or her watching spiritual or religious television programs or provide an opportunity to enjoy his or her favorite sacred or secular music, or other forms of art (Hermann, 2000). Practitioners may encourage opportunities for patients to experience nature in whatever ways they can, such as a walk or wheelchair ride in the garden or courtyard, or as they sit outside feeling the air and warmth of the sun.

Spiritual uplifting in the present moment can also occur as the practitioner attempts to create meaning and a source of pleasure in the present moment. As one example, a bed-bound patient with parkinsonism found a moment of meaning and pleasure in the day by retelling to the nurse practitioner a story from his childhood, while anticipating a favorite meal to be brought in by his family the following day. Spiritual care can also involve “making meaning” through other forms of life review, such as looking at old photographs or personal memorabilia, reading old letters, or diary entries. By such efforts, health care professionals can acknowledge the individuality of a person and promote his or her sense of connection to self, others, and nature, thereby supporting his or her spirits and sense of well-being.

Chochinov and Cann (2005) reinforce not only general approaches to spiritual care, such as those offered by PC and psychotherapeutic approaches, but also specific approaches, such as relief of symptoms, as well as exploring guilt, encouraging forgiveness of self and others, and complementary practices that promote healing. Other supportive interventions include music and art and supportive-affective programs that focus on the spirit, emotions, and relationships.

Spiritual support may also be available through Parish nursing, which expands home health and public health provider roles. Parish nursing uses the faith community as a cooperative means of successful health promotion and maintenance for the older adult (Boland, 1998).

## ■ SPIRITUAL AND RELIGIOUS PERSPECTIVES ON DEATH

Losses in life often challenge our faith and philosophical systems. Those who experience loss and grief may differ regarding religious and spiritual perspectives from which they seek answers, search for meaning, and to which they turn for ritual, comfort, and support (Doka & Davidson, 1998). Understanding the

ways that spirituality or religiosity facilitates or complicates the adjustment to loss and grief is a critical task for those involved in PC.

### Death From a Jewish Perspective

Judaism began when the descendants of Abraham's grandson Israel were enslaved in Egypt. Moses led them to Palestine. During this time, Jewish law, known as the Torah, was divinely revealed to Moses. The Sabbath is celebrated from sunset on Friday to sunset on Saturday evening. The Sabbath is the day of rest. The degree to which a Jew observes the Sabbath and other rituals depends on whether he or she is Orthodox, Conservative, or Reformed (Sherman, 2004a). The focus of those of the Jewish faith is on life and its preservation and in fostering and establishing religion in the life of people on earth, rather than focusing on the world beyond. The Jewish faith offers consolation in death by affirmation of life. Sickness and death are viewed as neither punishment nor reward. Death is not considered evil but rather inevitable and natural, as it comes from God and should not be feared. Jewish teachings are that the soul exists before the body comes into existence and continues to live on after the body is dead. Although the Orthodox believe in resurrection, this belief may be figurative rather than literal (Grollman, 1993).

Jewish death practices help the bereaved to realize that the loved one is dead and to gradually fill the void in a constructive way. The memory of the deceased must be perpetuated. Although Jews are usually buried, cremations are also done. A religious rite is the rending of mourners' clothes, signified by the cutting of a black ribbon that is pinned to the mourners' clothing in the funeral chapel or cemetery. This signifies the loss of a loved one. The Jewish funeral is a rite of separation, in which the casket actualizes the experience. The rabbi recites prayers expressive of the spirit of Judaism and the memory of the deceased. *Shiva* refers to the 7 days of intensive mourning beginning right after the funeral. The bereaved remain at home and condolence calls are made to pay respects to the family. The shiva candle burns for 7 days and the family prepares the meal of consolation, known as *seudat havra'ah*. Following shiva comes the 30 days of *sloshim*. During this time, normal activities are resumed but entertainment is avoided. If a parent dies, the mourning continues for an entire year. The mourner's prayer is called the Kaddish, which is recited during the weekly Sabbath as a pledge to dedicate one's life to God, acknowledge the reality of death, and affirm life. The anniversary of the death is called *yahrzeit*. The Kaddish prayer is recited and *yahrzeit* candles are again kindled (Grollman, 1993).

### Death From the Roman Catholic Perspective

In Catholicism, it is believed that Jesus experienced suffering, grief, and death. Jesus' death and the death of all others are viewed as a part of God's divine providence. As sinners, human beings experience the tragedy of death, yet are beneficiaries of its forgiveness and liberation. In Catholicism, resurrection is integral to death. Catholics believe that Christ died and rose from the dead, and that faith will allow them to see death as an entry into life with God. Confession and communion are important rituals conducted by priests. The sacrament of the anointing of the sick provides bodily and spiritual renewal, and has replaced the term "the last rites," which was viewed as a harbinger of death.

Since the second Vatican Council, the Catholic contemporary view places emphasis on risen life. There is a move from a preoccupation with sin and death toward an orientation of blessing for a Christian life. Christians follow Jesus into the mystery of death in order to find a life like his own (Miller, 1993). The funeral becomes one of thanksgiving and consolation; the funeral Mass is offered on behalf of the deceased, aiding them to the other side of death and giving the bereaved the consolation of hope. It is believed that Christ accompanies the dying person to heaven and that dying is an act of faith in God (Miller, 1993).

### Death From the Protestant Perspective

In Protestantism, spirituality is viewed as a dimension of humanness, a process of interaction, and an awareness of relationship. Spirituality cannot be lived in the abstract but rather is lived through one's religion, which is regarded as a cultural institution (Klass, 1993). God is viewed as a single being, who spoke to his people through the Bible; God protects but also judges. Each Protestant has a direct and personal relationship with God, unmediated by priest or sacrament. The church is viewed as a voluntary association of believers. The Protestant community is the local congregation or particular denomination supporting interpersonal relationships, yet is often split along racial, ethnic, and social class lines (Klass, 1993). Anointing the sick is accepted by some groups. Although there are no last rites, prayers are given to offer support.

Death is a challenge because it raises the problem of evil and the problem of the meaningfulness of suffering. Suffering and overcoming evil are the core of Protestant teaching. For Protestants, the focus is salvation, which depends on the moral QOL on earth. Heaven is known in hope, but not as a guarantee. The belief in an afterlife is through experiences of memory and sense of presence and shared community.



Although Jesus is a model for physical, emotional, social, and spiritual suffering, the individual faces the cosmos alone. The issue is not how the individual can participate in Jesus's suffering, but rather the individual's accepting the gift of God's grace in Jesus's death (Klass, 1993).

## Death From the Islamic Perspective

*Islam* means submission. *Muslim* means one who submits. A Muslim is one who submits to Allah, the Arabic word for God. Muslims, Jews, and Christians worship the same God. The founder of Islam is Mohammad, who received a vision while meditating, which later became the Koran. The five pillars of Islam are confession of faith daily in front of witnesses, prayer five times a day, fasting during the month of Ramadan, almsgiving, and a pilgrimage to Mecca. Fasting during Ramadan is not required of the sick. Second-degree male relatives (e.g., cousins or uncles) should be contacted when a person is sick. They determine if a person or family should be told the diagnosis or prognosis. The Islamic teachings encourage Muslims to seek treatment when they are sick, including modern medicine, spiritual healing, and traditional healing practices such as recitation of verses of the Noble Qur'an. They believe in divine predestination and perceive suffering as atonement for one's sins. When asking about the life expectancy of a patient, they are more likely to be comfortable with less definitive answers such as "it is in the hands of God," as Allah determines the time of death (Zafiral-Shahri & Al-Khenaizan, 2005).

Death is viewed as the beginning of a different form of life in which there are blessings from Allah. Some families may ask to have the patient face Mecca (east) and his or her head should be elevated above the body. Discussions about death are not usually welcomed. Grief may be expressed by slapping or hitting the body. Same-sex Muslims should handle the body after death; otherwise the individual should wear gloves so as not to touch the body. Islam forbids cremation, and burial should happen as soon as possible (Zafiral-Shahri & al-Khenaizan, 2005).

## Death From Eastern Perspectives

Hinduism originated in India, with belief in the cycles of being born and dying in an infinite series of lives or successive creations. Hinduism teaches the belief in karma, which is that every act of a human being, even an internal act, such as desire, has an effect on who that person becomes. One becomes virtuous by

good actions and bad by bad actions (Ryan, 1993). A Supreme Being exists in the individual's soul and is the ultimate all.

Originating in India, Buddhism does not include a belief in a God or a soul. Buddhism teaches that suffering is a part of life and that in death there is a transference of consciousness out of the body (Smith-Stoner, 2006). Buddhists believe in karma and rebirth. Karma is the principle of cause and effect. Buddhists train their minds to remain calm and peaceful as death approaches. Buddha taught that a way to overcome ignorance and attain truth is through the path to enlightenment or changed state of awareness called Nirvana. Buddhists believe that the way to Nirvana is through meditation, while others believe that it can be attained through faith.

Yet another Eastern tradition is that of Confucianism, which has its origins in China and stresses the importance of improving human relationships. The proper relationship between the living and dead is one of continuous remembrance and affection, through which one attains social immortality. The value of rituals is that they relate the living with the dead. Memories of parents and ancestors are kept through regular remembrance rituals, which also provide a vehicle for the expression of the human emotions of grief and affection.

Taoism has its origins in China. In Taoism, the focus is on nature and remedying society's disorder and lack of harmony. One looks toward nature to discover the principles of life. Life is viewed as the companion of death, and death is viewed as the beginning of life and part of the living-dying process. Taoism offers a way of transcending the limits of the world, as there are ceaseless transformations where the person is not lost. The yin and yang are the basic principles for all natural change. The yang is the light half, which is characterized as masculine, active, hot, bright, dry, and hard. The yin is the dark half, which is characterized as feminine, passive, cold, dark, wet, and soft. They are viewed as complementary forces that transform into the other. There is no light without dark, evil without good, or life without death (Ryan, 1993).

Many Asian patients—Chinese, Japanese, Koreans—have an Eastern perspective in which formal behaviors are valued. It is believed that to rebel against death reveals a fundamental lack of understanding about life. Therefore, sadness and grief are kept private. Such behavior sets a good example and contributes to one's good reputation (Ryan, 1993). Patients may seek comfort in images, such as Buddha, Krishna, or the Divine Mother, or in repeating holy mantras. Those from an Eastern perspective believe that a person's final dying thoughts may determine one's rebirth.

## Spiritual Issues in Death and Dying for Those Who Have No Conventional Religious Beliefs

Religion traditionally has provided a context for understanding and interpreting death. However, individuals who are not religious can still find comfort and meaning through spirituality and by stepping back from the material world (Orion, 1993). Individuals with no conventional religious beliefs often interpret life on the basis of a sense of being a part of a larger whole and from a scientific worldview. There is belief that an individual's life has a beginning and an ending, but the life process is indefinite. Whether the process is defined in terms of social or biological continuity, the brevity of life does not suggest insignificance. A particular life is short and seemingly inconsequential but assumes value and importance as a significant element in the entire ongoing process. Even brief life is viewed as a contribution to the life process.

Those without conventional religious beliefs often consider the present as the real world and take full responsibility for their decisions. There is the belief that immortality occurs by biological immortality such as living on in the genetic pool of one's descendants, or living on in the memories of others or one's contributions to the world (Orion, 1993). The focus is on actualizing human potential. From the naturalistic perspective, death is not avoided or denied. Death is viewed as real, final, and inevitable and a mark of humans' solidarity with nature and the evolutionary process. Naturalism leads an effort to place the death of an individual in a framework of the process of living and dying, emergence, and extinction. In this framework, death is:

- A working out of the natural law by which all living things die
- The absorption of the differentiated person in the natural process
- A contribution to the evolutionary process
- Cessation of life's potential for negative and positive contributions
- Reabsorption into new ways in nature (Orion, 1993)

Fear of death can be overcome by remembering that everything dies, but existence goes on. When death is seen as part of the natural order or part of the universal condition, it can be tolerated more easily. Life and death are continuous parts of the whole (Orion, 1993).

Given the dearth of studies regarding the perspectives of atheists in palliative medicine, Smith-Stoner (2007) conducted a study of 88 individuals who self-identified as atheists, which is defined as someone

who does not accept that there are any Gods, heaven, hell, devils, souls, miracles, an afterlife, or anything else supernatural. Based on an analysis of open- and closed-ended survey questions, the results of EOL preferences indicate that participants' view of a good death included respect for nonbelief and the withholding of prayer or any other references to God. However, consistent with a definition of spirituality, which includes intrapersonal, interpersonal, and a natural focus, atheists expressed a deep desire to find meaning in their own lives (intrapersonal), to maintain connection with family and friends (interpersonal), and to continue to experience and appreciate the natural world.

## ■ NURSES' NEED FOR SELF-REFLECTION AND SELF-HEALING IN PALLIATIVE CARE

Doka and Morgan (1993) describe the caregivers' assumptions and principles of spiritual care. First, nurses represent diverse spiritual or cultural backgrounds and, like patients, have the right to expect respect for their belief systems. Second, nurses should be offered opportunities to explore their own values and attitudes about life and death and their meaning and purpose in life. Third, nurses should be aware that they have the potential for providing spiritual care, and should be encouraged to offer spiritual care to dying patients and their families, as needed. Fourth, just as all caregivers, nurses should be flexible and realistic in setting spiritual goals. Fifth, ongoing care of the dying and bereaved may cause a severe drain of energy and uncover old and new spiritual issues for the caregiver. Spiritual growth and renewal are, therefore, a necessary part of staff support and a personal priority for each caregiver.

Indeed, in caring for dying patients and bereaved families, nurses may have experiences that create a grief response of their own because they have lost someone in whom they have invested themselves emotionally. Nurses' grief response, like that of their patients, will be influenced by their spiritual and cultural values and beliefs. If accumulated grief is not worked through, the nurse is vulnerable to the same manifestations of unresolved grief as any other individual who has had a loss but failed to complete the grief work (Sherman, 2004b). Nurses therefore need to resolve their own feelings of loss, with their spiritual convictions supported, sense of failure alleviated, and emotional strength replenished (Sherman, 2004b).

In coping with the stress of caring for the dying, Harper (1994) believes that professional caregivers progress through five stages of adaptation: (a) intellectualization; (b) emotional survival;



(c) depression; (d) emotional arrival; and (e) deep compassion (Harper, 1994). It is essential that nurses work through these stages in order to reduce their anxiety about caring for dying patients, as well as to engender personal and professional growth, and adapt to be able to comfortably care for patients and their families at EOL. Other stressful life events, previous personal and professional experiences with death and dying, the presence or absence of social supports for the caregiver, the degree of engagement in healthy self-care behaviors, and the ability to pursue and live a balanced life can all affect a caregiver's ability to adapt and cope with the stress of caring for the dying (Arnold & Egan, 2004). Recently, a sixth stage of adaptation, the doer, has been suggested to reflect professional caregivers, who have experienced and processed the previous five steps in a healthy way, who demonstrate a level of adaptation and integration of their knowledge, learning, and experiences in caring for dying patients. The result is a provider who is not only efficient and vigorous in the care given, but who also possesses a deep understanding of the meaning of the care in the greater context (Egan-City & Labyak, 2010).

In developing awareness and supporting nurses' spiritual well-being, nurse educators may ask their students or nursing colleagues the following questions:

- What expectations do you have about yourself in caring for the dying and bereaved?
- What would define success in your work?
- What are the three most difficult aspects of your work in caring for patients with life-threatening illness?
- What are you doing to help yourself cope with stress and replenish yourself to avoid becoming over stressed?

"Nurses must recognize their stress reactions and symptoms and employ self-care strategies to replenish themselves in physical, emotional, mental, and spiritual ways to overcome the various sources of stress" (Sherman, 2004b, p. 53). In reducing burnout in PC nursing, *physical health* is promoted as nurses care for their bodies by eating well, engaging in restful and relaxing activities, and counterbalancing fatigue by making improvements in lifestyle. *Emotional health* is bolstered by developing a calm mind with peaceful thoughts through such activities as meditation or listening to quiet music, as well as consciously letting go of negative thoughts and emotions. *Mental health* is strengthened by making choices, setting priorities, letting go of conflict, and saying no, while remaining open to new opportunities and possibilities. *Intuition health* is nurtured by listening to the soul's wisdom and recognizing the need for balance and wholeness.

In overcoming interpersonal stressors, particularly when relations with others are difficult, nurses may find it helpful to reflect on the rewards of their work and the moments in which they have made the greatest difference in the lives of their patients and families. To cope with feelings of grief and loss, nurses can take time to reflect on what happened at the time of the patient's death and lessons learned, and speak to colleagues or journal about feelings, perceptions, and experiences (Sherman, 2004b).

Within the context of EOL care, and given that spirituality has emerged as a vital component of health, it becomes necessary for nurses to acknowledge their own spiritual beliefs and values and to deal with their own spiritual and cultural issues. Based on a sample of 155 Israeli oncology nurses, Musgrave and McFarlane (2004) reported that nurses' attitudes toward spiritual care are influenced by their spiritual well-being, intrinsic and extrinsic religiosity, and education. In a descriptive, qualitative study of the spiritual care perspectives and practices of 204 hospice nurses, Belcher and Griffiths (2005) recognized that the majority of the sample stated that they personally expressed their spirituality by attending church and related activities, that there was an openness and level of comfort in being a spiritual caregiver, and that there was no role conflict in spiritual expression. The majority of hospice nurses learned of the spiritual needs of their patients and families through personal interactions and the support of pastoral counselors or learning from their own personal life experiences. As hospice nurses, most indicated that they conducted spiritual assessment and recognized the importance of addressing spiritual needs, although their basic educational programs did little to prepare them for this. It was clear that hospice nurses value education regarding spirituality, which they believe enhances the quality of care.

Clark et al. (2007) examined the spirituality of members of a hospice interprofessional team ( $n = 215$ ). Based on the Jarel Spiritual Well-Being Scale, the Chameic-Case Spirituality Integration Scale, and the Job Satisfaction Scale, respondents reported high levels of spiritual well-being, self-actualization, and job satisfaction. Structural path analyses revealed that job satisfaction is more likely realized by a model that transforms one's spirituality into processes of integrating spirituality at work and self-actualization.

According to Hunnibell, Reed, Quinn-Griffin, and Fitzpatrick (2008), nurses in hospice and PC, as well as oncology nurses, manifest self-transcendence, which is characterized by awareness of the spiritual self, one's relationship to others, a higher being, and finding meaning and purpose in life. Based on a sample of 563 nurses (244 hospice nurses and 319 oncology nurses), both groups of nurses scored

high on the Self-Transcendence Scale, although hospice nurses had higher scores. For both groups of nurses, the greater the level of self-transcendence, the lower the nurses' scores of burnout, measured by the Maslach Burnout Inventory, as emotional exhaustion, depersonalization, and personal accomplishment. Oncology nurses manifested higher levels of burnout than hospice nurses, particularly with respect to depersonalization. It was suggested that nurses should be encouraged to connect with other nurses and form support groups to share their experiences. Strategies such as keeping a journal, sharing one's stories, and recognizing positive individual contributions to care may increase sense of worth and reduce professional burnout.

The importance of spiritual care was emphasized in a position statement published by the Hospice and Palliative Care Nurses Association (2007). The statement emphasized the commitment of hospice and palliative care nursing to compassionate care at the EOL, acknowledging the importance of spiritual care, encouraging organizational support in the provision of spiritual care, commitment to education and resources to promote spiritual care, and recognition of the right of individuals to decline spiritual care.

In caring for people with life-threatening and progressive illness, nurses must remain in tune with their own spiritual needs, healing themselves as well as others. To do so, Halifax (1999) suggests a contemplative exercise for nurses to remain centered, renewed, and whole as they care for others. Sitting in a relaxed position, with eyes closed and aware of the rhythm of the breath, the nurse focuses one at a time on each of the following five phrases, which are repeated slowly twice. The nurse then allows the phrase to pass into the background of her or his awareness, moving attention to the breath and to the next phrase. The phrases are as follows:

- May I offer my care and presence unconditionally, knowing that it may be met with gratitude, indifference, anger, or anguish.
- May I offer love, knowing that I cannot control the course of life's suffering or death.
- May I remain in ease and let go of my expectations.
- May I view my own suffering with compassion just as I do the suffering of others.
- May I be aware that my suffering does not limit my good heart.
- May I forgive myself for things left undone.
- May I forgive all who have hurt me.
- May those whom I have hurt forgive me.
- May all beings and I live and die in peace.

Coulehan and Clary (2005) suggest that poetry can play a role in healing, as the written word becomes an instrument of healing and an opportunity for practitioners to reframe negativity, learn to function in the face of uncertainty, and support a compassionate presence in the care of the seriously ill and dying. Writing and reading poetry assists practitioners in understanding their own beliefs, feelings, attitudes, and response patterns, and in the process fosters empathic connection and a relationship that heals both patients and practitioners.

A survey of 605 ELNEC conference participants asked nurses to rate themselves on self-care behaviors and activities. Overall, the 605 participants rated taking vacation and having meaningful relationships outside work as their most common self-care activities. Relationships in the workplace were also seen as important. Participants rated the ability to emotionally debrief at work as the most challenging self-care activity. The current literature shows that nurses are well aware of the importance of self-care activities, and the need for balance between one's professional and personal life in order to properly care for their patients and help prevent burnout; however, this awareness is not always translated into self-care action, for a variety of reasons (Vachon & Huggard, 2010).

Spiritually and culturally competent care, therefore, requires self-reflection and self-care of nurses. Replenishing one's own vessel in spiritually and culturally renewing ways is important in supporting nurses' caregiving potential. Only by doing so will nurses come to the bedside with the strong healing presence and true compassion needed to alleviate the suffering of patients and their families.

## ■ CONCLUSION

Illness and dying are occurrences that take us to the very core of our being. Although they are intensely personal experiences, they occur within the context of our spiritual and cultural traditions. Culture and spirituality therefore cannot be separated from who we are, as they are often the very source of our nourishment and physical, emotional, social, and spiritual well-being. Through sensitive and competent cultural and spiritual care, nurses can protect patients and families from the ultimate tragedy of depersonalization. They will be able to sustain patients and families in a personalized environment that recognizes their individual needs, reduces their fears, and offers them hope and dignity. Sulmasy (1997) believes that "when patients collapse spiritually in the face of illness, a clinician with the right perspective will understand much more acutely how desperate their plight really is and will treat the wounds of such patients with



even more liberal applications of the wine of fervent zeal and the oil of compassion” (p. 52).

Cultural and spiritual values, beliefs, and practices profoundly influence life and living, and death and dying. Identifying cultural and spiritual factors pertinent to a patient’s health are critical to the development of a successful plan of care that supports a person’s sense of worth, integrity, and the continued actualization of her or his potentials. Within the context of culturally and spiritually diverse beliefs and practices, health professionals should preserve beliefs and practices of individuals that have beneficial effects on health, encourage the adaptation or adjustment of practices that are neutral or indifferent, and suggest the repatterning of those practices that are potentially harmful to health (Leininger, 1995).

Culturally and spiritually competent care requires self-reflection and self-care if health care professionals are to be therapeutic. Hence, health care

professionals need to replenish their own vessels in culturally and spiritually renewing ways to actualize their caregiving potential. In doing so, health care practitioners can offer a strong healing presence, true compassion, and sensitivity to the cultural and spiritual needs of patients and their families (Sherman, 2001).

Consideration of the cultural and spiritual backgrounds of patients and attention to their cultural and spiritual needs often enable older patients to live as fully as possible until death, and to maintain or restore quality to their lives. Byock (1997) reminds us that through competent and compassionate EOL care, older adults and all other patients can achieve a sense of inner well-being even as death approaches, and that “when the human dimension of dying is nurtured, for many the transition from life can be as profound, intimate, and precious as the miracle of death” (p. 57).

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### **CASE STUDY Conclusion**

Mrs. Martinez’s weakness and fatigue progressed, with only a slight improvement in her left-sided weakness. She spent the last 6 months of her life in the loving care of her family with the support of hospice. The nurse continued to address Mrs. Martinez’s physical needs, which were increasing pain, constipation, and nausea, while recognizing the multidimensional aspects of her suffering. Mrs. Martinez enjoyed her visits with the hospice chaplain, who was a Catholic priest. He prayed with her at her request, administered weekly Holy Communion, and anointed her with the Sacrament of the Sick. Like Mrs. Martinez, the family expressed their appreciation for the chaplain’s spiritual sensitivity and care. Spiritual support was further offered by the nurse practitioner who recognized the value of life review and sat with Mrs. Martinez and the family as they watched family videotapes and reminisced about special occasions. With help from the nurse, the daughter would take her mother in the wheelchair to sit for short periods in the yard. Mrs. Martinez’s face relaxed as she listened to the birds and enjoyed watching her grandchildren.

Until the very last days of her life, Mrs. Martinez experienced the love and support of her family. Sips of herbal teas were encouraged to give her strength or relieve the nausea. Latino music was played, reminding her of her cultural connection. Members of her church visited and prayer novenas were conducted. Mrs. Martinez died in her own room with her family and the hospice nurse at her side. The nurse and family discussed the cultural and spiritual practices of the family in preparing for Mrs. Martinez’s funeral and plans to celebrate her life.

During a follow-up bereavement visit, Mrs. Martinez’s family acknowledged their appreciation for the culturally and spiritually sensitive care received from the hospice team. Mrs. Martinez’s daughter told the nurse that they considered her a member of their family. This comment reveals the depth of connection that can be established with older patients and their families, and the importance of cultural and spiritual sensitivity in providing quality palliative care.

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## Evidence-Based Practice

### Level IV Evidence: Descriptive, Correlational, Qualitative

Delgado-Guay, M., Parsons, H., Hui, D., De la Cruz, M., Thorney, S., & Bruera, E. (2013). Spirituality, religiosity, and spiritual pain among caregivers of patients with advanced cancer. *American Journal of Hospice & Palliative Care*, 30(5), 455–461. doi:10.1177/1049909112458030

### Background

Caregivers of patients with advanced cancer often face physical, social, and emotional distress as well as spiritual pain. Limited research has focused on the spiritual aspects of caregivers' suffering.

### Purpose

To assess spirituality, religiosity, and spiritual pain in caregivers of patients with advanced cancer.

### Methods

Forty-three caregivers of patients with advanced cancer were interviewed in a palliative care outpatient clinic. Demographic characteristics, religious affiliation, and relationship to the patient were determined. Levels of spirituality, religiosity, and spiritual pain were self-reported using numeric rating scales (0 = lowest; 10 = highest). The participants completed various validated questionnaires to assess sleep disturbances, psychosocial distress, coping skills, and quality of life (QOL).

### Results

The median age was 52 years (range, 21–83); 29 (67%) were women, 34 (78%) were White, 7 (17%) were African American, and 2 (5%) were Hispanic; 39 (91%) were Christian, 1 (2%) was Jewish, and 1 (2%) was agnostic; 37 (86%) were married; 18 (42%) were working full time; and 25 (58%) were spouses. All considered themselves spiritual, and 98% considered themselves religious. All the caregivers reported that spirituality and religiosity helped them cope with their loved one's illness, and many reported that spirituality and religiosity had a positive impact on their loved one's physical (58%) and emotional (76%) symptoms. Spiritual pain was reported by 23 (58%), with a median score of 5 (interquartile range, 2–8). Caregivers with spiritual pain had higher levels of anxiety (median 10 vs. 4;  $p = .002$ ), depression (6 vs. 2;  $p = .006$ ), and denial (3 vs. 2;  $p = .01$ ); more behavioral disengagement (3 vs. 2;  $p = .011$ ), more dysfunctional coping strategies (19 vs. 16;  $p < .001$ ), and worse QOL (70 vs. 51;  $p < .001$ ) than those who did not have spiritual pain.

### Conclusions

The majority of caregivers of patients with advanced cancer considered themselves spiritual and religious. Despite this, there is high prevalence of spiritual pain in this population. Caregivers with spiritual pain experienced worse psychological distress and worse QOL. These findings support the importance of spiritual assessment of and spiritual support for caregivers in this setting.



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Marianne Matzo

# Sexual Health and Intimacy

## KEY POINTS

- Sexual health concerns exist throughout the trajectory of illness, including late-stage disease.
- Sexual health concerns for seriously ill patients are extremely diverse.
- Patients expect provider guidance on sexual health concerns.
- There is very little documentation concerning the wishes and expectations of patients with serious illness regarding their sexual health throughout the course of their illness.

## CASE STUDY

Sally is a 37-year-old woman who was one of my hospice patients; she has had a brain tumor for 3 years. During one of my visits, Sally was talking about her partner and their loss of intimacy since about a year after her diagnosis. Regarding her relationship with her significant other, she said, “We’ve grown apart, it’s very sad.” They had thought about counseling when their relationship began to change, but “didn’t think they were ready for that big a step...we were wrong.” She said she is dissatisfied with her sex life: “I think about it sometimes, I miss it, I don’t know where it went.” When I asked her where she would rank her sexual needs at this point in her life, she said, “toward the top.” I asked her if she could be more specific, and she said, “my favorite foods, then sex.”

Quality-of-life (QOL) issues are very important considerations in the delivery of palliative care (PC). Assessment of an individual’s ability to complete activities of daily living and basic needs are an integral part of PC. Sexual intimacy is not discussed openly, if at all. Sexual health within the context of PC may be directly impacted by the effects of disease on anatomical structures. However, direct anatomical effect is not the only concern; changes in a person’s

sexual interest or desire may also be affected by direct or indirect consequences of medical treatment or in association with being terminally ill.

For many people, when one talks about sexuality, the immediate reference is to intercourse. Different approaches can be taken to the study of sexuality and intimacy, but the focus of this chapter is on *sexual health*, which encompasses both concepts. One definition of sexual health is the integration of somatic,

intellectual, and social aspects of being sexual (Penson et al., 2000). The somatic aspect includes the physical ability to be intimate with a partner, that is, to be sexually functional (i.e., to have desire, become aroused, and obtain sexual fulfillment; Robinson, Bockting, Rosser, Miner, & Coleman, 2002). The intellectual aspect is the ability to communicate about sexual needs and desires, to act intentionally and responsibly, and to set appropriate sexual boundaries. Sexual health affirms sexuality as a positive force that can enhance other aspects of a person's life (Robinson et al., 2002). Social aspects include the ability to be intimate with a partner, sexual desire, self-acceptance and respect and feeling of belonging to and involvement in one's culture.

The sexual health care needs of the seriously ill patient facing the end of life has received some recognition in the professional literature (Anderson & Wolf, 1986; Ashby, Kissane, Beadle, & Rodger, 1996; Blagbrough, 2010; Cagle & Bolte, 2009; Caruso-Herman, 1989; Cort, Monroe, & Oliviere, 2004; Farkas, 1992; Freyer, 2004; Gideon & Taylor, 1981; Gilley, 1988a; Grigg, 2002; Hordern, 1999; Katzin, 1990; Kutner, Kassner, & Nowels, 2001; Laury, 1987; Moynihan, 2007; Rice, 2000a, 2000b; Smith, 1989; Stausmire, 2004; Wells, 2002; Wickett, 1986), but there are few research studies to support the assertions made in these publications. There is a growing public health awareness of sexuality related to health, well-being, and QOL (WHO, 2004). There is a need to gather patient data to inform a sexual health plan of care. In response to this, the WHO Department of Reproductive Health and Research has begun to recognize sexual health as a separate dimension of QOL warranting clinical investigation (WHO, 2004).

An Institute of Medicine (IOM, 2007) report addresses the importance of holistic care for cancer patients. The report concludes that to ensure appropriate psychosocial health, health care practitioners (HCPs) should facilitate effective communication between patients and care providers. In a study by Young (2007), 28% of the patients indicated that their physicians do not pay attention to anything other than their medical needs (Young, 2007). Sexuality assessment is frequently overlooked by PC providers when health care needs are being assessed. Health care professionals avoid discussion of sexuality for several reasons: (a) embarrassment, (b) assumption that the sex life is over due to the disease, (c) lack of knowledge, and (d) lack of time. Patient-reported barriers include: (a) embarrassment, (b) privacy, and (c) environmental (Blagbrough, 2010). In addition, patients report that psychological distress during diagnosis and treatment of malignancy can impair a healthy sexual response cycle (Krychman, Pereira, Carter, & Amsterdam, 2006).

The Sexual Health Model (Robinson et al., 2002; Figure 6.1) is a theoretical framework well suited for PC. The model reflects the complexity of human sexuality by identifying 10 broad components posited to be essential aspects of healthy human sexuality:

1. Talking about sex—This is a cornerstone of the model, and includes the ability to talk comfortably and explicitly about sexuality, especially one's own sexual values, preferences, attractions, history, and behaviors.
2. Culture and sexual identity—Culture influences one's sexuality and sense of sexual self; thus, understanding how one's cultural heritage impacts sexual identities, attitudes, and behaviors will influence sexual health.
3. Sexual anatomy and functioning—Sexual health assumes a basic knowledge, understanding, and acceptance of one's sexual anatomy, sexual response, and sexual functioning, as well as freedom from sexual dysfunction and other sexual problems.
4. Sexual health care—This item encompasses knowing one's body, obtaining regular examinations for sexually transmitted diseases (STDs) and cancer, and responding to physical changes with appropriate medical intervention.
5. Overcoming challenges to sexual health—Challenges to sexual health, which may involve sexual abuse, substance abuse, compulsive sexual behavior, sex work, harassment, and discrimination, are critical in any discussion of sexual health.
6. Body image—Body image is an important aspect of sexual health, challenging the notion of a single narrow standard of beauty, and encouraging the self-acceptance that is relevant to all populations.
7. Masturbation/fantasy—Sexual health includes a realistic appreciation of the important role of masturbation and fantasy. Encouraging masturbation as a normal adjunct to partnered sex can decrease the pressures on women to engage in penetrative sex with their partners more frequently than they desire.
8. Positive sexuality—This includes a developmental approach to sexual health over the life span, recognizing the reality that all human beings need to explore their sexuality in order to develop and nurture who they are.
9. Intimacy and relationships—Intimacy is a universal need that people try to meet through their relationships.
10. Spirituality and values—This model assumes congruence between one's ethical, spiritual, and moral beliefs and one's sexual behaviors and values.



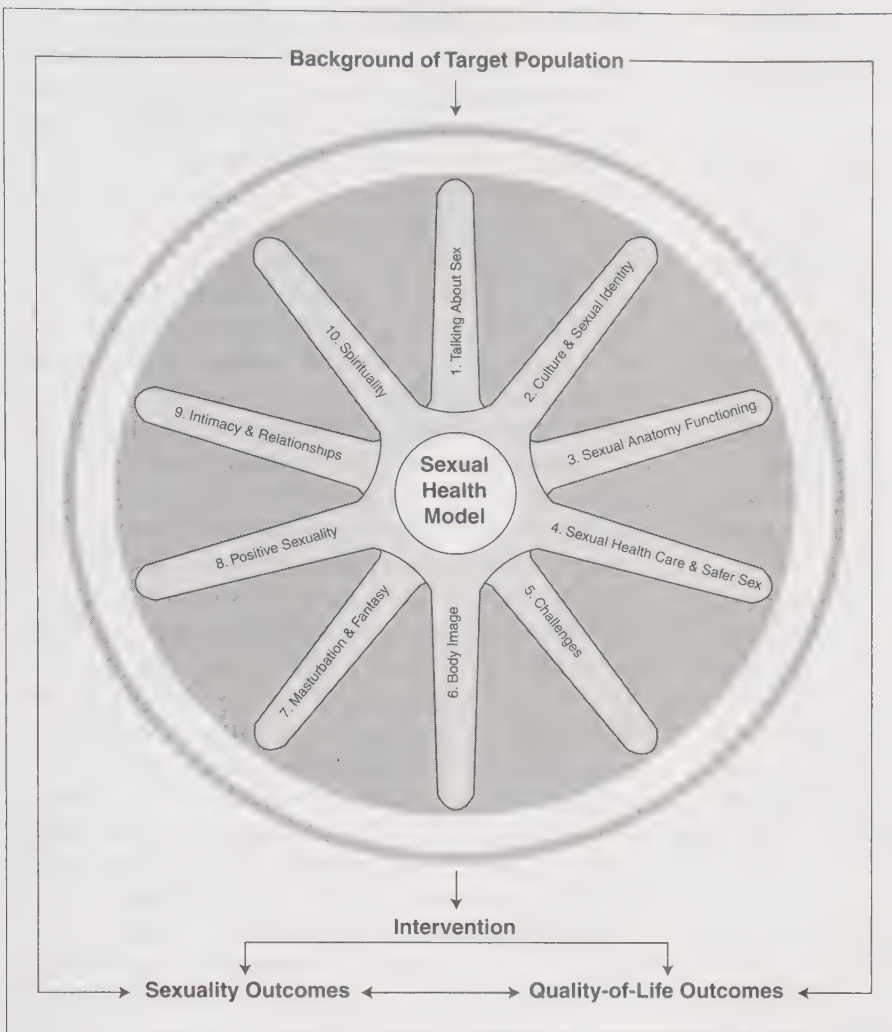


FIGURE 6.1 Sexual Health Model  
(Robinson et al., 2002).

The final two items in this model stress the importance of exploring and celebrating sexuality from a positive and self-affirming perspective. This is an essential feature of the model, the assumption being that when people are comfortable with their sexuality, they will know and be able to ask for what is sexually pleasurable for them. In this context, spirituality may or may not include identification with formal religions, but it does include the need to address moral and ethical concerns (Robinson et al., 2002). Several components of the model are addressed in this chapter.

## ■ TALKING ABOUT SEX

HCPs frequently avoid talking about sexuality with cancer patients (Harrison, Young, Price, Butow, & Solomon, 2009). Many studies regarding sexual health document universal themes related to communication about sexuality and intimacy between patients and their HCPs. These tend to fall into two categories: needs and communication. Regarding needs, patients have questions and concerns about

their sexual health that they would like to discuss with their HCP (Ananth, Jones, King, & Tookman, 2003; Grigg, 2002; Smith, 1989; Stead et al., 1999; Vitrano, Catania, & Mercadante, 2011). A survey of HCPs ( $n = 1,946$ ; Bachmann, 2006) documented that 60% of the respondents estimated that at least three fourths of their patients had sexual dysfunction, but 58% indicated that they initiated assessment of sexual health concerns with less than one quarter of their patients. Second, concerning communication, patients indicate that they do not initiate these conversations because they think HCPs are too busy, they do not want to “bother” them, they think that they should just be “grateful to be alive,” and that it is a private matter (Kralik, Koch, & Telford, 2001); many also think that if something could be done about the situation, the HCP would raise the issue (Smith, 1989).

HCPs’ barriers to discussing sexuality include embarrassment, misinformed beliefs and assumptions, lack of knowledge, inadequate communication skills, and time constraints (Blagbrough, 2010). Some examples of these are as follows. Sexual health is not routinely assessed due to the belief that the patient will bring up the topic if it is a concern; to the perception

that people are “too sick” to be sexual (Caruso-Herman, 1989); lack of their own comfort with the topic (Caruso-Herman, 1989; Dunn, 2004; Epstein & Street, 2007; Grigg, 2002; Wilmoth, 2006); preconceived ideas, attitudes, and values regarding sexuality (Grigg, 2002; Wilmoth, 2006); perceived lack of time for this conversation (Dunn, 2004); and the feeling that there are “more important” issues to be addressed (Ananth et al., 2003; Smith, 1989). In addition, lack of communication about sexual health may be the result of lack of evidence to support raising the issue (Stead, 2004). Sexual health is also not emphasized in HCP professional education (Caruso-Herman, 1989; Dunn, 2004; Grigg, 2002; IOM, 2007; Penson et al., 2000), which can result in this lack of communication, a conspiracy of silence, and a dominant communication pattern of evasiveness (Grigg, 2002).

Communication between the patient and the health care professional is an important factor in facilitating the assessment of the patient’s sexual health needs. There is disagreement as to who should initiate discussion regarding sexuality between the patient and caregiver (Levett, 2011). Some literature suggests that health professionals should initiate the discussion regarding changes in sexuality and sexual function that may be occurring related to effects of treatments or secondary to the disease process itself. Patients may not ask these questions themselves because they assume that health care professionals will initiate the discussion with them (Matzo & Hijjazi, 2009; Rice, 2000b). Park, Norris, and Bober (2009) reported that oncology practitioners acknowledge not discussing sexual health issues with patients during the course of treatment; Matzo and Hijjazi (2009) reported that most hospice nurses do not ask their patients about issues related to sexuality or intimacy. Patients, however, do want the opportunity to discuss their sexual needs with their health care provider (Matzo & Hijjazi, 2009). Assessing the patient’s needs by obtaining a sexual history and asking pertinent sexual health questions are important in identifying sexual health needs (Matzo & Hijjazi, 2009; Matzo, Whalen, & Pope, 2013; Rice, 2000b).

The most effective communication is that which addresses the needs of the patient at each stage of the illness. The initial assessment should begin when the diagnosis is made and continue throughout the disease process (Mercadante, Vitrano, & Catania, 2010). Communication with cancer patients is a dichotomous situation, in that the disease is both life-threatening and potentially treatable or curable (Epstein & Street, 2007), which creates much uncertainty and stress for the patient. Little is known about patient preferences for information, particularly the timing of communicating certain types of information (Tulsky, 2005).

## ■ SEXUAL ANATOMY AND FUNCTIONING

Any aspect of a terminal or life-threatening disease (either from the disease itself or from the treatment) can impact sexual health. For example, women with advanced ovarian cancer (OVCA) have an overall survival rate of 15% to 30% (Armstrong et al., 2006) and approximately 70% will have a recurrence at some point (American Cancer Society [ACS], 2012). This translated into approximately 21,650 new cases of OVCA in 2008 and 15,520 women dying from the disease (Karlan, 2008).

Women diagnosed with breast or gynecological cancers undergo physical and emotional challenges throughout their treatment and recovery (Arnold, Bachmann, Rosen, Kelly, & Rhoads, 2006; Carpenter, Andersen, Fowler, & Maxwell, 2009; Dorjgochoo et al., 2010; Jones et al., 2006; Parker, Baile, de Moor, & Cohen, 2003; Schover, 2006). Up to 90% of women with these cancers have sexual dysfunction as a side effect of treatment (Barton, Wilwerding, Carpenter, & Loprinzi, 2004; Barton et al., 2007; Carter, Stabile, Gunn, & Sonoda, 2013; Lee et al., 2011), which includes decreased libido (Barton et al., 2007), pain with intercourse, trouble reaching orgasm, and vaginal dryness (Barton et al., 2007). Treatments such as radiation, chemotherapy, and surgery improve the cancer prognosis (Salani et al., 2011); however, these treatments result in estrogen depletion, which negatively impacts vaginal health (Barton et al., 2007; Dorjgochoo et al., 2010; Frumovitz et al., 2005; Jones et al., 2006; Simonelli, Fowler, Maxwell, & Andersen, 2008; Wilmoth, 2006). The resulting vaginal atrophy is manifested by vaginal dryness, discomfort, burning, itching, and dyspareunia; this is a significant problem for female cancer survivors who cannot use estrogen as a treatment intervention (Lee et al., 2011), because even low-dose estrogen can have effects on tissue outside of the vagina and thus present cancer-related health risks. Regardless of interest in sexual activity, vaginal health maintenance is vital for all women; vaginal dryness and/or pain can increase anxiety about gynecological appointments, make examinations painful, and potentially result in noncompliance with follow-up care (Carter et al., 2013). Persistent vaginal dryness has been correlated with depression, decreased QOL (Barton et al., 2004; Lee et al., 2011; Panjari & Davis, 2011; Tan, Bradshaw, & Carr, 2012), and increased distress (Carter et al., 2013).

Gynecological cancer therapies exacerbate and accelerate processes seen in normal vaginal aging and are associated with sexual dysfunction (Derzko, Elliott, & Lam, 2007; Jones et al., 2006; Schover et al., 2011). Hormonal therapies such as selective estrogen receptor modulators and aromatase inhibitors



decrease vaginal pH and lubrication (Derzko et al., 2007; Schover, 2008) and increase vasomotor symptoms and dyspareunia (Derzko et al., 2007; Schover, 2008; Schover et al., 2011). Surgery is also associated with sexual dysfunction, vaginal atrophy, and dyspareunia (Derzko et al., 2007; Jones et al., 2006; Schover et al., 2011). Psychological distress that the patient or her partner experiences during diagnosis and treatment of malignancy can also impair a healthy female sexual response cycle (Krychman et al., 2006). Patients undergoing radiation therapy reported more sexual dysfunction than surgical patients (Frumovitz et al., 2005), and more vaginal atrophy and postcoital bleeding than surgical patients (Jones et al., 2006). Radiation therapy decreases blood flow to the vaginal mucosa, which leads to chronic pelvic fibrosis that may persist for up to 2 years after treatment (Jones et al., 2006).

The vaginal microenvironment affects flora, pH (Linhares, Summers, Larsen, Giraldo, & Witkin, 2011; Oakley, Fiedler, Marrazzo, & Fredricks, 2008; Tomás, Bru, & Nader-Macias, 2003; Valore, Park, Igteti, & Ganz, 2002), and hormonal health (Chen et al., 2003; Derzko et al., 2007; Moalli, Debes, Meyn, Howden, & Abramowitch, 2008), as well as sexual health (Carpenter et al., 2009; Derzko et al., 2007; Frumovitz et al., 2005; Linhares et al., 2011; Schover, 2008; Schover et al., 2006; Tunuguntla & Gousse, 2006). Dyspareunia in women with vaginal atrophy is mainly attributed to the lack of vaginal lubrication (Harmanli & Jones, 2010). Lack of vaginal lubrication is also associated with decreased antimicrobial activity (Linhares et al., 2011; Tomas et al., 2003; Valore et al., 2002). Vaginal dryness, vaginal atrophy, lack of elasticity, dyspareunia, and sexual dysfunction can be improved with the use of vaginal lubricants (Derzko et al., 2007; Frumovitz et al., 2005; Harmanli & Jones, 2010; Schover, 2008). Counseling women in the use of vaginal lubricants has been shown to be one of the most effective methods of offsetting the negative effects of cancer treatments (Derzko et al., 2007; Schover, 2006; Schover et al., 2011; Table 6.1).

Risk factors for poorer sexual functioning after being diagnosed with gynecological cancer are age, treatment, time since treatment, poor self-esteem/body image, physical symptoms, poor performance status, depression, and anxiety (Stead & Stead, 2004). Ovarian cancer is usually treated with a hysterectomy, oophorectomy, and chemotherapy, which can all affect sexual functioning, through a decrease in estrogen production (resulting in vaginal atrophy, loss of vaginal lubrication, and hot flashes) and loss of sexual interest resulting from changes in body, fatigue, and nausea (Carmack Taylor, 2005; Stead, 2004).

Women with OVCA above the age of 55 years have reported distress over the loss of reproductive

potential (Stewart, Wong, Duff, Melancon, & Cheung, 2001). In one study, more than 50% of the women with ovarian cancer reported moderate to severely worsened sexual function (Stewart et al., 2001). Carmack Taylor, Basen-Engquist, Shinn, and Bodurka (2004) compared the sexual health of women with breast cancer, ovarian cancer, and postmenopausal women and concluded that low desire, vaginal dryness, and dyspareunia are more common and severe in women with ovarian cancer (Carmack Taylor et al., 2004). Another study documented that, for women with ovarian cancer, their satisfaction with care for sexual problems was lower than with their overall cancer care (Lindau et al., 2007).

Treatments for cervical cancer result in numerous issues that can affect sexual health. Surgery shortens the proximal vagina by one third and radiation therapy causes stenosis, drying, and dyspareunia, which typically result in the need for the use of dilator and estrogen creams in order to help prevent vaginal atrophy (Suhatno, 2000). Hormonal changes often result from surgical removal of the ovary or irradiation without protecting the ovary (Suhatno, 2000). Psychological issues related to the diagnosis that can have a negative impact on sexual health are fear of the disease and metastasis, vaginal odor, and the perception of some women that they “deserve” the disease because of their previous sexual behavior (Suhatno, 2000).

Alterations in sexual health for men primarily focus on erectile function. Cancer treatments can interfere with erection by damaging a man's pelvic nerves, pelvic blood vessels, or hormone balance. Prostate, bladder, and colon cancer are often treated with radiation to the pelvis. The higher the total dose of radiation and the wider the section of the pelvis irradiated, the greater the chance of an erection problem later (ACS, 2013). Erectile dysfunction (ED) is a common complication of diabetes (secondary to autonomic neuropathy, vascular insufficiency, or psychological factors) in at least half of men above the age of 50 years (Kaye & Jick, 2003). ED can also occur as a result of cardiovascular disease, hypertension, hypercholesterolemia, smoking, and the abuse of drugs (including alcohol).

After standard radical prostatectomy, between 65% and 90% of men will become impotent, depending on their age. If the surgeon does not remove or damage the nerves on either side of the prostate, the impotence rate drops to between 25% and 30% for men below 60 years. The impotence rate is higher for men above 70 years, even if nerves on both sides are not damaged or removed (Zippe & Pahlajani, 2008). After surgery, there is no ejaculation of semen, although even with a dry orgasm, the sensation should still be pleasurable (ACS, 2013).

TABLE 6.1 Products to Maintain Vaginal Hydration

**Vaginal moisturizers versus vaginal lubricants:**

■ **Vaginal moisturizer:** Nonhormonal, over-the-counter, and usually water-based products intended to be used several times a week routinely for overall vaginal health or comfort, regardless of sexual activity. The goal of a vaginal moisturizer is to moisturize the vaginal mucosa for overall comfort. Sometimes a vaginal moisturizer is sufficient for vaginal comfort in regular daily life and for sexual intercourse. Moisturizers restore fluid into the cells of the vagina and vaginal pH. Some female cancer survivors need vaginal moisturizers up to three to five times per week. Most of these moisturizers are gels administered with a tampon-like applicator or as a vaginal suppository. Regular usage is the key to moisturizing performance.

■ **Vaginal lubricant:** Usually a liquid or gel (water-based), but may also be oil- or silicone-based. A vaginal lubricant is meant to be applied around the clitoris and labia minora and inside the vaginal entrance to minimize dryness and pain during sexual activity. Optimally, the lubricant should be applied to both partners' genitals prior to vaginal penetration, to minimize friction and irritation.

Base Types	Brands	Pros	Cons
<b>Water-Based</b>			
<b>Vaginal moisturizers</b>	Replens Lubrin Luvana	Vaginal moisturizers are applied 2–5 times per week (ideally every 3–4 days) and need not be applied directly prior to sexual activity.	It is possible that a moisturizer alone is insufficient to reduce frictional pain, so during sexual activity a vaginal lubricant may also be needed.
<b>Vaginal lubricants</b> Thin lubricants	K-Y Liquid Astroglide	All water-based vaginal moisturizers and lubricants share the following advantages: <ul style="list-style-type: none"> <li>■ Reactivate with a few drops of water</li> <li>■ Latex compatible</li> <li>■ Clear and nonstaining</li> <li>■ Clean up easily with soap and water</li> <li>■ Absorb into skin and evaporate</li> <li>■ Water-based lubricants are typically recommended by doctors and health care workers, and they are the kind usually made available for free at sexual health clinics</li> </ul>	All water-based vaginal moisturizers and lubricants share the following disadvantages: <ul style="list-style-type: none"> <li>■ Not compatible with sex acts in water</li> <li>■ May contain glycerin and ingredient that turns into sugar in the vagina; thus, may contribute to yeast infection in persons who are susceptible</li> <li>■ Tend to dry out</li> <li>■ May leave sticky residue (especially if high glycerin)</li> <li>■ Can be dispersed in water (not good for bathtub sex, etc.).</li> </ul>
Medium/thick lubricants (thick lubricants are especially helpful when a higher level of lubrication is needed, such as when pain is still experienced while using regular lubricants)	Slippery Stuff Liquid Silk (glycerin-free) ID Lube Astroglide Maximus Probe (paraben-free)		
Other	Maximus (glycerin-free) Sliquid H2O (glycerin-free) Hathor (paraben-free) Aphrodisia (paraben-free) BioGlide (contains carrageen, which has been shown to protect against HPV and other viruses) K-Y Slide + E, K-Y Liquidbeads		



Oil-Based				
Vaginal lubricants	Élégance (only FDA-approved for vaginal application) Vitamin E (puncture caplet and use as suppository) MenoMoist Mineral oil Coconut or olive oil Vegetable shortening	Durable Decreased vaginal bacteria/yeast in testing	Should not be used with condoms (breaks down latex)	
Silicone-Based				
Vaginal lubricants	Eros Lubricant Liquid Silver Wet Platinum Lubricant I-E Velvet Lubricating Liquid	Always slippery and never tacky feeling A little goes a long way More durable Does not dry up as quickly as other formulations Not absorbed by the skin Good for water use ("water play") Does not change the pH of the vagina (no yeast concerns) Washes away with soap and water Great for full body massage	May leave oily residue on sheets, but will wash out Not recommended with silicone-based toys Usually a little more expensive	
<b>Ingredients to consider staying away from include the following:</b> Glycerin or sorbitol may contribute to yeast infections in those susceptible. Petroleum-based lubricants may increase risk of vaginal infection and also tend to have an unpleasant odor and may damage latex condoms (possible pregnancy or sexually transmitted diseases). Perfume, spermicide, or other additives that may be irritating.				

Source: Carter, Goldfrank, & Schover, 2011.

One observational study of ED after chemotherapy for non-small cell lung cancer documented that ED was present for 8 months before the cancer was diagnosed (Hejna, Fiebigler, Reiter, & Raderer, 2001). Hedestig, Sandman, and Widmark (2003) conducted in-depth interviews with seven men (aged 62–69 years) with localized prostate cancer (Hedestig et al., 2003). These men reported that they were not as sexually active as before diagnosis, experienced reduced potency and diminished pleasure in ejaculation, felt their manhood was restricted, and had difficulty discussing sexual problems. Men will sometimes report pain in the genitals during sex, or if the prostate gland or urethra has been irritated by cancer treatment, ejaculation may be painful (ACS, 2013).

Sexual health can be impacted by almost any life-threatening illness and should be assessed in every patient. Assessing a patient's functionality and desire for sexual activity is a necessary skill for HCPs (Redelman, 2008). Asking if there are concerns regarding sexual health may be a good first question in determining how a person's diagnosis, subsequent treatment, or current health has affected him or her. Not all patients will report concern regarding their sexual health function; in these cases, no further intervention is needed except to encourage the patient to let the HCP know if the situation changes. Not asking about sexual health may be more comfortable for the HCP, but will not further the sexual health care of the patient.

Information to help patients with these concerns primarily focuses on preventing pain (genital and nongenital) during sex and interventions to help men get and keep an erection. In 1998, the Food and Drug Administration (FDA) approved sildenafil citrate (Viagra) to treat impotence. Oral phosphodiesterase-5 (PDE-5) inhibitors help achieve an erection by increasing blood flow to the penis. About half of men with impotence due to medical (rather than psychological) problems are helped to some extent by these drugs (ACS, 2013). Nerve damage from prostate cancer treatment may not respond as well to these drugs as some other physical causes of impotence.

Other treatments for ED include intracavernosal injection therapy and surgically implanted penile prostheses. Noninvasive drug-free solutions such as vacuum erection devices (VEDs) remain popular despite the availability of PDE-5 inhibitors. The VED is easy to use and a man can produce an erection in 2 to 3 minutes (which can increase spontaneity and patient compliance). Vacuum therapy uses a tube or cylinder that is placed over the penis. A vacuum is then applied to increase penile blood flow (due to negative pressure). The use of the VED has expanded; VED is now also used in combination with PDE-5 inhibitors in penile rehabilitation following radical prostatectomy and radiation therapy (Zippe & Pahlajani, 2008).

Pain during intercourse is one of the most common sexual problems for women (genital or nongenital) and can interfere with the feeling of pleasure during sex (Carter, Goldfrank, & Schover, 2011). Nongenital pain may be secondary to soreness in one arm after a radical mastectomy or tingling and numbness of the hands and feet after chemotherapy. The ACS (2009) makes the following recommendations for patients to overcome nongenital pain. First, plan sexual activity for the time of day they feel the least pain. If using pain medicine, take it an hour before planned sexual activity so it will be in full effect during sex. Second, find a position for touching or intercourse that puts as little pressure as possible on the sore areas, support the sore area, and limit its movement with pillows. If a certain motion is painful, choose a position that does not require it or ask your partner to take over the hip movements during intercourse. Encourage patients to talk to their partner regarding what brings the most pleasure. Third, encourage the patient to focus on feelings of pleasure and excitement; with this focus, the pain may fade into the background (ACS, 2013; Patient Handout, Table 6.2).

Genital-related pain results from a loss of vaginal lubrication and vaginal muscle scarring and shortening. Cancer treatments and menopause typically decrease the amount of vaginal lubrication. Common brands of lubricants include K-Y Jelly and Astroglide. Some products include herbal extracts (such as aloe or lavender) that can cause irritation or allergic reactions, and warming gels can cause a burning sensation in some people. Replens and K-Y Liquibeads are vaginal moisturizers that can be used two or three times a week to help keep the vagina moist and at a more normal acid balance (pH). The effects of these products last longer than those of lubricants, and they can be purchased without a prescription. Lubrin and Astroglide Silken Secret are other moisturizers that are marketed as longer lasting than typical lubricants (ACS, 2013). Luvena Prebiotic Vaginal Moisturizer and Lubricant is relatively new and the first paraben- and glycerin-free product, which utilizes bioactive enzymes naturally found in the vagina (<http://www.luvencare.com/index.html>). Table 6.1 lists the pros and cons of each form of lubricant.

Vaginal dilators are often used after radiation to the pelvis, cervix, or vagina. It is recommended that vaginal dilators be offered to patients undergoing radical radiotherapy to the pelvis as part of their cancer treatment, together with support and education. A vaginal dilator is a tube of plastic or rubber used to dilate the vagina and to help women learn to relax the vaginal muscles (ACS, 2013). Regular intercourse and/or the use of vaginal dilators may minimize stenosis. Vaginal changes develop over time, even up to 5 years after treatment, and may affect sexual function, sexual health, and well-being in addition to



**TABLE 6.2 BE-FEMM: A Straightforward Approach to Maintaining Sexual Health****Ways to Help Yourself**

There is a lot you can do to take back and maintain your sexual health, even while undergoing active treatment. The biggest thing to remember is to be proactive—prevention is much easier than treatment down the road. Although you may not feel up to activities now, you want to keep your body primed for the future!

Just remember BE-FEMM!

**B**lood Flow  
**E**njoyment  
**F**lora  
**E**lasticity  
**M**uscle Tone  
**M**oisture

**Blood Flow**

All over your body, healthy tissue needs good blood flow. When your body has had medical or surgical interventions, this becomes even more important. Menopause, whether it occurs naturally over time, or surgically, comes with its own challenges. As estrogen declines, your vagina will begin to atrophy. (Yes, the fun of being a woman goes on and on!) This atrophy can cause thinning of the tissues, shrinkage, and decreased lubrication of the vaginal walls. As if cancer is not enough fun all in itself, chemotherapy is the gift that keeps on giving, because it can also directly affect your vaginal health. Not only will all this lead to painful intercourse, but it will also make you more vulnerable to yeast infections. All of these things can be improved with one simple idea—keeping the blood flowing to this area.

Now, the good news. There are some easy (and even fun) things you can do to help improve your blood flow. Stimulation is a great way to accomplish this. You can use vibrators, or even a willing partner if you have one “handy” (no pun intended). You may want to explore a product called an Eros therapy device. This little gem was created to treat female sexual dysfunction. It is a gentle vacuum that will help to restore blood flow to the clitoris and genitalia. (Not a Hoover—I said a gentle vacuum!) The by-product of increased blood flow in this area can be increased orgasms, improved vaginal lubrication, and overall sexual satisfaction. (Let’s hear it for overall sexual satisfaction—yeah!) The Eros therapy device is available by prescription only (for more information, visit [www.eros-therapy.com](http://www.eros-therapy.com)).

**Enjoyment**

Now, with all that increased blood flow, you will be ready to move on to the best advice anyone can give: Please enjoy your sexual relations! Wait, finish reading first! That is better. Unfortunately, some women suffered from unsatisfying sexual relations before they ever got cancer. If you have been suffering in silence all these years, you just got your get-out-of-jail-free card. Look at cancer treatment as an opportunity to make some changes that will make the rest of your life richer, happier, and more rewarding—especially in the orgasm department (which is a very nice department).

If you have been shy about telling your partner what you need or have been afraid of bruising a delicate ego by saying that you have been less than satisfied, this gives you an excuse to open a new dialogue, and try some new techniques. Sometimes, since women can participate in sex without actually feeling any desire for sex, lazy partners can forget to give you adequate stimulation for the encounter to be enjoyable for you. If you are using an Eros therapy device or a vibrator, you may find yourself already stimulated, and take that opportunity to seek out your partner and initiate things yourself. Some guys need that little blue pill to get in the mood—why should not we have some help if we need it? Do not miss the opportunity to tell your partner what you need in the way of stimulation, where your pleasure spots are, and what makes you feel good.

Arousal is very important. We all know it is the key to proper lubrication, but did you know that there are also physical changes to your vagina when you are aroused? It actually causes your vagina to widen and elongate, which will greatly decrease any discomfort you may experience. An interesting note: In most women, the vagina elongates toward the back, but after hysterectomy, it will tend to elongate up more toward your stomach. This may change the angle that feels comfortable to you. The good old missionary position may become uncomfortable. Do not give up on intimacy, just roll over. You may prefer the angle from the back or even the side. Be adventurous. There is nobody there to see you but your partner, and believe me, they will want to work to make it better for you. You may also want to try a position where you can control the depth and the angle, such as from the top.

**Flora**

Now, a word from our sponsor, *Lactobacillus acidophilus*. Kidding. That is the name of the bacteria in “live-culture” yogurt. Did you know that it also plays a starring role in your vagina? That is the busy little bacterium that keeps yeast infections at bay. It occurs naturally in a healthy vagina, and keeps the environment acidic so that harmful bacteria are not happy there. Those little lactobacilli need estrogen too, so menopause can affect the balance of flora in your vagina, which can lead to an increase in urinary tract and yeast infections. You can help maintain the acidic environment in your vagina by using a product such as Luvena.

(continued)

**TABLE 6.2 DE-FEMM: A Straightforward Approach to Maintaining Sexual Health (continued)****Elasticity**

This is a fancy word that means keeping your tissues elastic, or stretchy. Remember, “use it or lose it” should be your mantra for elasticity. Tissue atrophy due to reduced estrogen can be minimized by maintaining good blood flow and by stretching the tissues. It is much easier to keep your vagina healthy than it is to return it to good health. It is not that easy with cancer treatments, surgical recovery, and what not to keep a good handle on your vaginal elasticity. (You do not get up every day and say, “Another day, another chance to keep my vagina elastic!”) But it is important. If you have not been using these tissues in a while, you may need to start small. Literally. A vaginal dilator can be helpful, and is available online (through regular websites like Amazon.com). You can ask your doctor for a prescription if you prefer. A dilator is just a plastic device with tips of various sizes. Used in combination with moisturizers and lubrication, your vaginal opening can gradually be expanded by their use. This can restore natural elasticity and improve comfort in sexual activities (a place where you really want some comfort).

If you experienced sexual pain before your cancer diagnosis, your body may have developed a pain response that can include spasms of the muscles near your vaginal opening, which you should discuss with your doctor.

**Moisture**

Of all the difficulties you face with the decline of estrogen, the loss of natural lubrication is one of the most heartbreaking. The good news is that with diligent treatment, you can easily improve the symptoms. Once again, your recovery and sexual health are completely in your control. The first component in treatment is a moisturizer. This is a product that you apply at least weekly. It is best to choose a product free of fragrances, dyes, or paraben, and one that is pH-balanced. Replens is available through your doctor; a new product called Luvena has recently become available that is not only moistening, but has a prebiotic formulation that will help you to keep your new commitment to balanced flora!

The second component goes hand-in-hand with moisture, and that is lubrication. You would add lubrication anytime you use dilators, vibrators, or share that magic moment with your partner. You can choose K-Y Jelly, Astroglide, or other lubricating products. See Table 6.1 for pros and cons of each form of lubricant. Each person's preference is different. Fortunately, trying out different lubricants is a really fun way to spend time with that special someone, so have fun, experiment, and decide what is best for you. The important thing to remember is that your lack of natural moisture should not be interpreted as a lack of desire for your partner, or as any kind of hindrance to wonderful love making!

**Muscle Tone**

The last key to maintaining good sexual health is muscle tone. Perhaps you tried Kegel exercises when you were pregnant? If not, you are about to gain an important tool in keeping both your vagina and your urinary tract healthy. Kegel exercises strengthen the muscles of your pelvic floor (the muscles that support your bladder, bowels, and the walls of your vagina). These muscles are vitally important for maintaining bladder and bowel continence as well as your ability to enjoy sexual relations for the rest of your life. Good. Now that I have your attention, let us try to isolate those pelvic floor muscles.

- Try to tighten the muscles you use to stop urinating, without moving the muscles of your abdomen, legs, or buttocks. If you have trouble isolating them, practice stopping and starting your urine flow (while on the toilet). Once you have found the correct muscles, go on to the next step.
- Squeeze these muscles for about 3 seconds. Then relax them for 3 seconds.
- Do 10 to 15 repetitions at a time, at least three times a day. If you have trouble remembering to do them, associate them with something you do several times a day anyway. Before you start breakfast, lunch, and dinner, try a set of Kegel exercises. If you are doing them right, nobody can tell you are doing them (unless you giggle).

There is a lovely side benefit to doing Kegel exercises. They may actually increase your sexual pleasure. Many women find that they have stronger orgasms after training these muscles, due to increased blood flow and stronger muscle contractions. The increased blood flow to your vaginal area not only speeds healing but also increases sensitivity, and that has got to be a good thing. Your partner will also enjoy the increased muscle tone in your vagina, and if you want to really blow his mind, try doing your Kegel exercises during sex. He will love it.

**Getting Help**

Finally, cancer does not occur in a vacuum. We are all balancing other concerns in our lives, and cancer is just one more challenge added to your particular mix. Sexual health can be impacted by treatments, by other medical conditions, past abuse or trauma, situational or emotional stress, and relationship issues (or by the absence of a relationship). Instead of letting these concerns cripple this important area of your life, use your cancer as a catalyst to make positive changes in your physical and emotional health! In other words, “Feel positive about your sexuality.”



**TABLE 6.3 Using a Vaginal Dilator**

Minimum use is three times weekly for an indefinite time period. Dilators can be used in conjunction with sexual intercourse to achieve a combined frequency of vaginal dilation.
Find a private and comfortable place where you can relax and use the dilator. Dilators can be used in the shower or bath if this provides privacy, and/or allows you to relax your pelvic floor muscles. If you wish, your significant other can also be encouraged to be involved.
A water-soluble lubricant should be placed on the dilator and around the entrance to the vagina prior to insertion. Some doctors will prescribe Premarin cream to be used for this purpose.
There are various positions in which to use the dilator: you can either lie down on your back with knees slightly apart and bent, or stand with a leg raised on the side of the bed or bath to insert the dilator.
Inserting the dilator into the vagina requires firm, gentle pressure. Insert it as deeply as is comfortable, without forcing the dilator. Do pelvic floor exercises during insertion.
Once the dilator is inside the vagina, it should be moved in a forward and backward motion, then a left to right motion. If possible, gently rotate the dilator using the handle.
Your doctor will fit you for the dilator. It is usual to start with the smallest size and progress to the largest (size 4) in the days or weeks following treatment, as it is comfortable.
When the dilator is in as far as possible, leave it in your vagina for about 15 minutes. You can pass the time by reading, watching TV, listening to music, or even talking over the phone. If the dilator slips out, gently push it more deeply into your vagina.
The dilator should be removed slowly rotating it in clockwise or anticlockwise movements.
Vibrators may also be used in conjunction with the use of dilators.
Slight vaginal blood loss and blood staining are not uncommon when using dilators. If you experience heavy vaginal bleeding or pain, contact your doctor.
When you remove the dilator, wash it with a mild soap and water. Be sure to rinse all the soap off so no film is left to irritate your vagina the next time you use it.

Source: National Forum of Gynaecological Oncology Nurses. Best practice guidelines on the use of vaginal dilators in women receiving pelvic radiotherapy, 2005.

causing considerable distress for a woman and her partner (Denton et al., 2000). Dilators work best when used early after radiation or surgery to prevent vaginal shrinkage prior to the vaginal tightening. If a woman goes for many months without a sexual relationship, it is very important that the dilator be used to keep the vagina in shape (ACS, 2013). Instructions for use are found in Table 6.3.

A systematic review of the unmet needs of cancer patients by Harrison et al. (2009), categorized them into 11 domains. Results of the 94 articles reviewed documented that the sexuality domain was the least frequently investigated in these articles or reports. These authors note that unmet sexual health needs were prevalent during the treatment phase, with little resolution in the posttreatment and survivorship phases (Harrison et al., 2009). This issue was further documented by Blagbrough (2010) in a literature review regarding barriers to assessment of sexual needs. Health care providers appear to assume that sexual desire is no longer present at the PC stage. Many HCPs may avoid discussing patients' sexual

needs because of their low level of comfort with the subject. It was also noted that health care professionals make assumptions based on culture, gender, and sexual orientation; a significant factor was highlighted in a review by Harding, Epiphaniou, and Chidgey-Clark (2012), who reviewed needs, experiences, and preferences of sexual minorities for end-of-life (EOL) care. Fear of discrimination may prevent disclosure of sexual identity to health care professionals. Health care professionals should provide services in a non-judgmental manner, allowing the patient to address sexual needs at the EOL (Matzo et al., 2013).

### ■ OVERCOMING CHALLENGES TO SEXUAL HEALTH AND BODY IMAGE

An urostomy, colostomy, or ileostomy presents challenges to maintenance of sexual health. Patients should be reminded to empty the bag and check the seal to reduce the risk of the bag leaking during intercourse. A special small-sized ostomy pouch could be worn during

sexual activity, or if a two-piece system is used, the pouch can be turned around on the faceplate so that the emptying valve is to the side. If an elastic support belt is worn on the faceplate, it can be tucked into the belt during sex or the bag can be taped to the body. Some people may be more comfortable wearing a T-shirt to cover the appliance. To reduce rubbing against the appliance, encourage patients to choose positions that will keep their partner's weight off the ostomy. If the patient prefers to be on the bottom during intercourse, he or she can put a small pillow above the ostomy faceplate so that the partner can lie on the pillow rather than on the appliance. Those with a colostomy may be able to plan sexual activity for that time of the day when the colostomy is not usually active. The colostomy can be irrigated, and a stoma cover or a small safety pouch can be used during sex (ACS, 2013).

Some cancers of the head and neck are treated by surgery to remove part of the bone structure of the face. These are public scars that can be devastating to self-image. Surgery on the jaw, palate, or tongue can also change the way that people are able to talk. Advances in facial replacement devices and plastic surgery include ears and noses that can be made out of plastic, tinted to match the skin, and attached to the face (ACS, 2013). These interventions can have a tremendous impact on body image and self-esteem.

Treatment for primary tumors of the bone typically includes amputation of the limb, which can result in the need to make some changes during intercourse. Wearing a prosthesis during sex may help with positioning and ease of movement, but the straps that attach it can get in the way. Without a prosthesis, the partner with an amputation may have trouble staying level during intercourse; pillows can be used to support the body. Phantom limb pain can interfere with sexual desire and distract a person during sex; the patient should be encouraged to take pain medications prior to intercourse.

One quantitative study focused on sexuality in patients with advanced cancer ( $n = 65$ ), assessing their feelings and attitudes regarding sexuality after diagnosis (Vitrano et al., 2011). Over half of the patients still felt attractive despite their diagnosis, and almost half felt that sexuality was important for their psychological well-being; however, only 7.6% were still sexually active. Most patients expressed the importance of communicating their sexual needs with experienced professionals (Vitrano et al., 2011).

## ■ MASTURBATION

Another component of the Sexual Health Model is masturbation. A stratified probability sample survey of the British general population, aged 16 to 44 years,

was conducted from 1999 to 2001 ( $n = 11,161$ ) using face-to-face interviewing and computer-assisted self-interviewing (Gerressu, Mercer, Graham, Wellings, & Johnson, 2008). These data were used to estimate the population prevalence of masturbation, and to identify sociodemographic, sexual behavioral, and attitudinal factors associated with reporting this behavior. Seventy-three percent of men and 36.8% of women reported masturbating in the 4 weeks prior to interview. Among both men and women, reporting of masturbation increased with higher levels of education and social class and was more common among those reporting sexual function problems (Gerressu et al., 2008).

For women, masturbation was more likely among those who reported more frequent vaginal sex in the last 4 weeks, a greater repertoire of sexual activity (such as reporting oral and anal sex), and more sexual partners in the last year. In contrast, the prevalence of masturbation was lower among men reporting more frequent vaginal sex. Both men and women reporting same-sex partner(s) were significantly more likely to report masturbation (Gerressu et al., 2008). Terminally ill people are likely no different than the general population regarding their masturbation habits. PC practitioners should routinely ask their patients if anything interferes in their ability to masturbate and then work with the patient to correct the problem if it is identified.

## ■ SEXUALITY, INTIMACY, AND RELATIONSHIPS

Lemieux, Kaiser, Pereira, and Meadows (2004) conducted a qualitative study that assessed patient perspectives regarding sexuality in PC. Overall, it was found that emotional connections took precedence over the physical expressions of love, although sexuality was considered to be very important even during the final stages of life. Barriers to sexual expression included lack of privacy, shared rooms, staff interruptions, and single beds. The patients generally agreed that holistic PC should include the impact of illness on sexuality, and these patients would prefer to be asked about these issues in a sensitive manner (Lemieux et al., 2004).

Cort et al. (2004) noted that sexuality is an integral aspect of PC, and couples are often seeking assistance and support in their relationship. Often, PC patients will feel decreased self-control and a decreased sense of self (Cort et al., 2004). Despite age or physical health, people remain sexual beings and sexual health needs do not end when a person is diagnosed with a terminal illness (Farrell & Belza, 2012). With respect to relationships, partners often fear causing pain to their significant other. In addition, other problems can occur, such as concerns



about body image, altered sexual function, relationship issues, feelings of loss and grief, and bereaved partners (Cort et al., 2004).

In a study of women with advanced cancer by Stafford and Judd (2010), their partners expressed unchanged interest in intimacy and sexual relations. Fifty percent remained sexually active and were satisfied with their sexual function. There was no significant difference in the reported satisfaction of either partner in the relationships.

Issues related to gay, lesbian, bisexual, and transgender (GLBT) individuals at the EOL were explored by Rawlings (2012), who reported that these persons experienced barriers to sexual health secondary to negative social attitudes. Some subjects reported that they felt pressure to disclose their sexual orientation, while others indicated that they have specifically sought out “gay friendly” practitioners (Rawlings, 2012).

Physical barriers to sexual health reported by hospice patients included fatigue, pain, and issues of incontinence (Park et al., 2009). A documented environmental barrier was the use of hospital beds for hospice patients (Bowden & Bliss, 2009). Hospital beds facilitate personal care and comfort, but they can interfere with intimacy and sexual expression.

## ■ INTIMACY AND LATE-STAGE DISEASE

Vitrano et al. (2011) conducted a study with 65 men and women with advanced cancer to assess their feelings and attitudes on sexuality after diagnosis. Results of the study concluded that more than half of the patients still felt attractive despite their diagnosis, and almost half felt that sexuality was important for their psychological well-being. However, only 7.6% were still sexually active for various reasons. Most patients expressed the importance of communicating their sexual needs with experienced professionals (Matzo et al., 2013).

De Vocht, Notter, and de Wiel (2010) interviewed cancer patients and their partners as well as health care professionals working in oncology and PC. Several themes arose from the interviews, including the need for closeness or intimacy with the partner (Palm & Friedrichsen, 2008); changes in sexual expression (Lemieux et al., 2004); and increase in QOL through sexual expression. Interviews highlighted barriers to sexual expression for hospice patients, such as hospital beds (Palm & Friedrichsen, 2008), which prevent partners from sleeping together; and institutionalized care, which can eliminate privacy and interfere with sexual expression (Lemieux et al., 2004). Gilley (1988) presented a case summary in which the HCP was involved in the care of a married couple where one of the partners was terminally ill. The case

illustrated changes in the quality of the sexual relationship between partners and provided examples of expressions of intimacy in the marriage dyad. The HCP's assessment of the sexual health needs of the patients and their partners was the focus of Wells's 2002 study. Interviews with practitioners documented their self-reported difficulty in asking patients questions about sexual health, even though they acknowledge that asking would facilitate patients' ability to express their needs (Wells, 2002). Professionals who addressed patients' sexual concerns reported that patients were not offended by this discussion (de Vocht et al., 2010; Matzo et al., 2013).

## ■ ADOLESCENTS

Adolescents in PC share the same developmental tasks as other adolescents. Cognitive thinking is required to link consequences to behavior. However, in early adolescence, thinking is predominately concrete (e.g., only the here and now are relevant) and long-term consequences are not considered. Abstract thinking begins in middle adolescence; at this point, consequences of behavior begin to be considered. However, under times of stress, the middle adolescent often reverts to concrete thinking (Wisnieski & Matzo, 2013). Late adolescence is a time when abstract thinking begins to mature and the consequences of behavior are considered (Fonseca & Greydanus, 2007; Shafii & Burstein, 2009). Adolescents are striving for autonomy and peer support. Issues of romance, sexuality, and reproduction are normal developmental tasks and should be given attention by health care providers. Life-threatening illness may also compromise the development of body image and self-esteem (Knapp, Quinn, Murphy, Brown, & Madden, 2010).

## ■ CONCLUSION

There is a significant lack of literature addressing issues of sexuality in PC that can guide evidence-based practice. Sexual health is a broad concept made up of multiple facets such as sexual desire, self as a sexual being, sexual orientation, sexual lifestyles, and relationships (Fogal, 2012). Intimacy, closeness, communication, and emotional support affect all facets of sexuality. Qualitative data obtained from patients reveal that they would prefer to be asked about these topics and given the opportunity to discuss them (Matzo & Hijjazi, 2009).

However, it appears that practitioners in PC settings often feel uncomfortable or unqualified to discuss these issues with their patients. Some suggestions for these practitioners to assist in overcoming their discomfort

include role-playing, increasing their knowledge base regarding these issues, and ignoring their discomfort and opening the discussion to better meet the patient's needs. If practitioners pursue sexual assessment with patients, they will quickly experience the gratitude patients express for having the chance to discuss their concerns, and soon their discomfort with the topic will disappear. The practitioner can include general sexual health questions (e.g., "Many patients have concerns about their sexual health and relationships; do you

have any concerns about your sexual health?") and proceed to more specific questions about opportunities for physical intimacy, touching, kissing, holding hands, "snuggling," massage, oral sex, and masturbation (e.g., "Are you able to pleasure yourself sexually" or "Are you able stimulate yourself to release sexual tension?") as examples of physical intimacy that promotes feelings of love and connectedness. In this way, PC clinicians can further enhance the QOL for their patients throughout the trajectory of their illness.

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### CASE STUDY Conclusion

At the end of my visit to Sally, I asked her what she wanted from her health care practitioners regarding sexual health promotion. She said "Don't just focus on my body, but help with the relationship." Sally died 4 days later.

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## Evidence-Based Practice

Farrell, J., & Belza, B. (2012). Are older patients comfortable discussing sexual health with nurses? *Nursing Research*, 61(1), 51–57.

### Background

Sexual health is an important component of quality of life, yet practitioners do not routinely query older adults about their sexual health concerns.

### Purpose

The aims of this study were to ascertain whether older adults (a) have unanswered questions about their sexual health; (b) are asked about their sexual health, disease, and medications that could affect their sexual health and their knowledge of STDs and HIV/AIDS; (c) would welcome a care provider initiating a conversation about their sexual health; and (d) would be comfortable discussing their sexual health with a nurse. The study also aimed to identify some barriers to discussing sexual health for the older adult.

### Method

This was a quantitative cross-sectional study that used a 24-item investigator-developed survey, which was distributed to residents of retirement communities and participants in fitness classes in the Puget Sound, Washington region.

### Results

A total of 101 surveys were completed. The participants' average age was 81 years (range = 62–96 years); 70.3% were women ( $n = 71$ ) and 25.7% were men ( $n = 26$ ). When asked what sexual health meant, participants said it encompassed physical pleasure with one's partner or oneself and psychological and physiological health; 47.1% ( $n = 41$ ) want to be asked about their sexual health at their health care visit, and 86% ( $n = 78$ ) reported that they were comfortable discussing sexual health and



were not embarrassed or offended. Male respondents preferred discussing with a physician rather than a nurse (52.2%,  $p = .01$ ,  $n = 12$ ), whereas female respondents indicated that they were willing to talk with either a physician or a nurse (56.9%,  $p = .01$ ,  $n = 37$ ).

### Implications

The results of this study have the potential to inform treatment approaches, improve outcomes, and enhance communication with older adults regarding issues of sexual health that affect quality of life.

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# Family Caregivers

## C H A P T E R

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### KEY POINTS

- Structure, function, and symbolism are categories of family definitions, but each family is individually defined by its members.
  - Family caregivers and care recipients are a unit when considering care requirements and care planning.
  - Careful, systematic family assessment should be the basis and foundation of all care planning for palliative care.
  - Caregivers can easily become overwhelmed by the magnitude of the work that their commitment entails, leading to depression and self-neglect.
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### CASE STUDY

DL is a 54-year-old man with chronic heart failure (CHF), emphysema, and prostate cancer. He lives alone in a house his family has owned for generations. His wife died 4 years ago in a motor vehicle crash while riding with DL when he was drunk. He has four daughters and a son who does not speak to him regularly or see him except at holiday family gatherings, although they live in the same city. His great niece and her family live three houses from his and she checks on him daily, cleans his house, and takes him to medical appointments. He was just discharged from the hospital after an exacerbation of his CHF caused by not taking his medication. He has been showing signs of cognitive dysfunction with mild memory loss. He becomes short of breath with minimal activity but refuses to give up his home or live with his niece.

DL's niece is 32 years old and is a single parent with children who are 3 months, 6 years, and 16 years old. She works as a school crossing guard mornings and afternoons. The 16-year-old has a learning disability and is frequently in trouble in school for acting out and has anger management problems. He spends a lot of time hanging out with friends who are gang members (although he is not a member of any gang) and uses drugs from time to time. He has started stealing from her purse to buy marijuana.

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Family is a cultural, legal, sociological, and individually defined concept. Traditional definitions of family include what we refer to as a *nuclear family*—father, mother, and one or more children—or the *extended family*, which adds grandparents, aunts, uncles, and cousins. In the past, people grew up and lived in the same community for a lifetime in close contact with the extended family. Family members counted on each other for help and there were usually one or more family members who were available to help with the care of children or older family members. This was usually a wife, mother, or grandmother. After World War II, more and more women moved into the workforce and a new child care industry emerged. Social forces, such as job mobility, air travel, increased divorce rate, and an increase in cohabitation accelerated during the 1960s and 1970s. This impacted the definition of family as well as the availability of family members to help each other. At the same time, advances in health care extended the longevity of humans and also increased the number of people living with chronic diseases that were untreated or unheard of when early definitions of family were valid. Today, blended families (those with parents who are on their second or more marriages with children from previous marriages), as well as single-parent families, same-sex families, and families that are childless by choice, are more common. Extended families are either smaller or in other locations and often have limited contact with each other. Legal and illegal immigration has led to communities of immigrants who often live in fear, do not speak English, and delay seeking health care because of limited resources or fear of deportation. Homelessness and the increase in the numbers of people with mental illness who are living on the street, without support or family connections, have created another community with family-like qualities and characteristics. These forces, along with the aging of the population and the incidence of chronic illness, have increased the need for family caregivers and have changed the way we look at family and their involvement in the care of individuals (Marriage and Family Encyclopedia, 2013a).

What, then, is a family? There are several definitions of family in the literature, which describe the structure, function, interactions, and symbolism of family. First, structural definitions describe families based on membership and relationships between family members. An example of a structural definition is “a single mother and her children” or “first-degree relatives including step- and half-siblings which would include a father, a mother, and all their collective children.”

A second category for defining families is functional. If the function of families is to procreate and then nurture children, then the evaluation of family function is based on the number of children born

within the family. A third category of definitions of family is based on interactions within the family group. It looks at the role of family members, the power dynamics within the family, and how family members relate to each other. This broad category would allow for work groups or societies to be defined as family as well as a group of friends who view themselves as a family. Finally, the last category of family definitions is a symbolic representation and is defined by the individual family using stories or symbols to define membership. For example, the family may be defined through its generational ownership of a home in which many family members have been born and died. The symbolic representation of a family may be also related to a piece of land on which the family has lived or worked for decades and which represents the experience and livelihood of the whole family.

Most definitions are a combination of these categories. Merely naming the members of a family related by blood or legal arrangements such as adoption or guardianship is most common, but it defines only a portion of groups who define themselves as families based on their purpose and relationship. Friends and domestic partners, with or without legal sanctions, often depend on each other and have the expectations of loyalty, love, and help that one usually associates with blood relatives and nuclear families. Even though they are in decline, the nuclear and to some extent the extended family of history are considered the norm legally, politically, and in medicine, where patient’s families are included in the plan of care.

Beyond the definitions of families, there are many different types of family groups based on the structure, including (a) couples without dependent children (married and unmarried); (b) single-parent families (never married, separated, divorced, or widowed); (c) two-parent family household (not married, first marriage, and second/third marriage); (d) foster families; (e) adoptive families; (f) “estranged” families; (g) nuclear, extended, or multigenerational households; (h) none/one/two/multiple wage earners; and (i) “living apart together” families (Policy Institute for Family Impact Seminars, 2013).

Furthermore, the type of family groups varies by socioeconomic characteristics, such as education level and income level. In addition, there are seven family life cycle stages, which vary by family type, including families with (a) no children; (b) infants and preschoolers; (c) school-age children; (d) adolescents; (e) no dependent children; (f) elderly dependents; and (g) elderly dependents with adult children/grandchildren. Family groups also vary by the ethnic/racial/cultural background, religion, informal social network (friends and neighbors), relationships to community, and the area where they live (rural/suburban/urban).



Myths about the family may influence health professionals' assumptions, beliefs, and expectations related to families and their interactions within the health care system. The first is that family members have the best interests of the patient at heart. This assumption persists in the face of reports of domestic violence, elder and child abuse, neglect, and abandonment. The second is the belief that children, especially female children, have an obligation to care for chronically ill or impaired family members, especially elders. This expectation is shared by family, medical providers, and cultural norms, irrespective of the burden this places on the individual, without recognition of their additional or other family and work responsibilities.

## ■ DEFINITIONS OF FAMILY AND FAMILY CAREGIVERS

A family may be defined as two or more people who have come together for a self-defined common purpose (U.S. Census Bureau, 2001). That purpose may be procreation, or it may be simple companionship, but the persons involved view themselves as family with the bonds and responsibilities one expects from a family of origin or blood relationship.

A family caregiver is a member of this family who has chosen or who has been designated as the caregiver for one or more family members who cannot manage normal activities of daily living without help. There are several definitions of family caregivers, such as:

- Family (informal) caregiver is any relative, partner, friend, or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an individual with an acute, chronic, or disabling condition. These individuals may be primary or secondary caregivers and live with, or separately from, the person receiving care (Family Caregiver Alliance, 2013b).
- Family caregiver is someone who is responsible for attending to the daily needs of another person. He or she is responsible for the physical, emotional, and often financial support of another person who is unable to care for himself or herself due to illness, injury, or disability (National Alliance for Caregiving, 2013).

There are also formal caregivers who are either trained and paid for their services, or who serve as volunteers to care for an individual. Formal caregivers may include home health care providers, or other professionals or volunteers (Family Caregiver Alliance, 2013b; National Alliance for Caregiving, 2013).

## Statistics Related to Family Caregiving

The statistics related to family (informal) caregivers are staggering. The National Alliance for Caregiving, in collaboration with AARP (2009), reported that there are 65.7 million people in the United States who have served as informal caregivers, with approximately 30% of people reporting that they have cared for at least one family member. Two thirds of family caregivers are female (66%), with their average age being 48 years. Family caregivers' age increases with the age of the care recipient. With a decline among younger caregivers (under the age of 50 years), there is an increasing number of family caregivers aged 50 to 64 years, and an even larger increase in the number of caregivers aged 75 years or older. One third of family caregivers is responsible for the care of two or more family members (34%). Due to issues of caregiver burden, a family member may also hire paid help from aides, housekeepers, or other people. The use of paid care increases with the caregiver's household income. More specifically, 48% of caregivers whose income is over \$100,000 use paid help. Approximately, 74% of caregivers live with their loved one or within 20 minutes from their home. Among caregivers who do not live with their loved one, 76% report that they visit at least once a week.

The typical recipient of care is a relative (86%), including a parent (36%) or a child (14%). The recipients of care are primarily female (62%), with an average age of 61 years. Seventy percent of the care recipients are adults, 50 years or older. Alzheimer's disease or dementia is the main problem for caregivers (12% in 2009). The average period of caregiving is 4.6 years, with 31% of caregivers caring for their loved one for more than 5 years. The average caregiving time is 20.4 hr/week; female caregivers spend more caregiving time than do male caregivers (21.9 vs. 17.4 hr/week; National Alliance for Caregiving in collaboration with AARP, 2009).

According to the Family Caregiver Alliance (2013c), it has been estimated that 70 million people will be older than 65 years in 2030. Therefore, family caregivers increasingly provide care for aging adults, most of whom have one or more chronic conditions and who wish to remain in their own homes and communities. Other family caregivers belong to the "sandwich generation," which describes the caregivers sandwiched between caring for elder parents or grandparents and spouse and/or children. These caregivers are pulled in both directions and often have jobs as well as these dual responsibilities (DeRigne & Ferrante, 2012). They are typically middle-aged women who are overwhelmed with responsibility and acting out of duty who, in the process of caring for

others, neglect themselves because there are competing demands for their time.

## The Burdens and Benefits of Family Caregiving

Family caregivers provide extraordinary uncompensated care, which is physically, emotionally, socially, and financially demanding. The caregiving role begins immediately at the point of diagnosis and continues over the illness trajectory (Given, Given, & Sherwood, 2012) with needs for information about care and the patient's disease (Stajduhar et al., 2010) that vary at the different stages of the patient's illness (Williams & McCorkle, 2011). Caregivers are a conduit for information between patient and provider and between provider and extended family (Given et al., 2012). Family caregivers experience the physical strain associated with caregiving and also fear, confusion, powerlessness, and a sense of vulnerability despite their attempts to maintain normalcy (Funk et al., 2010). They often suffer from symptoms of anger, depression, and anxiety and may become demoralized and exhausted (Zarit, 2006). Caregivers themselves may experience increased physical illness, exacerbation of comorbid conditions, and a greater risk of mortality (Family Caregiver Alliance, 2006a). Burdens associated with caregiving include time and logistics; lost wages or leaving the workforce entirely, which have severe economic implications; and personal, social, and institutional impact (Hudson, 2004; Papastavrou, Charalambous, & Tsangari, 2009; Rabow, Hauser, & Adams, 2004; Sherwood et al., 2008; Wong, Liu, Szeto, Sham, & Chan, 2004). Sources of anxiety for caregivers include residual effects of disease and treatment on the patient, altered household and family roles, and altered communication patterns (Given, Sherwood, & Given, 2011). As caregivers abandon leisure, religious, and social activities, there is heightened marital and family stress, with long-term consequences for the health and the stability of the family (Dumont, Dumont, & Mongeau, 2008).

Changes experienced across the cancer trajectory require caregivers to adapt to a new set of patient needs, creating increased distress, yet caregivers are reluctant to identify themselves as individuals who need support (Funk et al., 2010). This reflects the concept of "legitimacy of needs" or "caregiver ambivalence," as they do not want to "bother" professionals or shift attention away from the patient (Funk et al., 2010). According to Clukey (2007), some caregivers hide their feelings of loss and grief from the patient, which is termed "bridled grief" (Houldin, 2007; Wells, Cagle, Bradley, & Barnes, 2008). This may lead to increased caregiver isolation, depression,

and overwhelming misery when caregivers finally allow themselves to grieve (Moules, Simonson, Prins, Angus, & Bell, 2004; Wells et al., 2008).

The level of stress/strain varies by disease. Previous studies reported that caregivers of dementia patients have higher levels of burden than other caregivers due to long care hours and physically demanding caregiving (Alzheimer's Association, 2007; Brodaty & Donkin, 2009). A study by Kim and Schulz (2008) compared the strains of family caregivers of cancer patients to the strain of caregivers of frail elders and dementia and diabetes patients. The results showed that the level of strain of caregivers of cancer patients is greater than the strain on caregivers of elderly or diabetes patients, but cancer caregiver strain is comparable to that of caregivers of dementia patients. Cancer and dementia caregivers reported higher levels of physical strain, emotional stress, and financial hardship as a result of providing care. The crucial difference between cancer and dementia caregivers was that cancer caregivers are distressed by various acute medical conditions experienced by the patient, such as surgery, chemotherapy, or radiation therapy (e.g., catheter care or managing patients' emesis or fatigue symptoms), whereas caregivers of dementia patients are distressed by the significant cognitive and functional decline and behavioral changes, which progress over time.

Beyond the burden of family caregiving, the strengths of the family should also be considered. The strengths of individuals and families provide a means of dealing with any problems that exist (*Marriage and Family Encyclopedia*, 2013b). The goal should be to identify strong families and provide means of developing the strengths of families. Table 7.1 describes the qualities that reflect strength in families. The focus on family strengths does not deny the presence of stressors or perceived burden; rather, it offers a focus on the resources any family can develop and use in reducing the stressors or negative effects associated with caregiving.

Given the strengths of the family, the caregiving experience may also have benefits and possible gains, but yet these outcomes have received little attention. Health professionals should not miss the opportunity to identify the rewards and satisfaction that come from the role of caregiving. Studies indicate that family caregivers describe feelings of satisfaction for a job well done, particularly when the patient appreciates and acknowledges their care and support, and when caregivers feel a sense of giving back for the care and nurturing they themselves received (Narayan, Lewis, Tornaotre, Hepburn, & Corcoran-Perry, 2001; Neff, Dy, Frick, & Kasper, 2007; Schumaker, Beck, & Marren, 2006). The positive aspects associated with the caregiving experience may act as a buffer against overwhelming burden and traumatic grief (Hudson, 2004; Gaugler et al., 2005; Salmon, Kwak, Acquaviva,



**TABLE 7.1** Qualities of Strong Families

Categories	Qualities
Appreciation and affection	<ul style="list-style-type: none"> <li>■ Caring for one other</li> <li>■ Friends with one another</li> <li>■ Respect for individuality</li> <li>■ Playfulness</li> <li>■ Humor</li> </ul>
Positive communication	<ul style="list-style-type: none"> <li>■ Sharing feelings with one another</li> <li>■ Giving compliments to each other</li> <li>■ Avoiding blame</li> <li>■ Being able to compromise</li> <li>■ Agreeing to disagree</li> </ul>
Spiritual well-being	<ul style="list-style-type: none"> <li>■ Hope</li> <li>■ Faith</li> <li>■ Compassion</li> <li>■ Shared ethical values</li> <li>■ Oneness with humankind</li> </ul>
Commitment	<ul style="list-style-type: none"> <li>■ Trust among members</li> <li>■ Honesty among members</li> <li>■ Dependability</li> <li>■ Faithfulness</li> <li>■ Sharing</li> </ul>
Spending Time together	<ul style="list-style-type: none"> <li>■ Sharing quality time in great quantity</li> <li>■ Good things take time</li> <li>■ Enjoying each other's company</li> <li>■ Simple good times</li> <li>■ Sharing fun times</li> </ul>
Able to cope with stress and crisis	<ul style="list-style-type: none"> <li>■ Adaptability</li> <li>■ Crises are seen as challenges and opportunities</li> <li>■ Growing together through crises</li> <li>■ Openness to change</li> <li>■ Resilience</li> </ul>

Source: Adapted from DeFrain, J. (2007). *Marriage and Family Review* 41(1/2): 1–10.

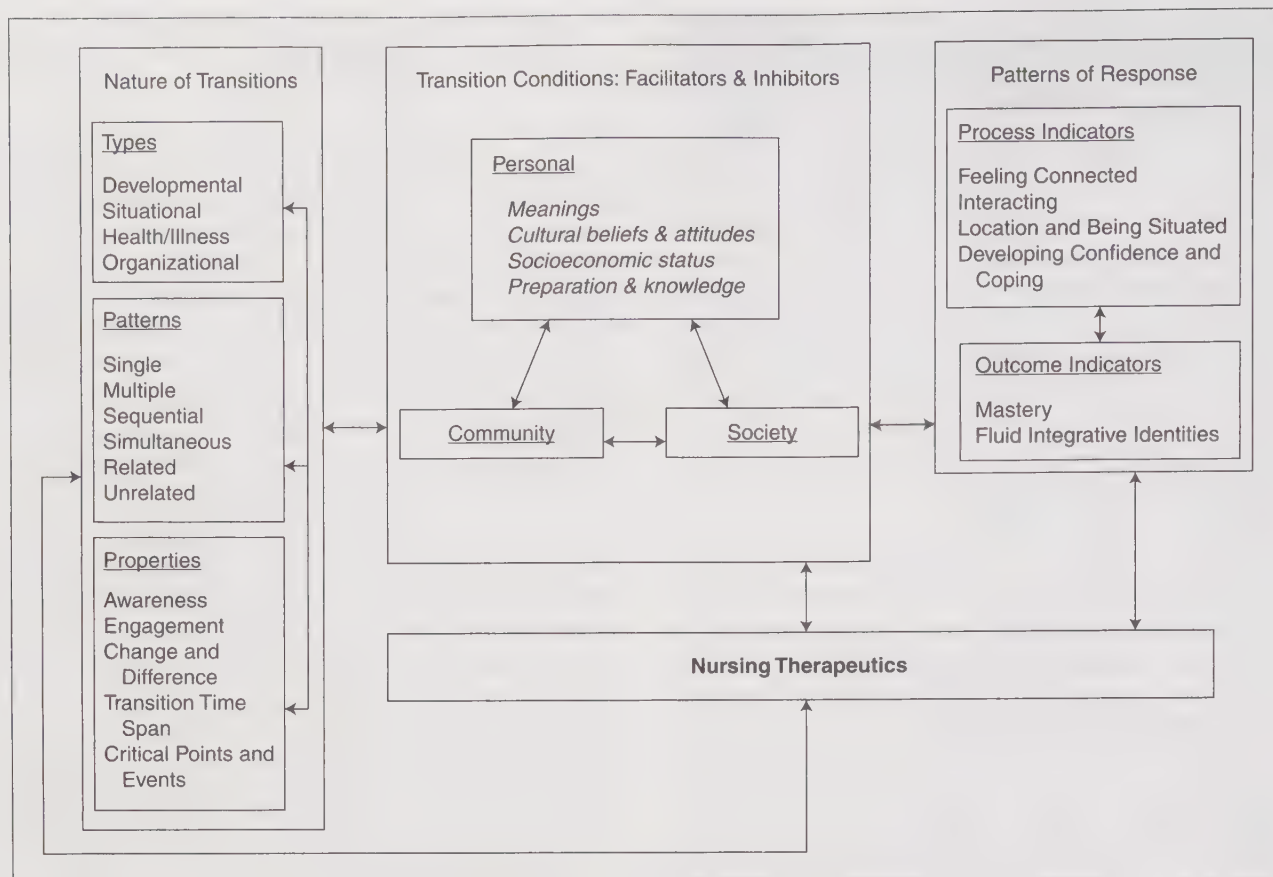
Brandt, & Egan, 2005; Steel, Gamblin, & Carr, 2008). Caregivers who have a positive approach to life are better able to cope with caregiving demands (Stajduhar, Martin, Barwich, & Fyles, 2008) and are motivated to maintain their caregiving role (Higginson & Gao, 2008). Based on a comprehensive review of quantitative studies, Stajduhar and colleagues (2010) reported posttraumatic growth of bereaved caregivers. Funk et al. (2010) reported a sense of existential meaning associated with the caregiver role, including a sense of pride, esteem, mastery, and accomplishment. Using the Stress Process Model, Haley, LaMonde, Han, Burton, and Schonwetter (2003) examined spousal caregiver depression and life satisfaction in the hospice setting, learning that caregivers found meaning and benefits in caregiving, and suggesting the need to identify caregivers at high risk and protective factors that could be incorporated into interventions.

## THEORETICAL FRAMEWORKS RELATED TO FAMILY CAREGIVING

How, then, does one begin to assess and intervene in ways that support relationships in which both the patient and the caregiver benefit? A number of theoretical frameworks have been proposed to evaluate the burdens, benefits, transitions, and associated factors related to family caregiving (Bahr & Bahr, 2001; Fletcher, Miaskowski, Given, & Schumacher, 2012; Grey, Knafl, & McCorkle, 2006; Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000; Pearlin, Mullan, Semple, & Skaff, 1990; Tsai, 2003).

Traditional family theories are useful for examining family structure and dynamics. From a family theorist perspective, Bahr and Bahr (2001) have also explored the concept of self-sacrifice and its meaning in the family. They take this stance in opposition to the theories that stress individual choice and the primacy of the individual over the good of the whole. They assert that self-sacrifice in the interest of the family should be viewed as a virtue. Bahr and colleagues go on to say that love is the motivation for this sacrifice, manifested as selfless generosity, and contrasts with the ethic of personal gain that characterizes social relationships outside the family.

It is understood that serious, acute, chronic, or life-threatening illnesses are disruptive not only to the patient but also to his or her family. Illness creates change with respect to daily adjustments and associated transitional events (Schumacher & Meleis, 1994). Caregiver transitions encompass the patient's phases of illness (Northouse, Katapodi, Schafenacker, & Weiss, 2012), and the caregiver's response to associated deficits, physical/emotional needs, and symptoms (Steinhauser, 2005). Transition is a concept of interest to nurse researchers, theorists, and health care providers (Schumacher & Meleis, 1994). Meleis et al. (2000) have developed a middle-range theory of transition, which asserts that clients in transition tend to be more vulnerable to risks that may in turn affect their health. Uncovering these risks may be enhanced by understanding the transition process (Meleis et al., 2000, p. 12). Major concepts of this transition theory (Figure 7.1) include the nature of transitions, including the types, patterns, and properties of transitions; transition conditions (facilitators and inhibitors) within the context of persons, community, and society; patterns of response in terms of process and outcome indicators; and nursing therapeutics. More specifically, the types of transitions include developmental, situational, health/illness, and organizational. The pattern of transitions can be single, multiple, sequential, simultaneous, or related/unrelated. The properties of transition experiences include awareness, engagement, change and difference, transition time span, and critical



**FIGURE 7.1** Transitions: A middle-range theory.

Source: Reprinted from *Advances in Nursing Science* (2000), with permission from Lippincott Williams & Wilkins.

points and events. Meleis et al. (2000) also identifies the transition conditions, particularly the importance of personal meaning and cultural beliefs and attitudes, as well as the families' socioeconomic status and their preparation and knowledge of the illness trajectory. For families, they contend that the patterns of response are measured by the process indicators of feeling connected, interacting, location and being situated, and developing confidence and coping ability. Furthermore, the outcome indicators are measured as mastery and having fluid integrative identities.

The Pearlin Stress Process Model (Pearlin et al., 1990) and a number of stress and coping measures are compared and are helpful for researchers studying stress in caregivers. The Pearlin Stress Process Model addresses the experience of caregiving, including caregiving transitions and transitional events that occur from one phase of the illness trajectory to another and one stage of caregiving to another. According to Pearlin et al. (1990), the five major components in caregivers' experience include:

1. **Caregiving context**—which includes sociodemographic characteristics of the caregiver and patient, history of illness, history of caregiving, and caregiving living arrangements.
2. **Primary stressors**—which arise directly from the patient's illness and may include the patient's symptoms or impairment, ability to perform activities of daily living, cognitive deficits, and behavioral problems as well as stressors such as caregiver burden, including the subjective assessment of the degree to which the caregiver perceives each event, including possible role overload (time and energy), role captivity (trapped in the caregiving role), and the loss of relationship (lost intimacy and social exchanges).
3. **Secondary stressors**—which include tension and conflict in maintaining other roles in one's life such as employment and family relationships; interruptions in other areas of the caregiver's life; intrapsychic strains, which erode a person's self-concept in terms of caregiver mastery and competence.
4. **Resources**—which include social, financial, and internal resources, which increase the ability to manage stressful experiences, including social support, which involves information, material, or financial support; as well as instrumental and emotional support and perceived gains from the caregiving experience.
5. **Outcomes**—which include positive and negative health outcomes related to caregivers.

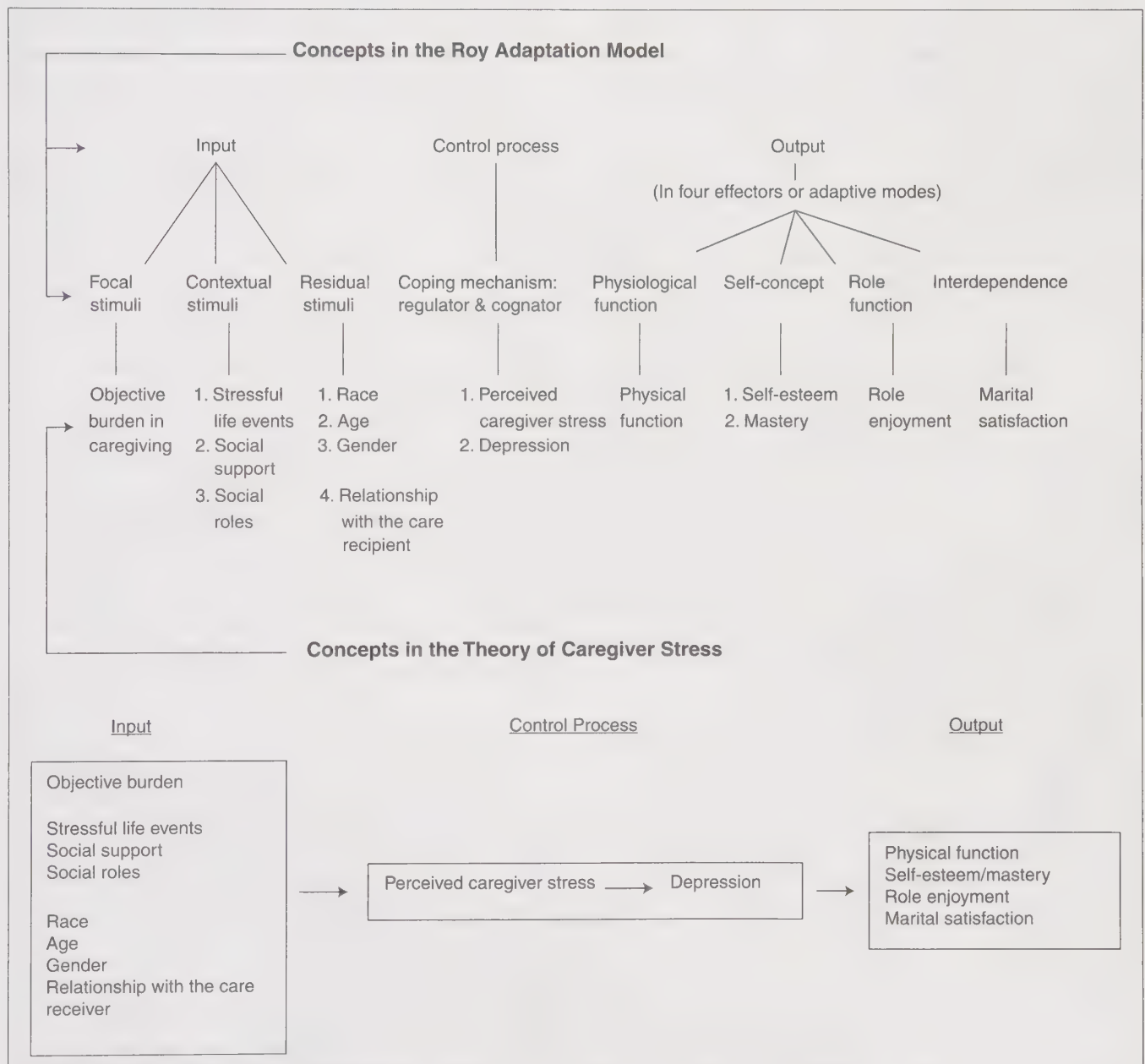


In addition, Tsai (2003) has developed a middle-range theory of caregiver stress. This theory reflects the philosophy and framework of the Roy Adaptation Model. The model and subsequent theory is an input/process/output type model (Figure 7.2) that makes four assumptions:

1. Caregivers can respond to change.
2. Caregivers' perceptions determine how they respond to environmental stimuli.

3. Caregivers' adaptation is a function of their environmental stimuli and adaptation level.
4. Caregivers' effectors (e.g., physical function, self-esteem/mastery, role enjoyment, and marital satisfaction) are results of chronic caregiving (Tsai, 2003, p. 139).

Fletcher et al. (2012) developed a theoretical model of cancer family caregiving experience. They reviewed the cancer family caregiving literature, analyzed the



**FIGURE 7.2** A middle-range theory of caregiver stress.

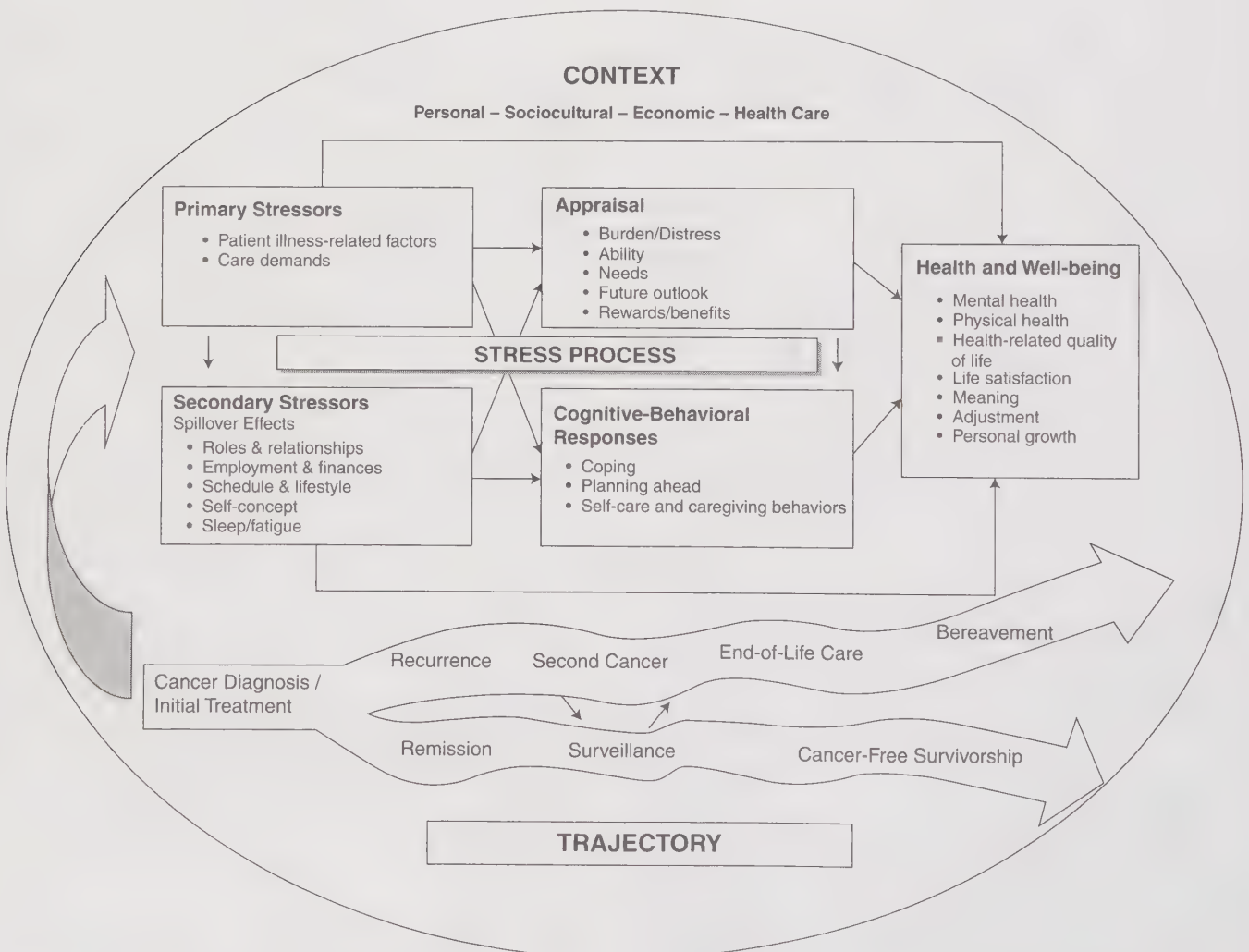
Source: Reprinted from *Nursing Science Quarterly* (2003), with permission from Elsevier.

concepts and variables used in previous studies, and synthesized the concepts and variables into a conceptual model. Major elements of this model include the following (Figure 7.3):

1. The stress process: primary stressors, secondary stressors, cognitive appraisal, cognitive and behavioral responses, and outcomes of health and well-being
2. Contextual factors: personal, sociocultural, economic, health care
3. Cancer diagnosis/initial treatment
  - a. Remission surveillance cancer-free survivorship
  - b. Recurrence or second cancer end-of-life (EOL) care bereavement

These models have yet to be tested sufficiently to determine their usefulness in studying caregivers and caregiving behaviors and stresses. Family caregiving is a complex experience, as it involves many

dynamics and processes, including the dynamics of family relationships in interaction with the community and health care professionals. The family history, social evolution, legal challenges, and medical advancements make decision making a challenge. How then should we view the commitment of family caregivers? Are the activities and responsibilities of caregiving a reflection of duty and obligation derived from social and cultural definitions of family? Or are the activities and responsibilities acts of love and self-sacrifice manifesting generosity? Are these activities and responsibilities merely the reflection of social, political, economic, and medical realities of the time and environment in which we live? Given current economic conditions, is there an ethical or legal obligation of society to care for people in our communities who have progressive, serious, or chronic illnesses or disabilities? If so, how should the limited resources be distributed to support family caregivers?



**FIGURE 7.3** The cancer family caregiving experience.

Source: Reprinted from the *European Journal of Oncology Nursing* (2012), with permission from Elsevier.



## ■ FAMILY ASSESSMENT

The Family Caregiver Alliance sponsors the National Center on Caregiving. The National Center on Caregiving aims to advance the development of high-quality, cost-effective policies and programs for caregivers and serves as a central resource on caregiving and long-term care issues (Gibson, Kelly, & Kaplan, 2012). It sponsors programs for family and informal caregivers as well as providers working toward family-oriented care that makes provider, family, or patient partnerships a reality. Speaking at the National Consensus Development Conference for Caregiver Assessment (Family Caregiver Alliance, 2006b), Levine (2006) spoke poignantly about her caregiver experiences. Her experiences were very different but equally descriptive of the world in which caregivers must navigate. Ahern points out how quickly one's life can change forever and how critical it is to have the support of family and of professionals in the care of loved ones; but ultimately, it is an act of love to care for them (Ahern, 2006). Levine's experience was different in many ways and she vividly describes the cruel and insensitive approach of the nurses and therapists at the rehab facility where her brain-injured husband was living (Levine, 2006). She felt there was no assessment of her commitment, resources, or willingness to be a part of her husband's care although she was doing all she was able to do. She experienced only judgment, which was rigid and subjective as providers sought a "one-size-fits-all" approach to family caregiving. Her experience is validated in many ways by Thomas (2006), whose young husband's brain injury changed both their lives forever.

One thing is clear; a "one-size-fits-all" approach to caregivers is at best not helpful and at worst destructive. How, then, does one begin to take a more helpful path in working out the partnership that will lead to successful caregiving for both the caregivers and the care recipients? That path begins with a caregiver assessment.

Caregiver well-being is closely linked with patient well-being (Kutner & Kilbourn, 2009; Porter, Keefe, Garst, McBride, & Baucom, 2008). As patient performance status and quality of life (QOL) decline over time (Velanovich & Wollner, 2011), the caregiver has negative outcomes, such as distress, which may limit optimal care (Northouse et al., 2012). Furthermore, without family caregivers, patients' survival rates are lower and societal costs for EOL care are greater (Zarit, 2004); furthermore, as patients are placed in more costly hospital or nursing home settings (Funk et al., 2010), they may also be at risk of poor care or neglect (Bee, Barnes, & Luker, 2009; Maslow, Levine, & Reinhard, 2006). Steinhauser (2005) wrote,

Characterizing the progression of multiple dimensions of patients' and caregivers' experience from serious illness through death of the patient by appropriate assessment and design is crucial to evidence based understanding of improving end-of-life care and to capturing transitions and end of life trajectories. (p. 40)

Despite the National Consensus Guidelines for Quality Palliative Care (National Consensus Project, 2013), which emphasize that both patient and family should be viewed as the unit of care, health professionals do not always intervene in ways that take caregiver well-being into account. Caregivers' needs remain unaddressed and resources are limited, fragmented, and discontinuous (Gaugler et al., 2005). Health risks and serious illness of caregivers may increase their utilization of health care resources, contribute to escalating health care costs (e.g., heart disease, hypertension, impaired immune function), and place caregivers at greater risk of cancer, infection, and other problems (Family Caregiver Alliance, 2006a). Many caregivers exhibit impaired cognitive functioning (McGuire et al., 2000) and either meet *DSM-IV* criteria for, or are being treated for, psychiatric problems (Vanderwerker, Laff, Kadan-Lottick, McColl, & Prigerson, 2005). Given the physical and emotional stress, including sense of burden, depression, and a sense of abandonment by professionals, a comprehensive family assessment and targeted interventions are critical to promoting the health and well-being of individuals of a family as well as the family as a unit (Given et al., 2004).

### Caregiver assessment is

a systematic process of gathering information about a caregiving situation to identify the specific problems, needs, strengths, and resources of the family caregiver, as well as the ability of the caregiver to contribute to the needs of the care recipient. (Feinberg & Hauser, 2012; AARP Fact Sheet, p. 1)

A systematic approach to assess the caregiver's needs and strengths is crucial in order to develop a dyadic intervention that can improve the outcomes for both caregivers and care recipients (Feinberg & Hauser, 2012).

Guberman (2006) discusses the nature of caregiver assessment from a clinical rather than a research perspective. Caregiver assessment can be used for determining eligibility for services, identifying unrecognized or subtle problems that might not be obvious although they have great impact on successful

caregiving. The assessment process also promotes the development of a strong, trusting, therapeutic relationship between the clinician and the caregivers. Guberman goes on to describe a number of tools that can be used to perform the assessment, although little consensus exists as to the best strategy. Guberman proposes that the best assessments include all family caregivers and the care recipient. Both the patient and the family should be assessed by the same provider in the caregivers' home or another place where they both feel safe to discuss all aspects of the situation.

The advantages of assessment as a basis for accessing services and support are many, but Zarit (2006) outlines some specific benefits. The first is the identification of problems in the caregiving context, including but not limited to interpersonal, relational, situational, or financial problems. These problems

may be potential or actual. The second advantage is the clarification of roles and responsibilities for family members, as well as a clear estimate of the resources available versus those that will be needed to provide the required care. The assessment can also reveal actual and potential stresses that can be dealt with before they reach overwhelming and incapacitating anxiety and depression leading to despair. The structured and systematic nature of a good caregiver assessment assures that important aspects will not be missed and that a comprehensive approach is implemented.

The Family Caregiver Alliance website is a treasure of resources for caregivers and providers alike. A section on caregiver assessment provides a comprehensive plan for how and when to perform the assessment and the content (Table 7.2).

**TABLE 7.2 Family Caregiver Assessment Domains, Constructs, and Questions**

Domain	Constructs	Questions
Context	<ul style="list-style-type: none"> <li>■ Caregiver relationship to care recipient</li> <li>■ Physical environment (home, facility)</li> <li>■ Household status (number in home, etc.)</li> <li>■ Financial status</li> <li>■ Quality of family relationships</li> <li>■ Duration of caregiving</li> <li>■ Employment status (work/home/volunteer)</li> </ul>	<ul style="list-style-type: none"> <li>■ What is the caregiver's relationship to the care recipient?</li> <li>■ How long has he or she been in the caregiving role?</li> <li>■ Does the care recipient live in the same household with the caregiver?</li> <li>■ Is the caregiver married? Have children?</li> <li>■ How many people live in the caregiver's household?</li> <li>■ Are other family members or friends involved in the care?</li> <li>■ Is the caregiver currently employed? Full-time or part-time?</li> <li>■ What is the caregiver's household income?</li> <li>■ How would the caregiver rate his or her quality of family relationships?</li> </ul>
Caregiver's perception of health and functional status of care recipient	<ul style="list-style-type: none"> <li>■ Activities of daily living (ADLs: bathing, dressing) and need for supervision</li> <li>■ Instrumental activities of daily living (IADLs: managing finances, using the telephone)</li> <li>■ Psychosocial needs</li> <li>■ Cognitive impairment</li> <li>■ Behavioral problems</li> <li>■ Medical tests and procedures</li> </ul>	<ul style="list-style-type: none"> <li>■ Can the care recipient carry out ADLs without assistance (bathing, dressing, etc.)?</li> <li>■ Can the care recipient carry out IADLs without assistance (managing finances, shopping)?</li> <li>■ Can the care recipient administer his or her medications correctly?</li> <li>■ Does the care recipient have any mental health diagnoses or emotional problems?</li> <li>■ Does the care recipient have any memory loss or cognitive impairment?</li> <li>■ Does the care recipient have any behavioral problems? How frequently do they occur and how much do they bother or upset the caregiver when they happen?</li> <li>■ What medical tests and procedures have been done or are needed?</li> </ul>
Caregiver values and preferences	<ul style="list-style-type: none"> <li>■ Caregiver/care recipient willingness to assume/accept care</li> <li>■ Perceived family obligation to provide care</li> <li>■ Culturally based norms</li> <li>■ Preferences for scheduling and delivery of care and services</li> </ul>	<ul style="list-style-type: none"> <li>■ Is the caregiver willing to assume the caregiver role? Is the care recipient willing to accept care?</li> <li>■ Does the caregiver feel he or she is obligated to provide care?</li> <li>■ What types of care arrangements are considered culturally acceptable for this family?</li> <li>■ What are the caregiver's (and the care recipient's) preferences for the scheduling and delivery of care and services?</li> </ul>

(continued)



**TABLE 7.2** Family Caregiver Assessment Domains, Constructs, and Questions (continued)

Domain	Constructs	Questions
Well-being of the caregiver	<ul style="list-style-type: none"> <li>■ Self-rated health</li> <li>■ Health conditions and symptoms</li> <li>■ Depression or other emotional distress (e.g., anxiety)</li> <li>■ Life satisfaction/quality of life</li> </ul>	<ul style="list-style-type: none"> <li>■ How does the caregiver rate his or her own health? Does the caregiver rate his or her health better, about the same, or worse than it was 6 months ago?</li> <li>■ Does the caregiver have any health conditions or symptoms?</li> <li>■ How often in the past 6 months has the caregiver had a medical exam or received treatment for physical health problems from a health care practitioner?</li> <li>■ How often does the caregiver feel anxious or angry when he or she is around the care recipient?</li> <li>■ How often does the caregiver get a full night's sleep?</li> <li>■ How does the caregiver rate his or her life satisfaction and/or quality of life?</li> </ul>
Consequences of caregiving	<ul style="list-style-type: none"> <li>■ Perceived challenges               <ul style="list-style-type: none"> <li>– Social isolation</li> <li>– Work strain</li> <li>– Emotional and physical health strain</li> <li>– Financial strain</li> <li>– Family relationship strain</li> </ul> </li> <li>■ Perceived benefits               <ul style="list-style-type: none"> <li>– Satisfaction of helping family member</li> <li>– Developing new skills and competencies</li> <li>– Improved family relationships</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>■ Perceived challenges               <ul style="list-style-type: none"> <li>– Does the caregiver have a social support network, or is he or she isolated?</li> <li>– Does the caregiver suffer any work-related difficulties due to the caregiving role?</li> <li>– Does the caregiver suffer from any emotional and/or physical health problems as a result of caregiving?</li> <li>– How much does the caregiver's health stand in the way of doing things he or she wants to do?</li> <li>– What has been the financial strain, if any, on the caregiver due to his or her caregiving role?</li> <li>– How much disagreement has the caregiver experienced with other family members over particular care issues?</li> </ul> </li> <li>■ Perceived benefits               <ul style="list-style-type: none"> <li>– Does the caregiver feel satisfaction in helping a family member?</li> <li>– Does the caregiver feel he or she has developed new skills and knowledge as a result of caregiving?</li> <li>– Has there been an improvement in family relationships (general closeness, communication, similarity of views, degree of getting along) as a result of the caregiving situation?</li> </ul> </li> </ul>
Skills/abilities/knowledge to provide care recipient with needed care	<ul style="list-style-type: none"> <li>■ Caregiving confidence and competencies</li> <li>■ Appropriate knowledge of medical care tasks (wound care, etc.)</li> </ul>	<ul style="list-style-type: none"> <li>■ How knowledgeable does the caregiver feel about the care recipient's condition?</li> <li>■ What are the skills and abilities needed to provide care for the care recipient?</li> <li>■ How would the caregiver rate his or her confidence and competence in these areas?</li> <li>■ Does the caregiver have the appropriate knowledge of medical care tasks (wound care, ability to administer medications correctly, etc.) and transfer techniques (moving from bed to chair, etc.)?</li> </ul>
Potential resources that caregiver could choose to use	<ul style="list-style-type: none"> <li>■ Existing or potential strengths (e.g., what is presently going well)</li> <li>■ Coping strategies</li> <li>■ Financial resources (health care and service benefits, entitlements such as Veteran's Affairs, Medicare)</li> <li>■ Community resources and services (caregiver support programs, religious organizations, volunteer agencies)</li> <li>■ Formal and informal helping network and perceived quality of social support</li> </ul>	<ul style="list-style-type: none"> <li>■ Can the caregiver rely on his or her social support network for help (i.e., respite)?</li> <li>■ What are the caregiver's coping strategies? Are these healthy/constructive?</li> <li>■ Has the caregiver accessed all financial benefits and entitlements he or she or care recipient is eligible for (e.g., Veteran's Affairs)?</li> <li>■ What other community resources/services is the caregiver utilizing or aware of (e.g., caregiver support groups, religious organizations)?</li> </ul>

The website also provides a list of helpful family assessment tools (see Exhibit 7.1).

Often caregivers are unaware of resources available to them or simply lack the energy to seek them out and then wade through all the red tape involved in documenting eligibility for the help. The financial hardships that develop over time are an added burden. There is also agreement that palliative care (PC) nurses, case managers, and therapists can break this cycle by advocating for the caregivers as well as the care recipients. What is less clear is why so many family caregivers fail to have access to these supports and services. It is too easy to fault the assessments of family resources. Assessment is critical, as has been presented earlier; however, assessment without intervention is of questionable value.

## Caring for the Caregiver

Family caregivers must be recognized as “care recipients” in their own right. There is agreement that many times caregivers simply burn out over the course of caregiving. Physical, emotional, compassion fatigue sets in, and the caregivers have no reserve to care for the recipients, much less themselves. This leads to neglect of their own needs and health and the development of depression and other emotional complications as well as physical illness (Family Caregiver Alliance, 2006a).

Family members experience role changes and transitions, stress, and ultimately bereavement as their loved one traverses life’s continuum (Dumont et al., 2008; Hebert, Schulz, Copeland, & Arnold, 2009; Hudson et al., 2008). It is important that health care professionals recognize physical, emotional, social,

spiritual, and financial changes and transitions at the EOL and into bereavement. The transitions and associated needs of family caregivers have not been addressed by the health care system. Studies have indicated the existence of issues, such as a lack of continuity of care with multiple care providers and locations of care (Holtslander, 2008; Waldrop, Kramer, Skretny, Milch, & Finn, 2005).

Family caregivers have a right to their own support and assessment of their needs, with their experience evaluated “not as a proxy response for patients but as an outcome itself” (Steinhauser, 2005). Their resources and capabilities are influenced by multiple factors, such as gender, age, ethnicity, education, socioeconomic status, and geographic location (Bernard & Guarnaccia, 2003; Stajduhar et al., 2010). Caregivers’ existing psychosocial resources and relationship with patients may indicate vulnerability to challenges of caregiving and may inform interventions that reduce stress and increase caregiver mastery in the role (Kim, Kashy, & Evans, 2007). With a holistic understanding of the caregivers’ views, including needs as care recipients and desired outcomes, limited resources can be appropriately allocated and interventions developed, which have a positive impact for caregivers and, in turn, for patients (Guberman, 2006). The family caregiving theoretical frameworks described here are extremely valuable not only in identifying important aspects of caregiver assessment, but also to inform health professionals in developing and implementing needed family caregiver interventions.

After one has completed a careful family assessment, identification of the family strengths and weaknesses that will have an impact on the caregiver and/or the care recipient and their relationship should be identified, clustered, and organized in a way that they reflect the priorities and function of the dyad. Generally, strategies can be successful by addressing four general areas:

1. Setting realistic goals
2. Having difficult discussions
3. Finding help
4. Negotiating expectations

■ **Setting Realistic Goals.** Setting realistic goals involves the identification of key tasks and responsibilities and then priorities for what must and can be accomplished in an hour, a day, or a week (Demiris et al., 2012; Sunnerhagen, Olver, & Francisco, 2013; Wittenberg-Lyles, Goldsmith, Demiris, Oliver, & Stone, 2012). It means looking honestly at the chronic disease or disability that is the focus of PC and estimating the level of functioning and participation the caregiver can expect from the care recipient. In the care of patients with various illnesses, clinicians may ask “Will the patient with the

### Exhibit 7.1

#### Assessment Tools

[www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=1709](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1709)

[caregiver.org/caregiver/jsp/content/pdfs/SelCGAssmtMeas\\_ResInv\\_FINAL\\_12.10.12.pdf](http://caregiver.org/caregiver/jsp/content/pdfs/SelCGAssmtMeas_ResInv_FINAL_12.10.12.pdf)

[www.familyassessmentform.com/](http://www.familyassessmentform.com/)

[humanservices.ucdavis.edu/Resource/index.aspx](http://humanservices.ucdavis.edu/Resource/index.aspx)

#### Assessment Tools by State

[www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=1717](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1717)

#### Annotated Bibliography of Assessment References

[www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=1719](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1719)



stroke regain any ability to swallow? Or will the patient with progressive, accelerated memory loss maintain their ability to dress themselves?” The answers to these questions may be different from the perspective of clinicians versus family members. The objective observer sees only the reality of permanent dysfunction. If the caregiver can come to see the situation realistically, then goal setting is easier, but more commonly, the caregiver exhausts himself or herself trying to reach the unrealistic goals and fulfill the expectation that he or she will be able to handle all the care required. It is just as important to be there for the caregiver when he or she reaches the time when he or she can no longer cope with the enormity of the caregiver experience. It is critical to have a safe, nonjudgmental place to come to and admit the need for help.

■ **Having Difficult Discussions.** Difficult discussions often involve EOL subjects, and there are many areas of life that are difficult to discuss for reasons of history, family dynamics, cognitive dysfunction, or embarrassment (Cherlin et al., 2005; Wright et al., 2008). Chances are that the more difficult the discussion, the more important it is to have that discussion. The imminence of dying often breaks down years of barriers to open, honest communication, leading to a restoration of family relationships (Branum, 2002). There is always the possibility that fissures in family structures will become vast crevices, but the potential for healing makes some discussions worth having. Financial discussions may be just as difficult as healing and EOL discussions. When a parent or sibling lacks the cognitive ability or judgment to handle his or her own finances, the rational thing to do is to manage those components for him or her (Family Caregiver Alliance, 2013d; Marson et al., 2009). However, the care recipients may not see the rationality of that action, particularly if they are paranoid or psychotic.

Difficult discussions require extensive planning and careful selection of place and time. It is best to be very direct, and use short, simple sentences (Ngo-Metzger, Srinivasan, Solomon, & Meyskens, 2008). It is good not to try to accomplish too much in any one meeting, taking time to work through issues with as little defensiveness and blame as can be accomplished.

■ **Finding Help.** There are two categories of finding help. First, and possibly most straightforward, is help that is available through social programs, support groups, and organizations (Family Caregiver Alliance, 2013e; National Alliance for Caregiving, 2013). There are specific criteria for Medicare, Medicaid, food stamps, even Meals-on-Wheels. It may be difficult for caregivers to navigate the endless maze of programs and program rules, but help from a case manager or social worker can facilitate this process. Support groups exist for both caregivers and for care recipients

recipients related to diagnosis, disabilities, and specific causes and charities associated with chronic disease and disabilities. For caregivers, simply entering the term “Family Caregivers” into Google returned 18,600,000 potential results (July 31, 2013). Most notable of those results and in the first 10 returned were the Family Caregiver Alliance, the National Family Caregivers Association, and the Family Caregivers in Cancer (PDQ®)—National Cancer Institute. Exhibit 7.2 is a sampling of organizations that exist to support family and informal caregivers.

The second and more difficult task of finding help may be enlisting the cooperation and contribution of other family members in the care of the recipient (Barbosa, Figueiredo, Sousa, & Demain, 2011; Family Caregiver Alliance, 2013b; National Alliance for Caregiving in collaboration with AARP, 2009). Family history and dynamics may make this impossible even with difficult discussions directed at resolving conflicts that fester with anger and resentment and/or blame for past experiences. It may be impossible and inappropriate to request some family members to overcome past abuse that they have finally resolved in order to provide care for the source of their abuse.

■ **Negotiating Expectations.** The most difficult of the four categories of intervention may be negotiating expectations. It depends so much on the other three and time to deal with the realities of caregiving and the development of a trusting relationship with the case manager or PC nurse. Caregivers often take on more than one person can truly or effectively accomplish (Stajduhar & Davies, 2005). Whether out of love, duty, or self-interest, the tasks of caring for someone who is physically and/or psychologically dependent may not appear overwhelming until the caregiver tries to get them all accomplished, alone, in the course of one day (Penson et al., 2007). Even if their caregiving activities are not accomplished in addition to a 40+ hour a week job and nuclear family responsibilities, it can be exhausting and mind-numbing. Some caregivers will persist in spite of pleading from family and friends to get help or give up some of the tasks. Release from the responsibilities comes only after the death of the care recipient. Even placement in a long-term-care facility may not release the caregiver from self-imposed responsibilities.

For others, the reality of the responsibilities sinks in quickly and they seek help from family, professional agencies, or through placement in a long-term-care facility. There is always some degree of guilt associated with this decision, but some will deal with their guilt in healthy ways and some will not (Brodaty & Donkin, 2009; Buhr, Kuchibhatla, & Clipp, 2006).

For some, the despair and hopelessness that come from this sense of being overwhelmed with work and responsibilities, lack of support and acknowledgment (if not appreciation) can be manifested in abuse (Funk

### Exhibit 7.2

#### Caregiver Support Websites

• AARP	<a href="http://www.aarp.org/home-family/caregiving">www.aarp.org/home-family/caregiving</a>
• Administration on Aging	<a href="http://www.aoa.gov/AoARoot/Index.aspx">www.aoa.gov/AoARoot/Index.aspx</a>
• American Red Cross	<a href="http://www.redcross.org/prepare/location/home-family">www.redcross.org/prepare/location/home-family</a>
• APA's Family Caregiver Briefcase for Psychologists	<a href="http://www.apa.org/pi/about/publications/caregivers/index.aspx">www.apa.org/pi/about/publications/caregivers/index.aspx</a>
• ARCH National Respite Network	<a href="http://archrespite.org">http://archrespite.org</a>
• Caregiving.com	<a href="http://www.caregiving.com">www.caregiving.com</a>
• Caring.com	<a href="http://www.caring.com">www.caring.com</a>
• Estimate the cost of eldercare in your workplace: Eldercare Calculator	<a href="http://www.eldercarecalculator.org">www.eldercarecalculator.org</a>
• Family Caregiver Alliance	<a href="http://www.caregiver.org">www.caregiver.org</a>
• Family Caregiver Handbook	<a href="http://web.mit.edu/workplacecenter/hndbk">web.mit.edu/workplacecenter/hndbk</a>
• Family Caregivers Support Network	<a href="http://www.caregiversupportnetwork.org">www.caregiversupportnetwork.org</a>
• Family Caregiver Web	<a href="http://www.familycaregiverweb.com">www.familycaregiverweb.com</a>
• Family Caregiving 101	<a href="http://www.familycaregiving101.org">www.familycaregiving101.org</a>
• Guide to Long-Term Care for Veterans	<a href="http://www.va.gov/GERIATRICS/Guide/LongTermCare/index.asp">www.va.gov/GERIATRICS/Guide/LongTermCare/index.asp</a>
• Johnson & Johnson Strength for Caring	<a href="http://www.strengthforcaring.com">www.strengthforcaring.com</a>
• Lotsa Helping Hands	<a href="http://www.lotsahelpinghands.com">www.lotsahelpinghands.com</a>
• National Alliance for Caregiving	<a href="http://www.caregiving.org">www.caregiving.org</a>
• National Caregivers of Veterans Support Hotline	<a href="http://www.caregiver.va.gov">www.caregiver.va.gov</a>
• National Family Caregivers Association	<a href="http://www.nfacares.org">www.nfacares.org</a>
• National Institute on Aging	<a href="http://www.niapublications.org/shopdisplayproducts.asp?id=29&amp;cat=Caregiving">www.niapublications.org/shopdisplayproducts.asp?id=29&amp;cat=Caregiving</a>
• National Transitions of Care Coalition	<a href="http://www.NTOCC.org">www.NTOCC.org</a>
• Next Step in Care	<a href="http://www.nextstepincare.org">www.nextstepincare.org</a>
• Rosalyn Carter Institute for Caregiving	<a href="http://rci.gsw.edu">http://rci.gsw.edu</a>

This is not an exhaustive list and state-specific programs are available. These sites were active as of publication.

et al., 2010; Moules et al., 2004; Wells et al., 2008; Zarit, 2006). It would be naive to say there are no mean and naturally abusive people who become caregivers for whatever reason. What could cause a kind, well-meaning caregiver, who has made a commitment to the care of a family member, go on to starve, slap, pinch, demean, or threaten an elder or disabled family member? Some instances can be explained by despair and hopelessness that leads to acting out on the perceived source of the despair; anger that becomes resentment and develops into rage; and too few resources to meet the demands of the caregiving. A few will themselves have mental illness that manifests in stressful situations such as extreme caregiving (Brodaty & Donkin, 2009). These are potential explanations, not excuses. Consequently, the PC nurse or case manager

must be vigilant for signs of abuse even in situations where everything seems to be going well. Abuse may be a call for help; it may be a manifestation of evil; but regardless, it must be identified and stopped. It may take all the nurse's negotiating skill to protect the care recipient while also getting help for the abuser.

### Evidence-Based Family Caregiver Interventions

A recently convened National Institute of Nursing Research (NINR) Summit Conference on End of Life and Palliative Care made numerous recommendations for research related to identifying caregiver needs and developing interventions for them as care recipients



(McGuire, Grant, & Park, 2012). Many caregivers are not confident in their ability to provide adequate care (Bucher et al., 2001) and the financial problems and the lack of social support make caregivers feel helpless.

Studies indicate that most caregivers of advanced cancer patients have reported the need for more information about medication and pain management, physical symptoms and comfort, nutrition, personal hygiene and elimination, positioning, technical equipment, professional/local support, and emergency measures (Bee et al., 2009). A systematic review to identify the evidence for the existence and consequences of financial distress at the EOL for patients dying with cancer was conducted (Hanratty, Holland, Jacoby, & Whitehead, 2007). Thirteen studies among a total of 24 studies reported that caregivers experienced financial stress. Approximately 17% to 38% of cancer patients or their caregivers reported that they use most or all of saving for treatment of patients. Also, in the United States, 10% to 40% of caregivers gave up their job to take care of patients. Financial stressors and strain should be assessed as a regular part in family caregiving (Hanratty et al., 2007).

Systematic reviews of caregiver interventions in terminal illness (Candy, Jones, Drake, Leurent, & King, 2011) and in cancer caregiver populations (Applebaum & Breitbart, 2013; Northouse, Katapodi, Song, Zhang, & Mood, 2010; Northouse, Williams, Given, & McCorkle, 2012) have evaluated the effectiveness of various caregiver interventions (e.g., psychoeducation, problem solving/skill building, supportive therapy, family/couples therapy, interpersonal therapy, complementary therapies). A recent systematic review identified that supportive interventions for caregivers of patients with a terminal phase of a disease including cancer improved caregivers' outcomes, such as coping ability and QOL (Candy et al.,

2011). A meta-analysis found that there were three types of interventions offered to caregivers: psychoeducational, skill training, and therapeutic counseling. These interventions significantly improved caregiver outcomes, such as burden, coping ability, self-efficacy, and QOL, although these interventions had small to medium effects (Northouse et al., 2010).

## ■ CONCLUSION

PC is care that alleviates suffering when cure is not possible. Physical, emotional, and psychological suffering have meaning when they add meaning to our lives, but much of the suffering we are exposed to serves no meaningful purpose. As formal, educated caregivers, we seek to provide support and nurturing to those informal caregivers who bear the brunt of the work and sacrifice what is necessary to care for those with chronic illness and disability. Extensive research has shown not only what a burden this can be, but also how rewarding it can be. Health professionals need to assist caregivers in balancing resources so that the burden of caregiving does not consistently outweigh the rewards. This is a difficult task in itself and requires a careful assessment of the resources and skills of the caregivers so they can be matched with the tasks they will have to perform as well as the advocacy, perseverance, and stamina they will need to meet their goals. We can influence their expectations to help keep them from becoming overwhelmed by the caregiver role.

No human care can give endlessly without some reciprocity within the caring relationship. Family caregivers must perceive some acknowledgment and/or appreciation for the commitment and hard work they do for the care recipient. As health professionals, we are no less in need of the same things in the therapeutic relationships we form.

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## CASE STUDY Conclusion

DL's condition worsened. His cognitive dysfunction led to forgetfulness in taking his complex medication regimen. DL needed medication supervision. Although his niece lived near to him, she worked full time. With the demands of having teenage children, she was already very distressed. The PC nurse and case manager jointly interviewed DL and his niece at DL's home. Careful questioning revealed that DL had broken off relations with his children after their mother's death because he felt guilty for driving intoxicated. He was not injured in the accident that took his wife's life. He felt his children blamed him and, although he blamed himself, he could not bear his children's feelings. DL's daughters were concerned about their father and hoped to restore their relationship. His son blamed his father for his mother's death and did not want to be

involved in DL's care. DL knew that his heart medications kept his CHF controlled and him out of the hospital. His scores on the Mini-Mental State Examination (MMSE) and the Beck Depression Inventory suggested that he was quite depressed. He agreed to meet with his daughters and niece to discuss their differences and his health needs. Since he was a veteran as well as disabled, he was eligible for a number of services that he was not aware of to help him with activities of daily living and housekeeping. This enabled him to continue living independently in his home for as long as possible. Yet, even when families are not living with the patient, the amount of time needed to ensure the patient's physical and emotional health can be overwhelming to caregivers.

## Evidence-Based Practice

Fegg, M. J., Brandstätter, M., Kögler, M., Hauke, G., Rechenberg-Winter, P., Fensterer, V.,...Borasio, G. D. (2013). Existential behavioural therapy for informal caregivers of palliative patients: A randomised controlled trial. *Psycho-Oncology*, 22(9), 2079–2086. doi:10.1002/pon.3260

### Background

Existential behavioral therapy (EBT) was developed to support informal caregivers of palliative patients in the last stage of life and during bereavement as a manualized group psychotherapy comprising six sessions. The effectiveness of EBT on mental stress and QOL was examined.

### Methods

Informal caregivers were randomly assigned (1:1) to EBT or a treatment-as-usual control group using computer-generated numbers in blocks of 10. Primary outcomes were assessed with the Brief Symptom Inventory (subscales somatization, anxiety, and depression), the Satisfaction with Life Scale (SWLS), the WHOQOL-BREF, and a numeric rating scale for QOL (QOL-NRS, range 0–10). Data were collected at baseline, pretreatment, posttreatment, and follow-ups after 3 and 12 months. Treatment effects were assessed with a multivariate analysis of covariance.

### Results

Out of 160 relatives, 81 were assigned to EBT and 79 to the control group. Participants were  $54.5 \pm 13.2$  years old; 69.9% were female. The multivariate model was significant for the pre-/postcomparison ( $p = .005$ ) and the pre-/12-month comparison ( $p = .05$ ) but not for the pre-/3-month comparison. Medium to large effects on anxiety and QOL (SWLS, WHOQOL-BREF, QOL-NRS) were found at posttreatment; medium effects on depression and QOL (QOL-NRS) emerged in the 12-month follow-up. No adverse effects of the intervention were observed.

### Conclusion

EBT appears to exert beneficial effects on distress and QOL of informal caregivers of palliative patients. Further longitudinal evidence is needed to confirm these findings.



## Evidence-Based Practice

Hudson, P., Trauer, T., Kelly, B., O'Connor, M., Thomas, K., Summers, M., ... White, V. (2013). Reducing the psychological distress of family caregivers of home-based palliative care patients: Short-term effects from a randomised controlled trial. *Psycho-Oncology*, 22(9), 1987–1993. doi:10.1002/pon.3242

### Background

PC is expected to incorporate comprehensive support for family caregivers, given that many caregivers suffer psychological morbidity. However, systematically implemented evidence-based psychological support initiatives are lacking.

### Aim

The objective of this study was to prepare caregivers for the role of supporting a patient with advanced cancer receiving home-based PC by offering a one-to-one psychoeducational intervention. We hypothesized that primary family caregivers who participated in the intervention would report decreased psychological distress (primary outcome), fewer unmet needs, and increased levels of perceived preparedness, competence, and positive emotions.

### Methods

A three-arm randomized controlled trial was conducted comparing two versions of the intervention (one face-to-face visit vs. two visits) plus standard care to a control group (standard care) across four sites in Australia.

### Results

A total of 298 participants were recruited; 148 were in the control group, 57 in Intervention 1 (one visit), and 93 in Intervention 2 (two visits). Relative to participants in the control group, the psychological well-being of participants in the intervention condition was improved by a small amount but nonsignificantly. No significant reduction in unmet needs or improvements in positive aspects of caregiving among the intervention group were identified. However, the intervention demonstrated significant improvements in participants' levels of preparedness and competence for Intervention 2.

### Conclusion/Implications

This research adds to an accumulating body of evidence demonstrating that relatively short psychoeducational interventions can enable family caregivers to feel more prepared and competent in the role of supporting a dying relative. Further investigation is required to determine the longer term outcomes of such interventions.

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# Communicating With Seriously Ill and Dying Patients, Their Families, and Their Health Care Practitioners

## CHAPTER

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### KEY POINTS

- Conveying or discussing “bad news” requires preparation—locating a private place for the conversation, asking the patient or family to have a significant other present, having as much information available as possible, and practicing what will be said.
  - Patients and their families may respond to “bad news” with disbelief, anger, or denial. Nurses and nursing students should practice their reactions to these defense mechanisms.
  - Nurses may inappropriately block patient or family communication by ignoring what the patient or family member has to say, offering elaborate explanations or inappropriate advice, and providing their opinions without being asked.
  - Nurses may assist patients and their families to decide what is important to them while the patient is dying by asking the patient, “What would be left undone if you died sooner rather than later?”
  - Byock believes that it is essential that patients, their families, and significant others find time before the patient dies to say to each other, “Please forgive me; I forgive you; thank you; and I love you.”
  - It is imperative that nurses demonstrate to patients and their families by their words and deeds that health care providers will not abandon the patient after a decision has been made about end-of-life care.
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## CASE STUDY

Gloria Richards, an 82-year-old woman with severe chronic obstructive lung disease, consented to surgery for an intestinal obstruction. Following the surgery, she required reintubation in the postanesthesia care unit (PACU) and was transported to the intensive care unit (ICU) for postoperative care. Although she was being ventilated with low tidal volumes, shortly after her arrival in ICU several blebs burst in her lungs; she developed crepitus from her chin to her waist and required multiple chest tubes. This marked the beginning of a difficult postoperative course. Three weeks after surgery, her chest tubes could finally be removed. However, she remained intubated and every effort to wean her from the ventilator resulted in her becoming hypoxic and unresponsive.

After her first week in the ICU, Gloria was awake and responsive during the day. She was able to mouth words to the staff and was involved in developing her plan of care. Although Gloria was able to communicate her wishes clearly, communicating with her was very time consuming. During the second week, Gloria announced that she “was fed up.” She believed she was not improving and said she either wanted to get better or have the ventilator removed. Gloria had been living with her brother who had died 6 months before her hospitalization, so there was concern among members of the health care team that she was depressed. During interprofessional rounds, a trial of an antidepressant was proposed and Gloria and her niece, her next of kin, agreed to the plan. However, as time progressed, Gloria indicated that she was “tired of all this and did not want it anymore.” She wanted to know what was happening to her and if she was likely to get better.

Like Gloria in the case study, seriously ill or dying patients and their families want their health care providers to communicate prognoses and treatment options with honesty (Furukawa, 1996; Parker et al., 2007) and caring (Czerwiec, 1996; London & Lundstedt, 2006). In 1995, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) demonstrated that this discussion does not occur as often as families and hospitalized patients would prefer. Despite years of effort to improve EOL communication, the SUPPORT finding was reaffirmed in 2007 when a study by Sullivan et al. (2007) found that only 33% of physicians reported that anyone on the health care team had spoken with hospitalized patients identified as likely to die about the possibility of dying. However, in the same study, the majority of physicians did report that a few days before the patient’s death, someone had spoken about the likelihood of death with the patient’s family. Regrettably, the problems with communication continue. In 2011, Curtis and colleagues reported that a multifaceted, interprofessional intervention intended to improve communication and care at EOL had not been associated with any improvement in the communication or the quality of dying in critical care units of American hospitals.

Most Americans die in hospitals, so the absence or poor quality of such discussions is a major shortfall in the care of dying Americans. Moreover, even for patients who are cared for at home and referred to

hospice, discussion and preparation for death are often avoided until hospice referral. Because most patients are not referred to hospice until the last weeks of their lives, this means that discussion of EOL care is often postponed, as in Gloria’s situation, until it is unavoidable.

According to Servaty, Krejci, and Hayslip (1996), health care providers with less anxiety about death are more likely to talk meaningfully with dying patients. In their study, nursing students were less anxious and more willing than other college students and beginning medical students to communicate with dying people. Thus, they reasoned, nursing students may be responsive to educational endeavors to promote honest, caring communication with patients and families at the EOL. This chapter explores ways to encourage both nursing students and graduate nurses to facilitate communication with dying patients, their families, and their health care providers.

In addition to patients and their families benefiting from communication with nurses at the EOL, the nurses may also benefit. Stiles (1990) described seven types of personal growth that nurses dealing with dying patients felt they experienced as “gifts” from their patients. These included learning to confront their own mortality, learning about self, developing a faith in self and in a higher being, transcending their limitations, learning realistic expectations, and clarifying personal responsibility. Although experienced nurses perceived these opportunities for personal growth as gifts from their patients, undergraduate



nursing students may be more distressed by them. Ways in which nursing faculty members might assist undergraduate nursing students to enrich themselves by working with dying patients will also be explored in this chapter.

This chapter is organized according to the phases of the therapeutic relationship because in many ways the phases of the therapeutic relationship—introductory, working, and termination—parallel the dying trajectory. When appropriate in the phases, distinctions are made between the roles and educational needs of the undergraduate nursing student, the nurse with an undergraduate degree, and the nurse with an advanced practice degree.

## ■ INTRODUCTORY PHASE

During the introductory phase of the therapeutic relationship, the nurse and patient open the relationship, begin to clarify and define the problem that has brought the patient in contact with the nurse, and begin to define their relationship.

### Opening the Relationship

The components of this phase include conveying respect for the dying patient and his or her family as well as establishing a trusting relationship. These constituents are no different from their establishment in any therapeutic relationship. The nurse should introduce herself or himself to the patient and identify how the nurse will be involved in the patient's care. If a student nurse is involved, the nursing faculty member ought to note if the student caring for a dying patient seems unusually reluctant to engage in care of that patient. If the student appears hesitant, the faculty member might demonstrate, by introducing himself or herself to the patient, that this portion of the relationship is no different merely because the patient is dying. At this very early stage in the relationship, the health care provider probably ought to avoid discussing the subject of death and dying unless the patient brings up the topic (Byock, 1997).

Unfortunately, sometimes, it may be the responsibility of the advanced practice nurse or physician, during one of their initial meetings, to explain to a patient that the patient is severely ill and may be dying. It would always be preferable that the health care provider and patient have had an opportunity to establish a trusting relationship before the provider is required to deliver such bad news to the patient. However, in today's fast-paced health care environment, especially in emergency departments and critical care units, that is not always possible.

Conveying bad news requires thought and preparation. When preparing for the discussion, Buckman, Lipkin, Sourkes, and Tolle (1997) recommend that the health care provider locate a private place for the discussion, ask the patient to have a family member or friend present, have all information available to explain to the patient, and practice what she or he is planning to say. Buckman et al. (1997) suggest that after introductions are made to the patient and family, the patient be asked if it would be permissible to tape the interview. They state that taping the interview and providing the tape to the patient when the interview is finished enhances the patient's long-term adjustment. The steps recommended by Buckman (1992) for breaking bad news are listed in Table 8.1. Although these steps have been advocated and circulated for years, there is little consistent, good-quality evidence to support any interventions to convey "bad news," and they are recommended either on the basis of limited quality patient-oriented evidence (B level) or consensus and expert opinion (C level; Barclay, Blackwell, & Tulsy, 2007; Ngo-Metzger, August, Srinivasan, Liao, & Meyskens, 2008).

Buckman et al. (1997), Barclay et al. (2007), and Arnold et al. (2010) recommend starting the interview by finding out what the patient knows or suspects. Often the patient has a preconception of the problem, and it may be necessary not only to convey bad news but also to counter the patient's and family's misconceptions of the situation. In numerous studies, families have indicated that prognosis should be conveyed in an honest, caring manner, but that they need to be prepared for a poor prognosis and it should be tempered with hope rather than delivered bluntly (Barclay et al., 2007).

Not all patients want to know the extent of their illness. Therefore, Ngo-Metzger, August, Srinivasan, Liao, and Meyskens (2008) recommend that patients be asked directly and at the start of the interview how

**TABLE 8.1** Breaking "Bad News"

■ Be sure to get the context right
■ Find out what the patient and family already know
■ Find out how much information the patient or family really wants to know
■ Share the information: start from the viewpoint of the patient and family, and step-by-step bring their understanding closer to the medical facts
■ Respond to their reactions with empathy
■ Explain the treatment plan and prognosis, summarize, and make a contract

Source: Adapted from Buckman (1992).

much information they want to know about their prognosis. Kagawa-Singer and Blackhall (2001) note that people from other cultures may not emphasize autonomy as much as Americans do. In some cultures, it is the members of the family and not the individual who learn the prognosis and agree to a plan of care. To uncover the desires of such patients and families, Kagawa-Singer and Blackhall suggest utilizing the following question: “Some patients want to know everything about their condition, others prefer that we talk with their families. How would you like to get information?” (p. 2,995).

Before actually stating the problem, Buckman et al. (1997) and Arnold et al. (2010) suggest foreshadowing the news in simple language such as “I’m sorry, I have some bad news for you.” They suggest that the situation then be explained in simple terms that are understandable to the patient. Patients and families consistently identify the use of medical jargon as a major deterrent to their understanding of the prognosis. After conveying the information in understandable terms, both Buckman and Arnold and their colleagues recommend something that can be very difficult for the beginning practitioner—at least 10 to 15 seconds of silence. During the period of silence, the patient will have an opportunity to absorb the information, react, and ask questions.

After the information is conveyed to the patient and the patient has had a chance to react, Buckman et al. (1997) and Arnold et al. (2010) suggest an empathetic approach. This implies that the person conveying the bad news should first identify the emotion that the patient or family is experiencing and identify the origins of the emotion. Then, the nurse should respond in a way that tells the person that the nurse understands what the person is experiencing. This means the nurse should “reflect, name, and legitimize the person’s feelings” (Buckman et al., 1997, p. 63). For example, the nurse might say, “I can see that this has really upset you. Was that something that you weren’t expecting?” (Radziewicz & Baile, 2001, p. 952). Arnold et al. (2010) suggest using the evidence-based mnemonic NURSE to uncover and respond to the patient’s or family’s emotions. The mnemonic followed by sample statements for the nurse to use is as follows:

- Name the emotion: You seem (insert appropriate emotion—e.g., worried).
- Understand the emotion: I can see that this is difficult for you.
- Respect: I can see that you are trying to \_\_\_\_\_.
- Support the participants: I (or we) will help you to \_\_\_\_\_.
- Explore possibilities: Tell me what options you can envision.

The final step in breaking bad news is providing an initial explanation of potential treatments and prognoses. Later in the therapeutic relationship, the nurse may become involved in empowering the patient to be an active participant in the decision-making process about treatment and developing an agreement about care. At this stage, the possibilities for treatment are usually just described, to provide the patient and family with an opportunity to begin thinking about goals of treatment. Before the interview is complete, the nurse or other member of the health care team should summarize the discussion for the patient.

Gordon, Buckman, and Buckman (2007) suggest using the SPIKES mnemonic as a tool to remember the steps for delivering bad news to patients and families. This mnemonic summarizes the steps previously described and serves as a way to remember the steps. The steps of the mnemonic with an explanation of what occurs in each step are as follows:

- Set up: Set up an interview with the patient and family.
- Perception: Find out what the patient and/or family understand about the prognosis.
- Invitation: Ask who should be provided with the prognosis.
- Knowledge: Convey the bad news to the appropriate person in an understandable way.
- Emotions: Empathize with the person’s emotions.
- Summary and Strategy: Summarize the discussion and start to think about a plan of care.

Tulsky, Chesney, and Lo (1996) recommend that a new practitioner be observed several times and offered feedback before being allowed to discuss bad news without supervision. Emanuel (1998) suggests the new practitioner be provided with talking points so that all of the appropriate information is covered. Latimer (1998) describes criteria for ethical communication of information that might be used to evaluate the communication skills of a beginning practitioner. To be ethical, according to Latimer, the communication should be timely and desired by the patient. The information must be accurate. The words should be understandable to the patient and family and the information must be conveyed in a gentle, respectful, and compassionate manner.

There is developing awareness that an individual health care provider should not confront a patient and family with bad news without informing other members of the health care team of the details of the discussion (Davis, Kristjanson, & Blight, 2003; Fallowfield & Jenkins, 2004; Larson & Tobin, 2000; Pattison, 2004). Unfortunately, more than 80% of physicians in a study by Ptacek, Ptacek, and Ellison (2001) did not have another health



care provider accompany them when they delivered bad news. When individual providers provide bad news to patients and families without informing the other members of the health care team, the lack of communication can be a significant barrier to quality EOL care (Yabroff, Mandelblatt, & Ingham, 2004). Patients and families who are anxious often do not hear or understand bad news the first time they hear it. Nurses describe feeling caught “in the middle” or “going in blind” when they don’t know what a patient has been told and the patient or family is requesting further information or explanations (Davis et al., 2003). To improve communication and develop an alliance among health care providers, patient, and family, Pattison (2004) suggests a policy change requiring that a senior or primary nurse be present when such discussions are initiated in the hospital.

### Clarifying the Problem

There are several components to the phase of clarifying the problem. They include facilitating the patient’s expression of emotions, identifying what the patient and family believe are problems, and identifying and responding to the patient’s and family’s concerns about care. Nurses should be expert in assisting patients to clarify what they believe are their significant health care–related concerns.

When the health care provider delivering the bad news has not informed the other members of the health care team about the discussion, it is often difficult for a nurse to identify if a patient has received bad news or when the patient is prepared to discuss such news. May (1995) suggests that if the nurse was present at the interview when the bad news was delivered, the patient will feel free to initiate a conversation when the patient is ready. If the nurse was not present during the interview, but suspects such an interview has occurred, the nurse might say to the patient, “I noticed the physician was speaking with you. What did she have to say?” Larson and Tobin (2000) suggest asking a more general question, such as “How is this hospitalization going for you and your family?” or “What has been the most difficult thing about this illness for you?” (p. 1,574). May (1995) emphasizes that the nurse should not initiate such a discussion unless the nurse is able to sit down and actively listen to the patient.

Shannon, Long-Sutehall, and Coombs (2011) suggest a structured format for obtaining information about what the patient or family understands, the ASK–TELL–ASK format. Arnold et al. (2010) believe that the ASK–TELL–ASK model is an essential communication skill that all health care providers should utilize.

Beginning with the first ASK, the nurse might say, “I was not available during multidisciplinary rounds this morning, would you please tell me about the discussion?” This allows the patient or family to explain what they heard and understood from the meeting. Or, if the nurse was present but wants to learn what the patient or family believes is important, the nurse might ask, “What do you believe is the most important issue for us to talk about after the meeting today?”

The second phase is described by Arnold as the TELL phase when the physician explains to the family what is occurring. However, Shannon notes that it is also the TELL ME MORE phase during which the nurse clarifies that the patient or family understood what was said. For example, the nurse might say, “You mentioned that the team said your wife was holding her own, would you tell me what you understood when they said that?”

Finally, the nurse might summarize and ASK a second time.

We talked about how your wife is not improving despite having been on a ventilator for some time and the health care team is concerned that although she is stable, she might not improve. Does it make sense to you why the team is concerned? Do you have any questions for me? (Shannon et al., 2011, p. 125)

If the nurse wants to explore the patient’s or family’s emotional responses, questions may have to be phrased differently.

May (1995) warns that when a nurse asks a patient how the patient feels, the patient usually responds by describing her or his physical condition. Thus, if a nurse wants information about the person’s psychological concerns, the question will have to be phrased somewhat differently. Byock (1997) began using the phrase, “How are you feeling within yourself?” after he had noticed that hospice workers in England successfully cut through defenses and learned how the patient was feeling when they were asked that question. He suggests it as a way of getting immediately to the heart of the patient’s concerns. Emanuel (1998) recommends several questions including: “During the last few weeks, how often have you felt downhearted or blue?” “What do you believe is bothering you?” “Who are you able to confide in?” (p. 1,124)

Wilkinson (1991) examined factors that influenced how nurses communicated with cancer patients. She concluded that in general, nurses had difficulty employing facilitative communication with patients with cancer. She noted that nurses frequently used blocking techniques when dealing with patients who had had a recurrence of their cancer. Because these blocking techniques prevented the nurses from

identifying patient concerns, the nurses obtained only a superficial nursing assessment and planned nursing care based on assumptions rather than on actual patient concerns.

Wilkinson (1991) identified three groups of nurses who used different methods to block patient communication. These were ignorers, informers, and mixed responders. *Ignorers* ignored patient cues to talk about specific problems or issues throughout the interview. These nurses changed the subject, engaged in conversation with the patient's relative, or began social chitchat to avoid emotionally laden conversations. *Informers* were nurses who gave elaborate explanations of procedures, offered inappropriate advice, or stated their opinions without being asked. These nurses indicated that providing such detailed, unasked-for information allowed them to maintain control of the situation and avoid difficult or emotionally laden conversations (Wilkinson, 1991). *Mixed responders* were the largest group of nurses in Wilkinson's study. They utilized both facilitative and blocking responses, attempted to understand patient problems, and were more aware of their blocking behaviors when questioned about them.

Although they had been taught facilitative communication, most of the practicing nurses in Wilkinson's 1991 study were unaware that they were blocking their patients' attempts to communicate important needs and concerns until they listened to an audiotape and discussed their responses. In 1996, Heaven and Maquire noted that demonstration with audiotaping and feedback improved the facilitative communication skills of registered nurses (Heaven & Maquire, 1996). However, since the improvement was not to a statistically significant extent, further study of this approach was recommended. An additional constraint on utilizing audiotaping to improve nursing communication is that there may be issues surrounding patient consent and privacy issues with audiotaping.

Boyd, Merkh, Rutledge, and Randall (2011) found that nurses missed opportunities for important conversations with patients and families about dying and hospice care even though the nurses reported that they were not afraid to engage in such conversations. Searching for low-risk ways to assist nurses to initiate communication with patients about dying, Boyd et al. recommended role modeling by experienced, effective nurses and providing support and positive reinforcement to nurses when they utilize therapeutic communication skills. Having experienced nurses or encouragement available can prove especially beneficial for nurses who lack confidence in their ability to initiate sensitive conversations (Thompson-Hill, Hookey, Salt, & O'Neill, 2009).

Practice and encouragement in therapeutic communication is important; less than a quarter of the nurses in Wilkinson's 1991 study used primarily facilitative communication techniques when interviewing cancer patients. Nurses who used these techniques were able to do so no matter how ill the patient was or how emotionally laden the material to be divulged. By employing such standard facilitative communication techniques as active listening, use of open-ended questions, reflection or clarification of patient concerns, and empathy, they were able to obtain a more in-depth understanding of their patients' problems and concerns. In "An Interview With Dr. Stuart Farber" (1999), Farber states that patients and families most welcomed and remembered interactions with nursing staff that were personalized to the needs of the individual patient and family.

Yabroff et al. (2004) emphasize that it is not only health care providers who may establish barriers to good communication and optimal patient care. Patients and families may also establish such barriers by their inability to confront death and their utilization of defense mechanisms like disbelief, anger, and denial. Radziewicz and Baile (2001) describe ways that the nurses might recognize and respond therapeutically to each of these behaviors. They define disbelief as "the patient or family's attempt to make sense of what they have heard" (p. 952). They recommend the nurse respond to the patient's disbelief by saying something like "Accepting such a serious illness must be hard because you have taken such good care of yourself" (p. 952). They believe that anger can be one of the most difficult emotions for an inexperienced nurse to deal with, especially as it may be targeted at health care providers. Radziewicz and Baile recommend that the nurse realize the anger is often masking another strong emotion such as fear or disappointment. So, the nurse might respond to the angry patient or family member by saying, "I can see how frightening this is for you. Do you want to tell me more about it?" (p. 952).

Radziewicz and Baile (2001) define denial as the patient's refusal to believe bad news, saying that the news is a mistake and not real. Block (2001) notes that denial is a natural response that may be helping the patient to deal with the illness and should be respected. Radziewicz and Baile believe the nurse should not argue with the patient or family expressing the denial; should acknowledge the difficulty in accepting the truth; and suggest a possible reason for the difficulty, but avoid continuing any blaming or feeling of mistake (Radziewicz & Baile, 2001, p. 953). For example, a family member might say, "The doctors don't know what they're talking about. My father is going to be fine! He's going to walk again. I don't want anyone to tell me otherwise." The nurse



might respond, "It must be difficult believing something so unimaginable could be happening when everything was fine a few days ago." Block agrees with this approach unless the patient is one of the 10% of patients who are in severe denial and the denial is likely to cause problems. In such a circumstance, Block recommends challenging the patient's denial to achieve a greater good. The nurse might say, "I know that making a decision about this is extremely painful, yet if we don't make plans now, we may lose that chance" (Block, 2001, p. 953).

Rosenbaum and Kreiter (2002), Farrell, Ryan, and Langrick (2001), and Ambuel (2003) have demonstrated that health care providers can learn to respond to such patient and family behaviors by role-playing case studies. Some authors suggest scripted case studies; others establish a general style of patient/family behavior and allow the health care participants to practice a variety of responses. In either instance, after role-playing, health care providers indicate more confidence in their abilities and greater willingness to communicate with patients who have received bad news. It is also important to realize that just because the topic is dying and the problems are serious, the talk does not always have to be solemn. Langley-Evans and Payne (1997) noted that lighthearted talk about illness, symptoms, bereavement, and personal mortality was quite valuable to outpatients in a palliative day care center. What was important was the nursing staff created an atmosphere that facilitated rather than blocked patients' disclosure of their concerns. Nursing administrators can do a great deal to encourage nurses to communicate with dying patients. Studies by Wilkinson (1991) and Booth, Maguire, Butterworth, and Hillier (1996) found that the major predictor of nursing staff's use of facilitative communication with patients with cancer or in hospice was the supportiveness of the nurses' supervisor. In the study by Wilkinson, the ward sisters (unit managers) who took assignments, cared for patients, and demonstrated facilitative communication with patients to their staff were more likely to communicate therapeutically with their patients. These same ward sisters also encouraged their nurses to work autonomously and make decisions about nursing care. They had negotiated with the physicians who admitted patients to their units to obtain permission for the nurses to talk truthfully with any patient who requested information about her or his prognosis or treatment.

### Structuring and Formulating the Care Agreement

There are several components to this phase of the therapeutic relationship. In any therapeutic relationship, the nurse and patient should be continuing to

develop trust during this phase, coming to an agreement about the frequency of meetings, and developing goals for care and the relationship. At this point in a dying patient's care, the health care team will initiate a discussion of the patient's treatment goals. Murphy and Price (1995) emphasize that the nurse should avoid using any phrase that resembles "There is nothing more that we can do." Ngo-Metzger et al. (2007) place "There is nothing more we can do" foremost in the commonly misconstrued phrases used in EOL discussions with patients. Although the phrase may be intended by the health care provider to convey that the patient's disease will progress and the patient will eventually die, it often implies to the patient and family that the health care team will abandon the patient.

Instead of focusing on what will not be done, the patient, family, and members of the health care team should begin to identify goals for patient care. Patients and families recall feeling supported by health care providers when they were told something like "We promise we will work with you to manage your symptoms and we will stay with you as your disease progresses. We can set goals for this portion of your life together."

Farber ("An Interview With Dr. Stuart Farber," 1999) identified a number of possible goals that a dying patient might choose. These included living to the last possible second, living until the burden becomes too great, living at home with family, avoiding medical interventions, living as comfortably as possible until death, and avoiding medical treatments unless they will have meaningful outcomes. Once a goal has been identified, the health care team, patient, and family can begin to identify interventions that will achieve that goal.

In 1993, Cotton noted that many physicians avoid initiating discussions about EOL treatment with their patients for fear the patients will become depressed or distrustful of the physicians' willingness to care for them (Cotton, 1993). Unfortunately, there has been only limited improvement since then. In 2012, Aslakson et al. studied what surgical ICU nurses believed were the most prominent barriers to communication of prognosis and planning for EOL care. One of the four major barriers they identified was inadequate skill and training in communication. Included in this barrier were concerns such as discussions about prognosis being so rushed that patients and families had little time for questions; the use of jargon during conversations so that the patient/family could not understand what was being said; and, sadly, the patients/families not even being able to schedule a meeting with appropriate staff to obtain information or develop plans. In summary, the authors noted that surgical ICU nurses often found that the communication of prognostic

information and discussion of goals of care at EOL was “done quickly, inadequately, and ineffectively” (p. 914).

Often physicians of dying patients will delay the conversation until the patient is unresponsive and the family must be consulted (Shmerling, Bedell, Lilienfeld, & Delbanco, 1988; Sullivan et al., 2007). In fact, patients, especially elders, want to identify goals and interventions for EOL care and are relieved when the subject is broached. Most Americans do not have an advance directive, yet as long as they are competent, it is their right to have the deciding voice in the type of health care they receive. When the members of the health care team avoid discussing the goals of EOL care until the patient is unresponsive, the patient is deprived of the right to determine appropriate EOL care.

The role of the nurse is usually to interpret the medical information into terms the patient can understand and repeatedly explain the EOL treatment options to the patient. Patients and families often indicate that listening to the health care provider’s explanation of a patient’s prognosis and possibilities

for treatment is like trying to understand a foreign language. In addition, most patients and their families experience stress when they receive bad news. Thus, they are unable to hear or retain much of what has been said to them. Being able to repeatedly replay the taped information is one of the reasons a tape recording of the initial interview may be beneficial for some patients and their families (Buckman et al., 1997). However, most of the time, it is the responsibility of the nurse to translate medical jargon into “lay terms” that the patient can comprehend and to reinforce the information regularly. The nurse might try a variety of teaching strategies, such as diagrams or written explanations, to help the patient and family understand the information. Treece (2007) recommends acknowledging that the information is complex to prevent the patient and family from feeling inadequate, and asking them to explain what they understand. It is essential that nurses determine not only what treatment the patient believes she wants but also what she believes will happen if she has the treatment that she wants, as shown in the following portion of the case study.

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### CASE STUDY *Continued*

By the end of the third week, Gloria Richards was more adamant that she wanted the ventilator and endotracheal tube removed. Gloria’s niece was scheduled to arrive for a discussion with the interprofessional team after she finished work one Tuesday. That morning a student nurse and new graduate were caring for her. While giving Gloria her morning bath, the nurse said to her, “Gloria, we’ll be meeting this afternoon to talk about your plan of care; would you tell me again what you would like to have done?”

“I want this tube out now,” she mouthed.

“Would you please tell me what you believe will happen if we take out the tube?” the nurse asked.

“It will be harder for me to breathe and I probably will die but I have had it,” replied Gloria.

Shortly after, Gloria’s primary care physician arrived. He asked what she wished to have done and informed her that she would most likely die if the health care team followed her wishes. Gloria reaffirmed that she wanted to be extubated.

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### WORKING PHASE

During the working phase of the therapeutic relationship, the nurse explores and understands the patient’s feelings and expectations, elaborates on the goals of treatment developed in the previous phase, and facilitates or takes actions that the patient desires. In this case, the feelings and expectations explored relate to the dying process and the goals include defining what the patient believes constitutes dying well.

### Exploring and Understanding Patients’ Feelings and Expectations About Death and Dying

Nurses should be able to assist a patient to define what she or he believes constitutes dying well or represents a good and timely death. Quill (2000) recognizes that health care providers often do not agree about appropriate indications to begin a discussion with patients and families about EOL care. Although he believes the



discussion should begin sooner, he states it is urgent to have such a discussion with patients who are facing imminent death, are talking about wanting to die, are inquiring about hospice, have been hospitalized for a severe progressive illness, or are suffering out of proportion to the prognosis. Quill suggests beginning the conversation with a question such as “What would be undone if you were to die sooner rather than later?” (p. 2,504). Quill believes this question subtly conveys the message that time may be short and plans ought to be made now. Griffie, Nelson-Martin, and Muchka (2004) suggest a different question that conveys a similar message: “Now that we’ve discussed the uncertainty of your situation, what’s most important to you?” (p. 51).

Nurses should be involved in helping to identify with the patient which issues would be most important to address so the patient might die well. Some of the issues that may be important to patients at the EOL include participating in those EOL rituals that provide meaning to the patient and family, completing unfinished business, resolving relationship concerns with family and friends, and carrying out a life review. Once the issues are identified, members of the health care team may assist in addressing them.

The nurse will need to inquire of the patient and family about any EOL customs or rituals that provide meaning to them. Because a range of responses occurs within cultural and religious groups (Kagawa-Singer & Blackhall, 2001; Mazanec & Tyler, 2004), it is imperative that the nurse not assume that specific rituals will be of significance to a patient and family simply because they are members of a particular ethnic or religious group. The nurse might want to inquire, “What is your faith or belief? Is there a religious or ethnic community that is a source of support for you? Would you like me to notify the community or arrange for something for you?” Once these customs or rituals have been identified, Mazanec and Tyler (2004) state that they should be integrated into the plan of care for the dying patient.

If it is necessary to use an interpreter to have a discussion with a patient about EOL care, the use of a professional interpreter is supported by Grade A evidence. A meeting with the interpreter prior to the discussion is recommended to plan the approach for the discussion, to identify cues for stopping points, and to decide how much should be disclosed before stopping. During the discussion, the health care provider needs to continue to respond to the nonverbal cues that the patient and family display and convey empathy. Following the discussion, it is recommended that the health care team meet with the interpreter to clarify any misunderstandings (Barclay et al., 2007).

Patients may have a wide variety of unfinished business. Often these issues are related to the patient’s

age and developmental level. For example, a teenager might want to graduate from high school or an older adult might want to witness the arrival of a first grandchild. To identify what business, if any, the patient would like to complete, the nurse might ask, “If you were to die soon, what would be left undone?” or “Is there some event that would add a great deal of meaning to your life? What do we have to do so that event can take place?” Once the issue has been identified, rules might have to be bent (e.g., a child be allowed to participate in graduation ceremonies without completing required coursework, a grandchild or pet allowed into an intensive care unit [ICU]), resources expended, or help mobilized to permit the event to happen.

Patients may need both time and assistance to resolve relationship problems with their family and friends. Byock (2004) advocates that patients and their families make every effort to say four things to each other as they prepare to say farewell: “Please forgive me; I forgive you; thank you; and I love you” (p. 5). He believes that saying these four things “offers essential wisdom for completing a lifelong relationship before a final parting.” When dying people “can reach out to express love, gratitude, and forgiveness...they consistently find that they, and everyone involved, are transformed for the rest of their lives, whether those lives last for decades or just days” (p. 7). Exline, Prince-Paul, Root, Peereboom, and Worthington (2012) demonstrated that unfortunately the opposite is also true. When family members believe that communicating forgiveness at EOL is important and it does not occur, patients and family members have been shown to become depressed. Emanuel (1998) notes that some patients seem to be able to postpone dying so that they can complete their family business. Often, deaths occur after important events such as birthdays or holidays. One woman who was dying from respiratory failure asked to have her life prolonged by whatever means necessary until her estranged daughter, whom she had not seen in 10 years, arrived from across the country. After the daughter’s arrival, arrangements were made for counseling sessions for the mother and daughter. Two days later, the mother died with the daughter present, holding her mother’s hand.

Life review is another important part of both the aging process and the dying process. According to Butler (“Roundtable Discussion,” 1996), life review is a normal developmental task of the later years characterized by the return of memories and past conflicts. In some cases, this can contribute to psychological growth, including the resolution of past conflicts, reconciliation with significant others, atonement for past wrongdoing, personality integration, and serenity (p. 42).

Mazanec and Tyler (2004) encourage nurses to participate in patients' life reviews. They believe that when patients are encouraged to tell their life stories, the patients are often able to recognize meaning and purpose in their lives. Being present with the patient while the patient begins a life review means a commitment on the part of the nurse to listen actively and devote time to the patient. This is a skill that all nurses ought to have, although it does not require the presence of a nurse or even a professional for the patient to conduct a life review. Life review can provide the patient with a powerful way to work out family relationships and gain a sense of inner peace.

### **Talking With Patients Across the Life Span and Their Families About Death**

A nurse caring for a dying child must establish a trusting relationship with the child and his or her parents. Novice nurses should be especially aware of their emotions and though empathizing with the family should avoid burdening them with the nurses' own emotions (Buckman et al., 1997). Children want to know varying amounts of information about their illness. However, most children want to have an appreciation of how the illness will affect the way they will be able to live their lives. Like adults, however, children vary in how much information they are able to understand and absorb even when it is presented at an appropriate level. Young children's verbalization about their potential death can vary across a continuum and may be fluid over time (Buckman et al., 1997). At one end of the continuum, children will state that they are very sick or have a bad disease but will not mention death. Often, children younger than 7 or 8 years of age view death as temporary and reversible, happening only to others and perhaps caused by previous thoughts and actions (Freyer, 2004). Other children may mention an uncertainty about living but will not allude to dying. At the far end of the continuum, usually when the child is older than 7 or 8 years, the child may understand the central aspects of death and may state that she or he could die from this illness. Freyer believes that children today are more insulated from death than in the past and are more likely to learn about death from television and video games than from real-life occurrences. In order to understand children's concerns, the nurse might utilize play therapy or drawing with various colors to help children express their emotions, fears, and realizations about death. Ewing (2009) states that in their drawings, children who are very ill may reveal an edited version of their internal life. If they feel they are different from other children, isolated and in pain, they

may wish to be in a faraway place meeting someone special or possessing a special item. These wishes are often depicted in the children's drawings.

Adolescents, especially ones who have been chronically ill, usually have an accurate understanding of death and are able to verbalize its personal significance as well as its effect on others. Freyer (2004) notes that adolescents "who are medically experienced often demonstrate remarkable insight into their illnesses, prospects for survival, and preferences for how they wish to spend their remaining time" (p. 383). Due to this insight, "adolescents older than 14 are usually assumed to have functional competency to make binding medical decisions for themselves, including decisions relating to the discontinuance of life-sustaining therapy and EOL issues" (Freyer, 2004, p. 383). Freyer emphasizes it is essential that a truthful, honest relationship be established with the adolescent from the very beginning. He believes this can be accomplished if health care providers establish an agreement with the adolescent to share all relevant information with the adolescent as soon as it is available and the adolescent agrees to ask all questions, no matter how trivial. To ensure that the adolescent feels free to ask all his or her questions, the nurse will want to ensure that the nurse has time to spend speaking with the adolescent alone, without either parent present. Freyer (2004) notes that because most adolescents really do not believe they can ever die, they may talk about death and plan for their eventual death in ways that seem contradictory. At one moment they may be making plans for termination of chemotherapy and a few moments later they may be talking about attending an event that is years in the future. The nurse may want to help the adolescent arrange to attend important life events (e.g., school prom or graduation) in the near future while helping the adolescent recognize and accept his or her deteriorating condition.

Because there was not sufficient evidence to guide communication with parents of dying children, in 2003 the Institute of Medicine (IOM) put out an urgent call for descriptive research on the process (Hendricks-Ferguson, 2007). This was designed as a first step prior to developing intervention studies. In 2013, Gilmer, Foster, Bell, Mulder and Carter reported on a first multimethod approach to communicating with children at EOL and their parents. The researchers indicated that although parents were pleased overall with their communication with nurses and involvement in family conferences, they wished they had been offered more assistance and involvement in decision making about EOL care for their children.

Decision making can be very difficult for the parents of seriously ill, possibly dying children. The parents may have difficulty making sense of what is



being said or experienced (Anderson & Hall, 1995). They may feel unable to make decisions, especially if they believe that both minor and major decisions are needed simultaneously. At times, according to Anderson and Hall (1995), the parents may feel they cannot differentiate between decisions that merely involve personal preference and ones that have grave implications. They may need help from nurses in untangling these concrete issues, but also in dealing with more philosophical ones such as how to determine the line between what is best or right for their child and what is best or right for them.

Nurses can help these families by reminding them that “forced or hasty decision making may cause them to abrogate responsibility because they have not had an opportunity to understand the issues, their feelings or their roles” (Anderson & Hall, 1995, p. 16). Experienced nurses can assist the parents to understand the issues, express their feelings, and delineate their roles so that the parents can be actively involved in the decision-making process for their children. Crozier and Hancock (2012) emphasize that the importance of silence as a communication tool cannot be underestimated and it should be used at this time both with children with life-threatening illnesses and with their parents.

Most importantly, nurses should ensure that EOL care discussions with parents are sensitive and caring. In a descriptive study by Hendricks-Ferguson in 2007, 50% of parents believed that health care providers conveyed a recommendation that their child be referred to hospice in an uncaring or insensitive manner. This happened when a health care provider said something like the following: “We can treat your child but it will convey no benefit.” In contrast, the 17% of parents who felt the recommendation to hospice was conveyed in a caring manner were told, “We have a wonderful hospice team and we will be sure that your child is at peace.” Multiple studies of family members of both dying adults and children have indicated that at least as important as the content that is provided is the sensitivity with which the content is conveyed.

Young or middle-aged adults who are dying may feel they have a great deal of unfinished business or many unresolved relationships. The dying patient may need professional assistance in dealing with anger at leaving so much undone. A parent who is dying and leaving young children behind may need assistance from a nurse to find ways to leave mementos or lasting words of wisdom for the children. Some dying parents pick out special Christmas mementos in July for their children. One mother made 12 audiotapes with words of love and encouragement for her only child, one for each year until he would reach age 21.

Older adults are often perceived by health care providers as having lived a full life and being prepared

to die. Yet, according to Cavendish (1999), nurses should assess all elders’ quality of life (QOL) prior to the illness and realize that many have the potential for additional healthy, happy years. Farber (“An Interview With Dr. Stuart Farber,” 1999) states that adults older than 70 years usually do not believe they have a choice in health care treatment. When asked how they had made decisions, they answered, “What do you mean? The doctor told us what to do and we did it.” Elders in a study by Schroeffer (2007) on sources of suffering at the EOL indicated that being excluded from discussions and decisions about pain management or withdrawal of treatment resulted in their experiencing unnecessary pain and suffering. Nurses need to assist elders in participating in their treatment decisions whenever they appear to desire a decision-making role. Finally, life review is particularly important for the dying elder (“Roundtable Discussion,” 1996), so time and a compassionate listener should be allotted to this important activity. A nurse might be this compassionate listener, or the nurse might delegate another individual for this task.

## Facilitating and Taking Action

There are several components of this phase. The first part is determining that the patient will die soon. The nurse may be involved with other health care providers in deciding when the patient is entering the active dying phase. According to Cassem (Stein, 1999), nurses are the people who guide patients along the path to a peaceful death by recognizing when the patient is suffering needlessly because of inappropriate aggressive treatment. The physician, in some settings, may be the last to realize that the patient is dying. Therefore, it becomes incumbent on nurses to relay their impressions to the physician and possibly to the family. The SUPPORT Principal Investigators’ (1995) study indicated that there were problems in the way such information was communicated in hospital settings, and Curtis et al. (2011) indicate that those problems are still ongoing.

Griffie et al. (2004) note that it may be necessary for nurses to act as go-betweens between patients and physicians when there is disagreement about whether a patient is dying and what type of EOL care should be provided. They argue that initiating a discussion of EOL care should be part of standard nursing practice. Crucial elements for nurses to establish effective communication with physicians during disagreement about EOL care include:

- Assessing the patient by learning the details of the situation and identifying any questions that the nurse or patient has prior to contacting the physician

- Focusing on the patient's and family's desires and concerns while identifying their readiness for additional information
- Identifying medications or interventions that the nurse and/or patient believes might be effective, recommending them to the physician, and providing a rationale for their use
- Respectfully questioning interventions chosen by the physician with which the nurse, patient, or family does not agree

An example of a student nurse communicating with a physician about her patient's wishes is shown in the continuation of the case study.

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### CASE STUDY *Continued*

By midmorning, when multidisciplinary rounds were in progress, Gloria Richards's nurse had another patient who needed to be prepared for emergency surgery and there were several other events occurring in the ICU. The student nurse represented the nursing team at multidisciplinary rounds. The intensivist was hurrying due to the multiple events in the unit and did not have time to have a discussion with the patient. He announced he was concerned that no one was present who had assessed and could voice Gloria's wishes about EOL care so he wanted to postpone the family meeting planned for the afternoon. He was deeply concerned that Gloria might not understand the repercussions of her decision. The student responded:

Both Gloria's primary nurse and primary physician spoke with her this morning about her desires. She told each of them separately that she wanted the endotracheal tube and ventilator removed and that she understood that she would probably die when they were discontinued. Repeatedly this morning she has said she has had enough and asked when the meeting and removal would occur.

The intensivist agreed to hold the meeting later in the afternoon.

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Determining and agreeing that the patient is dying is extremely important, because most deaths in the United States occur in hospitals and all patients in hospitals must receive cardiopulmonary resuscitation (CPR) unless the physician or advanced practice nurse has written a do-not-resuscitate (DNR) order. Once there is a determination that the patient is dying, the physician or advanced practice nurse should discuss a DNR order with the patient, family, and other health care providers.

Inexperienced practitioners commonly make two mistakes when discussing a DNR order. The first is to ask: "Do you want everything done?" Most laypersons do not assume that "everything" means compressing the chest of a person who has already died. They assume it means comfort, care, and support. So, they often answer yes when they really would not want CPR. The second mistake is to use the words: "There is nothing more we can do." Although the patient is dying and medical interventions will not prevent the death, there is much that health care providers can do to help the patient die well. The role of the advanced practice nurse is to initiate this discussion using Latimer's (1998) criteria for ethical

communication described earlier and listed in Table 8.2. However, Tulskey et al. (1996) stress that new practitioners, such as residents and advanced practice nursing students, should be evaluated by skilled professionals before being allowed to attempt such a discussion on their own.

The nurse is usually the staff member to whom the patient and family turn to discuss exactly what a DNR order is and what the ramifications are likely to be for the patient (Peel, 2003). If that nurse was not present for the discussion, he or she might use the question, "I noticed the physician was speaking with you. What did she say?" The nurse might follow that with, "Many people have questions about what this means for them. What questions do you have?" Most people want reassurance that they are not foregoing an intervention that is likely to offer them benefit. Because only about 12% of all patients survive from CPR to hospital discharge, this reassurance is easy to provide.

As noted previously, the nurse is often the guide on the path to a peaceful death (Stein, 1999). This role is important because the decision to forego CPR is merely the first of many decisions the patient and family may need to make about EOL care. After



**TABLE 8.2 Criteria for Ethical Communication of Information**

- |                                                                                        |
|----------------------------------------------------------------------------------------|
| ■ Ensure that the communication is timely and that the patient desires the information |
| ■ Ensure that the information is accurate                                              |
| ■ Use words that are understandable to the patient and the family                      |
| ■ Convey the information in a gentle and compassionate manner                          |

Source: Adapted from Latimer (1998).

deciding to forego CPR, the patient and family might choose to forego any further curative therapy, or might opt to have only comfort measures provided for the patient. Palliative care (PC) decisions may have to be made regarding the amount of pain medication the patient desires and whether the patient wishes to receive medical interventions for hydration and nutrition or even to continue eating and drinking. Nurses who are caring for a dying patient should be able to describe the benefits and burdens of each of these therapies to the patient. They should also be able to facilitate patient and family decision making about these choices through effective communication.

The nurse may be responsible for advocating for the patient's wishes for EOL care and communicating them to the family and other health care providers. This is easier if the patient has verbally expressed a preference to the nurse and is willing to state that preference to the physician and family. It may be more difficult when the nurse, physician, and family are trying to interpret an advance directive that does not fit the patient's situation precisely, when the person who has the durable power of attorney for health care purposes is not clear about the patient's wishes, or when there is no advance directive. Harlow, in "Family Letter Writing" (1999), recommends that the family or proxy consider the following:

1. What type of person was the patient?
2. Did the patient ever comment on another person's situation when they were incapacitated or on life support?
3. Did the patient relate those experiences to his or her own personal views for herself or himself?
4. What vignettes can you recall from the patient's life that illustrates her or his values and beliefs?

In "Family Letter Writing" (1999), Harlow then asks the family to write a letter incorporating the answers to these questions. He believes that the process is almost a spiritual one for the family that often brings members closer together. It helps them

to review and clarify the person's life and understand what was meaningful to the person. Harlow notes that family letter writing may be "experienced by the family as a last act of commitment and caring toward their loved one." The nurse may be the person who encourages the family to begin such an activity.

A more detailed exercise called facilitated values history is suggested by Scheunemann, Arnold, and White (2012). They believe that families have difficulty identifying the most important values to utilize when making decisions for patients, especially if they have simply been asked, "What do you think the patient would choose?" They suggest a series of questions that will help the family identify what the patient values about being alive and what he or she is willing to endure for an acceptable QOL. The questions cover eight different domains. Examples include the following: What would your loved one think about living if he or she were unable to speak, unable to interact with people, unable to think clearly or dress himself or herself?

Either in conjunction with family letter writing, a facilitated values history, or alone, family conferences are often convened to help the patient, family, and health care team reach a decision about EOL care. According to Griffie et al. (2004), it is essential to identify the purpose of the conference beforehand. It is also necessary to determine where the meeting should be held. If the patient is able to participate, it may have to be in the patient's room. Some health care providers argue that the meeting should always be in the patient's room because it makes everyone consider the patient in the decision. Others believe that if the patient cannot participate, the meeting should be held in a comfortable, private setting away from the patient. If the patient is incapacitated, whoever is the patient's legal decision maker should be present, as well as the people whom the patient considers to be family.

After the purpose of the meeting has been identified and participants have been introduced, Randall (2008) suggests that health care providers focus on specific behaviors that can enhance family satisfaction during a conference. These behaviors include:

- Assuring the family that the patient will not be abandoned by the health care team
- Assuring the family that the patient will not suffer
- Providing support for the family's decision whatever the family decides

Furthermore, Randall recommends that health care providers use the mnemonic VALUE to guide their communications with families during the conference. The behaviors described in the VALUE mnemonic have been shown to improve communication between

health care providers and the families of intensive care patients. The mnemonic stands for

- V—Value family statements
- A—Acknowledge family emotions
- L—Listen to the family
- U—Understand the patient as a person
- E—Elicit family questions

Once a decision is made to limit further aggressive, curative treatment, the nurse may be involved in establishing a PC understanding with the patient and family. This is an understanding of what the health care team will do for and with the patient and family. Byock (1997) offers the following version of a commitment between the health care team and a dying patient:

We will keep you warm and we will keep you dry. We will keep you clean. We will help you with elimination, and your bowels and your bladder function. We will always offer you food and fluid. We will be with you. We will bear witness to your pain and your sorrows, your disappointments and your triumphs; we will listen to the stories of your life and remember the story of your passing. (p. 247)

Although the physician may be the person who establishes this PC understanding, it is the nurse who is responsible for ensuring that it is carried out. It is imperative that the nurse demonstrate, by words and deeds, that the health care providers will not abandon the patient after EOL choices are made; that, instead, nurses and other health care workers will provide the care the patient needs or will teach and assist family members or friends to provide the care and support the patient requires while dying.

## ■ TERMINATION PHASE

During this phase in the therapeutic relationship, the nurse, family, and patient prepare for the end of the relationship, accept the feelings of loss, and review or evaluate what has occurred. As a patient is dying, this phase may entail withdrawing medical interventions, preparing the patient and family for the physical signs of impending death, smoothing the passage, consoling the bereaved family, exploring personal reactions, and evaluating nursing responses.

### Withdrawing Medical Interventions

During the termination phase, medical interventions, such as ventilators, intravenous (IV) fluids and nutrition, or dialysis may be withdrawn. The nurse reassures the family that withdrawing such aggressive medical

interventions from the dying patient is acceptable to most of the major religious and ethical traditions. The nurse demonstrates that despite the withdrawal of curative measures, the health care team will remain present and will provide aggressive comfort measures and respect the patient's individuality.

### Preparing the Patient and Family for Physical Signs of Impending Death

The nurse will need to be able to explain the final stages of the dying process to the patient and family. A family that does not understand the dying process may become anxious and feel unable to cope with the patient's care. The nurse may initiate the discussion by stating:

There are some common signs and symptoms that identify when a person's life is coming to an end. Not all of the signs occur in every person nor do they happen in the same sequence in each person. But it might be helpful if we talk about what may be occurring soon and what you may need or want to do.

### Smoothing the Passage

As death approaches, patients may display a variety of typical behaviors. Nurses should be able to explain these behaviors to family members and assist families and dying patients to communicate with each other during the patient's last days and hours. According to Callanan (1994), when a patient is approaching death, she or he may begin to speak in symbolic language. The patient might say, "Oh, here are my mother and brother-in-law, they've come to get me. We have to catch the train." Or, "It's a beautiful place that I'm going to now." Callanan cautions that the family may fear the patient is "losing his mind" or believe she or he is reliving the past. In actuality, it is believed that the patient is preparing to detach from this life. Callanan suggests that nurses should help the family listen to the patient's statements and respond with gentle, open-ended questions such as, "When does the train leave?" The family should be discouraged from trying to reorient the patient ("Your mother died years ago") or contradicting the patient ("You're not going anywhere!"), as these deathbed visions have been shown to calm the patient and ready him or her for death (Fenwick & Brayne, 2011).

Close to the moment of death, the patient may appear more withdrawn, almost detached from the surroundings. The nurse should inform the family that although the patient may appear unresponsive, they should still communicate verbally with the patient because the patient can probably still hear



what people in the room are saying. The family may want to say good-bye or one of the four things that Byock (2004) believes matters most—"Please forgive me; I forgive you; thank you; and I love you" (p. 5)—if they have not done so already. This might be a time for the family to recount some favorite memories that illustrate what the dying person meant to them. A member of the family might say, "We will miss you, but we will always love you and we understand that it is time for you to go." Or, a family member or close friend might simply be present with the dying person, sitting nearby, holding the person's hand or lying next to the person and embracing him or her.

It is the role of the nurse to help the patient and families find an appropriate way to express their feelings and to smooth the patient's passage from this life. Individuals take their own time dying, and each death occurs at its own pace. The nurse may need to help the patient's family understand how idiosyncratically and sometimes how slowly the final moments may pass.

### **Consoling the Bereaved Family**

Nurses need to be able to console families through the bereavement process. If the family was not present during the death, the nurse will want to prepare the body and attempt to create a peaceful environment for the family to view the deceased. Because the nurse is often the professional present at the death or the one who views the body with the family, the nurse will need to demonstrate an acceptance of death and display respect for the deceased. If the family was not present for the death, the members may want a description of the patient's last moments. The nurse should respond both tactfully and truthfully. If it is true, saying to the family, "She was not alone" or "He seemed to be at peace" may be a great source of comfort to the family.

Although students and recent graduates often are worried about what they ought to say to the family at this time, bereaved families usually are more in need of someone to listen to them. Thus, one of the major roles of the nurse at this time is active, compassionate listening. Short statements like "I'm sorry" and "I'll keep you in my thoughts or prayers" may be helpful but the nurse usually does not need to say much. Trivializing statements such as "She is better off now" or "I know just how you feel" are inappropriate. Depending on the nurse's relationship with the family, a hug might be helpful to both the family and the nurse. The nurse's expression of emotion through tears is not unprofessional when it is an expression of the attachment between the nurse and the patient.

When the death is sudden and unexpected, it is often more difficult for both the health care providers and the family to understand. It is usually the physician or the advanced practice nurse who conveys the fact of the death to the family. Buckman et al. (1997) recommend a simple unequivocal statement that the patient (her or his name should be used) has died, and the cause of death. Then the health care provider should remain silent and allow an opportunity for the family to respond and ask further questions. A truthful statement that the nurse is sorry helps some families. Though some people prefer a human touch at this point, others may withdraw in grief. When the initial response has subsided, Buckman recommends focusing on the needs of the family, determining if they need to phone anyone or if they would like an opportunity to view the body. If there is a possibility of organ donation, the advanced practice nurse would broach the subject at this time.

### **Review of the Relationship, Exploration of Personal Feelings, and Evaluation of Nursing Responses**

Although not a specific step in the therapeutic relationship, it is always wise, following the termination of a relationship, for the nurse to review the process to explore her or his feelings and evaluate her or his behavior. A nursing student encountering his or her first experience with death may need to explore it with the faculty member or preceptor after the patient and family have been cared for. Ambuel (2003) suggests that a faculty member or preceptor who is debriefing a student should include questions such as the following: What went well? What was difficult? What did you learn from this experience that will influence your work with patients and families in the future? In most circumstances, it is helpful for the student to be involved in preparing the body and talking with the family. For the first experience with death, it is helpful if a nursing faculty member or an experienced nurse prepares the body with the student. While preparing the body, most nursing students find it helpful if the faculty member provides simple factual statements of how the body changes after death. Many students will remark how different the deceased seems once the suffering is over and life has departed.

Novice nurses often state that listening to the family helps them to find some meaning in the dying experience. If the death has been anticipated, the family will frequently discuss how the patient felt in the last few days and weeks and will often convey a sense of relief that the patient is no longer struggling. The family may review the person's life and help the student to realize that it had reached its natural end.

When the death is sudden and unexpected, nursing students often are distraught. This is especially true if the patient was close to their own or their parents' ages. A review of what happened to the patient with an emphasis on how the health care team responded may at least help the student realize there was no way in which the health care team could have prevented the death. Later, many nursing students and nurses question why the person had to die at this time in his or her life. Active listening by the nursing faculty member or perhaps the hospital chaplain is most likely to assist the student to come to some understanding of the death.

Novice nurses may idealize death; they may want each experience to be mystical and transcendent. However, death, like birth, is both messy and difficult as well as beautiful and transcendent. Learning to live and care within the realm of what is possible for people at the end of their lives is often difficult for the nursing student and the new graduate. Nursing faculty should help the student recognize

the realities that shaped the way in which this particular patient died and identify factors that the student would want to modify when caring for future patients.

## ■ CONCLUSION

When nurses communicate with their dying patients and the patients' families, they have a clearer understanding of their patients' needs and goals at the EOL. Once these goals are established, the nurse may assist the patient in dying well. That death might include limited technology, symptom relief, life review with resolution of past uncompleted business, and the presence of loving family and friends. Or it might involve fighting for the last breath, remaining alive until the last possible second, using the latest medical technology. However, without thoughtful communication with the patient and family, the nurse cannot be sure which course to take to help the patient die well.

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## CASE STUDY Conclusion

By early afternoon, Gloria announced she was tired of waiting and disconnected the ventilator from her endotracheal tube. Her nurse explained that her niece would be arriving soon for a short discussion so that the niece would understand Gloria's wishes and so she could say good-bye. Gloria wanted to know the precise time. An hour later, Gloria attempted to disconnect the ventilator again and said, "It's time." The nurse explained it was only 3 o'clock and her niece wasn't coming until after 4 and turned Gloria so she could see the clock in the room. The niece arrived promptly at 4 and a conference including the patient, her niece, the nurse, the intensivist, and a social worker took place at the patient's bedside. The nurse asked the patient again if she wanted the tube and ventilator removed. Her niece asked if she was certain, and the patient nodded emphatically yes. An hour later, a morphine drip had been started, Gloria was extubated, and her niece was sitting at her bedside with the lights in the room dimmed, holding her hand. Within an hour Gloria was unresponsive and she died peacefully later that evening.

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## Evidence-Based Practice

### Nurses' Perceptions and Experiences With EOL Communication and Care

Boyd, D., Merkh, K., Rutledge, D., & Randall, V. (2011). Nurses' perceptions and experiences with end-of-life communication and care. *Oncology Nursing Forum*, 38(3), E229-E239.

Q: What are oncology nurses' attitudes toward care at the EOL, and what are their experiences with hospice discussions with families and patients?



## Methods

**Data sources:** A descriptive correlational study that utilized an adapted version of the Caring for Terminally Ill Patients Nurse Survey.

**Study selection and assessment:** Sixty-six nurses from a Magnet hospital oncology unit, infusion unit, and radiation oncology unit were invited to participate in the study. Thirty-one (46.9%) agreed.

**Outcomes:** Nurses' attitudes toward care at EOL and care experiences with terminally ill patients.

## Main Results

Despite positive attitudes toward hospice and recognizing the importance of having a discussion about prognosis with terminally ill patients, nurses reported missed opportunities for having such discussions. On average, nurses reported caring for seven dying patients in a 3-month period while having the aforementioned discussions with only a third of the patients or their families.

## Conclusion

Missed opportunities may reflect nurses' attitudes. However, lack of patient and family member acceptance was the most important barrier to discussion of hospice.

## Commentary

Nurses in this study were aware that they had missed opportunities for important discussions with the majority of their terminally ill patients. The reasons the nurses in the study cited for the lack of conversation were unwillingness of the patient and family to accept the diagnosis, a sudden change in patient status, physician hesitance or nurse discomfort with discussion of the terminal diagnosis, and nurse desire to maintain hope for the patient and family.

Nelson and colleagues (2010) studied how patients and families defined high-quality PC in the ICU. They learned that what patients and families valued most was timely, accurate, and compassionate communication of information of patient prognosis and treatment plan. Despite this, and despite the fact that the health care community has known since the SUPPORT study in 1995 that such communication is lacking, studies like this one by Boyd et al., continue to find that opportunities to initiate these important discussions are missed by both physicians and nurses.

Boyd et al. (2011) conclude that the missed opportunities identified by nurses indicate that nurses should be more involved in EOL discussions and suggest initiation of a question prompt list or a list of triggers that would spell out for nurses when they should introduce EOL or hospice discussion. Weissman and Meier (2011) have developed a list of triggers for PC assessment in the hospital setting. It might be possible to develop a variation on these criteria so that nurses and physicians would begin discussion of PC with patients on a consistent basis.

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# Health Promotion and Rehabilitation in Palliative Care

## CHAPTER

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### KEY POINTS

- The provision of palliative and end-of-life (EOL) care does not preclude interventions that optimize health, well-being, and functional status even in the presence of incurable illness.
  - The application of the principles and practices of health promotion to palliative and EOL care enhances the health and well-being of individual, families, and communities.
  - Rehabilitation is a valid intervention in advanced disease, promoting optimal function and mitigating deficits in activities of daily living, well-being, and quality of life (QOL).
  - The role of the nurse in rehabilitation is vital in responding to the complex needs of those with advanced disease.
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### CASE STUDY

Jack is a 55-year-old man with a diagnosis of lung cancer. On admission to the palliative care (PC) service, he is still receiving chemotherapy. He is moderately breathless at rest and needs home oxygen. Jack reports pain and fatigue on mobilizing, is unable to walk more than 5 m on flat ground, and is also unable to climb more than three stairs without needing to sit down. He needs minimal assistance with getting to the toilet and moderate assistance with showering. When seated or in bed, Jack needs to be sat upright to be comfortable.

Jack lives with his wife, Mandy, and has two stepchildren who visit them on weekends. He worked as a maintenance worker at a local school and has been a heavy smoker in the past. He and Mandy have always struggled financially and would often forfeit purchasing medication so they could afford food. Jack and Mandy are functionally illiterate and are supported by Mandy's ex-partner to complete paperwork.

Jack and Mandy live in a two-story public housing building, with about 20 steps between levels. Jack sleeps on a mattress on the floor in the upstairs bedroom where there is an adjacent bathroom. The toilet, laundry, kitchen, and living areas are all downstairs.

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## ■ OPTIMIZING HEALTH AT THE END OF LIFE

At first glance, thinking about health and well-being at the end of life (EOL) might seem contradictory. But there is a growing sense that when we talk about holistic palliative care (PC) and optimal comfort, we are actually talking about health and well-being. Even in the presence of advanced, life-limiting illness, people can—and do—report feeling “as well as possible” in all the levels that holistic care addresses. These include physical, psychological (or emotional), spiritual, and social domains of wellness. Promoting wellness also has the potential to restore some functional deficits that come with advanced disease. It’s in this sense that we discuss palliative rehabilitation and the promotion of optimal health as key issues for nursing practice in PC.

### Understanding Health-Promoting Palliative Care (HPPC)

HPPC emerged in the 1990s in response to concerns that as PC reentered mainstream health care, its aspirations to provide holistic support were under threat from increasingly medicalized care. The notion of integrating health promotion and PC is not a new one in the global PC world. Australian sociologist Allan Kellehear (1999) provided the first substantive consideration of this in his groundbreaking book, *Health-Promoting Palliative Care*. In this book, Kellehear proposes that the principles of health promotion, as articulated in the World Health Organization’s (WHO) *Ottawa Charter for Health Promotion* (WHO, 1987), could not only enhance the care and support of dying people but also address some of the emerging deficits in contemporary models of PC. Kellehear’s premise was that “if health is everyone’s responsibility then it is also the responsibility of those living with a life-threatening or terminal illness as well as those who care for them” (p. 31). He applies the five action statements of the *Ottawa Charter* to PC, identifying five core concerns of HPPC:

- Provide education and information for health, death, and dying
- Provide social support at both personal and community levels
- Encourage interpersonal reorientation
- Encourage reorientation of PC services
- Combat death-denying health policies and attitudes (Kellehear, 1999, pp. 19–20)

Kellehear’s *Health-Promoting Palliative Care* is a social model of care based upon a perspective that promotes optimal health even in the presence of incurable disease. In *Compassionate Cities* (Kellehear,

2005), he again observed the transference of responsibility for dying from the community to the health care professions across the 20th century, with much of the care provision determined by clinical services rather than by consumers of those services. He suggested that the PC profession continues to focus upon individualized responses to need rather than to social change, as this quote illustrates:

Dying, death and loss are defined as personal problems rather than targets of social change in community attitudes, values and behaviour. This reinforces the view that clinical rather than community skills should take priority in palliative care education and training. (Kellehear, 2005, p. 9)

It should be clear, then, that HPPC addresses not only the ways in which clinicians support dying people, but also how communities can be more effectively engaged in the care and support of their dying members; this speaks to the nature of the relationship between health services and the communities they serve. In North America, you can find examples of these in the EOL coalitions found in many states and provinces.

### ■ Utilizing the Ottawa Charter to Change Practice.

To better understand the implications of HPPC for PC nursing practice, it’s important to be familiar with its foundational concepts. HPPC sits within the public health paradigm, to which health promotion belongs, and PC is understood at a global level to be a public health concern (Stjernswärd, 2007). In Table 9.1, the five core components of the *Ottawa Charter for Health Promotion* (WHO, 1987) are mapped against PC (Rosenberg, 2012). Each component that promotes health has application to the provision of PC, which, in turn, has implications for nursing practice.

Although the key action areas of the *Ottawa Charter* were described discretely, their interrelatedness was acknowledged by its authors; each represents an area of strategic action to promote the physical, social, and personal aspects of health and well-being. Significantly, the *Ottawa Charter* explicitly asserted that responsibility for health promotion rests not simply with the health sector and its clinicians but also with governments, social and economic sectors, industry and the media, and communities themselves. Health promotion, therefore, was proposed not as just another health program but an entire approach to the health and well-being of people.

Take note that the foundations upon which HPPC has been built are evident in a number of places in the *Ottawa Charter*. In the key action area of *developing personal skills*, for example, it makes explicit mention of lifelong learning for people preparing themselves for



TABLE 9.1 Translating the Ottawa Charter to Palliative Care

Key Action Areas to Support Health	Health Promotion Description	Application to Palliative Care
Build public policies that support health	Health is on the agenda of all policy makers who consider the health consequences of policy decisions.	Participation of organizations in the development and uptake of public policy relating to palliative care.
Create supportive environments	Health cannot be separated from other societal goals. The links between people and their environment are embraced.	Contributions from palliative care organizations to enhance well-being for consumers and employees.
Strengthen community action	Communities set their own health priorities, make decisions, plan and implement strategies to promote their empowerment. Community development enhances participation in health matters.	Palliative care organizations engage with the community beyond the provision of clinical services to promote communication toward improved support of dying people.
Develop personal skills	Enhanced life skills are attained through personal and social development that promotes people exercising control of their health throughout life.	Participation of palliative care organizations in the development of personal skills to deal with issues of death, dying, grief, and loss.
Reorient health services	Health services move beyond clinical and curative services to support individual and communities for a healthier life. Strategies include research, professional education, and training.	Palliative care organizations reorient their members from a conventional to a health-promoting approach, focusing particularly on holistic needs of patients and organizational attitudes.

*all of life's stages* [author's emphasis]. Although dying was not mentioned in the *Ottawa Charter*, or for many years thereafter in the health promotion literature, it is interesting to note this phrasing in such a key document in light of the later development of HPPC.

In the United States, a critique of these approaches to EOL care was offered by D'Onofrio and Ryndes (2003). In considering WHO's definition of health, consumer stakeholders identified the *preservation of social relationships* at the EOL as a priority; this clearly sits within the psychological and social domains of holistic care. Yet, do our approaches to PC support this? D'Onofrio and Ryndes (2003) identified that EOL care is currently considered a lower priority in the allocation of scarce health resources and noted that this represents a structural barrier within the health system that disadvantages dying people. However, they also suggested that public health approaches could bring about improvement to care at the EOL through its whole-population perspective and policy development. To achieve this, public health systems would need to acknowledge death as the outcome of chronic disease and aging, find new means to measure quality of dying, and consider a reevaluation of resource allocation policies.

■ **Wholeness and Health at the EOL.** Wholeness and health have close conceptual associations—early definitions of health were built upon pre-World War

II assumptions about the relationship between health and disease, where to be healthy was to be without disease (DeSpelder & Strickland, 2002). WHO's definition, in acknowledging the multifaceted and interrelated nature of health and well-being, instead asserted the place of a whole-person approach (WHO, 1978). The concept of wholeness for people at the EOL presents few philosophical hurdles to commentators on health promotion in PC. Suffering is regarded as a complex, subjective experience, the amelioration of which produces an optimal state in a person even in the presence of incurable illness (Woodruff, 2004). The founder of the modern hospice movement, Dame Cicely Saunders (1987), herself described good PC in terms now commonly ascribed to holism: namely, that care should be directed from the time of diagnosis at the physical, psychological, social, and spiritual dimensions of a person's experience, by a team comprehensively representing the various disciplines with the expertise to address these areas of need. She is joined by others who describe a *whole-person response* to the *whole-person experience* (Woodruff, 2004), moving beyond a philosophical position to providing guidelines for the provision of care.

Significantly, public health has explored in detail the relationship between human health and well-being with social and environmental factors (Talbot & Verrinder, 2005). Contemporary understandings of health recognize the impact of disease, illness, and

health-related issues upon all aspects of human existence (McMurray, 2003) and the participation of individuals, communities, and societies in determining their own health outcomes. Recipients of care and their family caregivers are recognized as the unit of care, with sympathetic stakeholders in the wider public who are engaged in the kind of local activism that has brought many hospice and PC services into existence (Small, 2003). A central tenet in the support of dying people is the relief of suffering for the whole person—a state often described as a *good death*. Indeed, the hospice pioneers' work shows that to die well was to die with ease of distress across the range of domains of human existence: physical, psychological, social, and spiritual.

Byock, Norris, Curtis, and Patrick (2001) also undertook substantial work toward facilitating a transition from EOL care that focused upon individuals, to care that focused on the community, which is a *social* approach. Their justification for this links strongly to the principles of social models of PC:

The experiences of serious illness, dying, caregiving, grieving and death cannot be completely understood within a medical framework alone. These events are personal, but also fundamentally communal. Medical care and health services constitute essential components of a community's response, but not its entirety. (Byock et al., 2001, p. 760)

These authors saw the community's engagement in EOL issues as having a reciprocal effect: The community members' perspectives of death and dying inform their engagement while their engagement reshapes their perspectives.

■ **Health Promotion in PC.** In North America, Rao and colleagues (Rao, Anderson, & Smith, 2002; Rao et al., 2005) have been asserting the need for the concrete inclusion of a public health foundation in PC service planning for a number of years. They have argued that connecting health to the community by providing information and establishing partnerships will raise death awareness and empower the community to contribute to the debate of issues related to quality of life (QOL) at the EOL. Indeed, in their study of public health priorities for EOL initiatives, Rao and colleagues (2005) identified nine clusters of public health activity that were directly relevant to the provision of PC. Of these, five were identified as most feasible:

- Public education
- Patient and family caregiver education
- Research, epidemiology, and evaluation
- Professional education
- Policy and planning

Importantly, each of these clusters was accompanied by a set of recommendations for action that can inform practice. For example, in the public education cluster, Rao et al. (2005) advised the use of strategies to raise public awareness of PC, increase the use of advance health directives, integrate EOL issues into chronic disease educational materials, and operate some form of information clearinghouse for EOL issues. One can see ways in which PC nursing, as a specialty public health care, can and does contribute in these clusters.

It's also possible to see ways in which PC nursing, as a discrete component of health care, can and does contribute in these clusters. You might be able to immediately identify some of the ways this already takes place with your service. With reflection, you may also be able to identify some gaps in your model of care relating to HPPC. So, where do you start?

The framework that follows is one approach to understanding the integration of HPPC in your practice, in your workplace and the community it serves, and in the health systems that govern your clinical practice. It's the *macro-meso-micro* framework, perhaps already familiar to some of you in other contexts.

■ **Macro-Systems Level.** In considering the possibilities for HPPC at the *macro* level, you are examining systems of palliative and EOL care. Do systems that are in place:

- Support changing knowledge, attitudes, and behaviors around death and dying, and aim to encourage a greater willingness to discuss death and bereavement issues?
- Promote political and policy action?
- Incorporate research into the HPPC approach?

It might be unfamiliar territory to consider advocating for a systemic approach to wholeness at the EOL as part of the scope of practice for PC nurses. But nurses, of course, are well positioned to understand and represent the needs of the people who receive their clinical care. Whether individually or collectively, PC nurses have an important knowledge base that may be very valuable in public education programs addressing issues of death and dying.

■ **Meso-Organizational Level.** In thinking about HPPC at the *meso* level, consider the activities regarding palliative and EOL care at the service level. Does the organization:

- Include life and death education activities for the wider community?
- Support professional development of its staff toward HPPC approaches?



- Create partnerships for media engagement, research, and community engagement (e.g., through schools, clubs, church groups, etc.)?
- Promote reorientation of itself toward HPPC (after the WHO *Ottawa Charter*)?

Once again, you can see how, in a supportive organization, PC nurses can contribute to an approach that promotes optimal health and well-being at the EOL. Nurse educators in particular can include these strategies in their role.

■ **Micro-Individual Level.** This is perhaps the most familiar level for most PC nurses: considering how, at the individual level, you can promote wholeness at the EOL. How do you promote the normalization of dying and the engagement of the community in your practice?

- Do your role, attitudes, and behaviors lead to individual and community empowerment?
- Do you have an understanding of demographics of the community in order to tailor an appropriate, individualized response?
- Do you provide a follow-up program of patient, family, and caregiver education?
- Are there support groups for carers/bereaved?
- Do you assist in creating supportive environments for your colleagues?

These approaches are well within the scope of practice of the PC nurse. As you can see, much of it is attitudinal; it relates to how you understand your role.

These are just some ideas regarding an HPPC approach—but in the spirit of community development, there is no one way, no recipe that spells it all out for you. Each organization, each practitioner, each community must be assessed so that the strategies developed in response are relevant, focused, and “owned” by all the key stakeholders.

## Implementing HPPC Into Organizations

For PC organizations committed to the implementation of HPPC approaches to their models of care, it’s essential to utilize existing, effective quality improvement approaches. It is most effective to take an organizational approach, including obtaining strategic buy-in from the executive management, as it cannot rest in the hands of a few champions. Rather, building a critical mass of health professionals with knowledge and vision within the personnel of the organization is a key strategy. With a realistic plan for service development that includes a sustainable approach to robust evaluation, then HPPC becomes a realistic goal.

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## CASE STUDY *Continued*

The registered nurse looking after Jack requested permission from him and Mandy to provide face-to-face learning about his condition and its impact. His stepchildren were invited and the teaching activities were action oriented, rather than provided as written information. A support group of carers was found nearby for Mandy. With her children’s help, she was able to attend weekly meetings. She was aware that they also provide support to bereaved carers.

The nurses and other staff of the PC service were concerned about Jack and Mandy’s living conditions. With the support of their organization’s CEO, they began to lobby local housing authorities about the impact of the design of public housing on people living with advanced disease, seeking a review of housing allocation practices.

Mandy’s new friends within the support group raised public awareness of the challenges facing families in their predicament. They approached the local community newspaper to feature this story. With the PC organization’s help, the group ran life-and-death education activities for their community.

The nurses caring for Jack and Mandy identified the need for more robust community evaluation processes that promote appropriate care for the communities they serve. They have entered into a mentoring partnership with a nearby university with expertise in community development, to develop, test, and evaluate a community assessment tool for ongoing use in their service’s model of care.

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## ■ REHABILITATION IN PALLIATIVE CARE

At the EOL, a patient often experiences progressive deterioration in his or her ability to complete his or her everyday activities. This functional decline often results in a person being unable to participate in life as he or she once did. Patients' functional limitations often result from the progression of advanced disease, extended bed rest, chemotherapy or radiotherapy, and surgery. These factors typically present symptomatically as pain, dyspnea, depression, generalized weakness, fatigue, nausea, and vomiting (Lorenz et al., 2008; Santiago-Palma & Payne, 2001). Although the journey at the EOL is different for each person, most want to maintain as much independence for as long as possible and aim to remain symptom free (Belchamber, 2004). However, functional decline that results in an increasing dependency on others negatively affects a person's overall QOL.

Typically, if a patient presents with functional limitations and an inability to complete his or her day-to-day activities, he or she would be offered rehabilitation. Rehabilitation centers on restoring a person's functional ability by addressing any physical, social, psychological, vocational, or spiritual problems that arise due to illness or disability (Jones & Bunnell, 2011; Santiago-Palma & Payne, 2001). These are familiar terms in our earlier discussion about wholeness. However, in PC, patients present with fluctuating health statuses that will ultimately result in a loss of function rather than restoration of previous functional abilities.

In palliative rehabilitation, the aim is to increase a person's QOL by supporting and enabling him or her to live as normal a life as possible (Bray & Cooper, 2004; Tester, 2008). This phenomenon has previously been defined as "rehabilitation in reverse" (Pizzi & Briggs, 2004, p. 123), as it is at odds with the traditional rehabilitation approach that encourages skill development and increased independence to enable a person can reach his or her previous functional ability (Tester, 2008). This creates a paradox of practice approaches and requires health professionals to reconceptualize their practice to focus on assisting the person to adjust to his or her current and future health and functioning status, while still valuing his or her remaining life (Bye, 1998; Pizzi & Briggs, 2004).

While at present the effectiveness of palliative rehabilitation has not been supported with high-level evidence, it's known that palliative rehabilitation can help with symptom control, improving QOL and assisting people continue to live until they die (Cramp & Byron-Daniel, 2012; Mills et al., 2013; Okamura, 2011; Rueda, Sola, Pascual, & Casacuberta, 2004). This is achieved by enabling people to use aids and

equipment, modifying their daily activities, implementing emotional support and coping strategies, and remediating their symptoms (Tester, 2008). To assist a patient to maintain as much independence as possible, health professionals need to view each person and his or her situation individually and acknowledge that the person's abilities will fluctuate and deteriorate over time (Tester, 2008).

Palliative rehabilitation is appropriate to start from the time of diagnosis through to the terminal phase of illness (Okamura, 2011), and can occur in the home, hospital, and hospice settings. Before commencing interventions with patients with advanced illnesses, it is important to have an understanding of the person's needs and his or her expected illness trajectory. The most accepted classification system to determine a person's needs that is used in palliative rehabilitation was initially designed for use in cancer care; it classifies people based on their physical and psychosocial needs (Dietz, 1981). Because it classifies people on a needs basis rather than a diagnosis basis, this classification system has strong relevance for any advanced illness, regardless of diagnosis (Okamura, 2011; Tookman, Hopkins, & Scharpen-von-Heussen, 2004). Dietz's classification (Table 9.2) system is helpful for identifying different rehabilitation goals and planning interventions dependent on the current phase of a person's illness (Bray & Cooper, 2004; Okamura, 2011; Tookman et al., 2004).

### The Role of the Interprofessional Team in PC Rehabilitation

Both PC and rehabilitation focus on the provision of interprofessional coordinated care. Interprofessional teams involve the coordination of care from a variety of specialized health professionals who work together to assist a patient and his or her family to adapt and cope with the impact of the illness or disability (Hearn & Higginson, 1998; Waldron et al., 2011). The number of health professionals in the interprofessional team is numerous and might include a variety of health care disciplines. The most common are general practitioners, PC specialists, surgeons, oncologists, nurses, social workers, occupational therapists, physiotherapists, speech and language therapists, dietitians, psychologists, and pharmacists (Palliative Care Australia, 2008). Most PC services should also have access to alternative therapies and pastoral care workers to complement mainstream care (Palliative Care Australia, 2008). Working as part of the interprofessional team is important in palliative rehabilitation, as it enables the patient to be viewed holistically and receive planned, effective, integrated treatments (Hearn & Higginson, 1998; Tookman et al., 2004).



TABLE 9.2 Rehabilitation Phases in Palliative Care

Phases of Rehabilitation	Goal
Preventive rehabilitation	Should commence at time of diagnosis to reduce the impact and severity of disease impairment. Can be performed pre- or postoperatively or posttreatment and without functional impairment being present. Typically occurs in inpatient settings and focuses on education and information provision.
Restorative rehabilitation	Commences when functional impairments are present. Aims to restore a person to his or her preillness level of functional ability. May occur in inpatient or outpatient settings.
Supportive rehabilitation	Commences when impairments cause functioning to continue to decline and disease advances. Goal is to maintain functional ability through adaptation of the person and the environment, rather than restoration. Compensatory methods such as task modification, energy conservation, equipment, and environmental modifications may be prescribed.
Palliative rehabilitation	Commences in the terminal stages of illness. Aim is to reduce the impact of advanced disease by increasing a person's quality of life through symptom control. Treatment is client centered and targets symptoms such as pain, dyspnea, edema, and contractures through positioning, breathing assistance, relaxation, and assistive devices.

## The Role of Nurses in Palliative Rehabilitation

Nurses are essential in interprofessional care teams in palliative rehabilitation. An early systematic review identified that PC interprofessional teams have been found to be more effective in improving patient and family satisfaction levels and meeting patient and family needs when compared to conventional care (Hearn & Higginson, 1998). Studies have also found that nurses have the role of communicating care plans, updating health professionals on patients' current symptoms and the progression of illness, and providing practical, hands-on assistance both physically and emotionally to health professionals, patients, and their families (Chapple, Ziebland, & McPherson, 2006; Dunne, Sullivan, & Kernohan, 2005; Skilbeck & Payne, 2003).

■ **Goal Setting.** Goal setting is an integral part of the rehabilitation process. However, establishing meaningful and achievable goals in the PC setting can be challenging (Chen & Bradley, 2010). Challenges exist due to a patient's fluctuating functional ability, rate of disease progression, acceptance of diagnosis, and hopes and expectations for the future (Cheville, Khemka, & O'Mahony, 2007). While the central goal of PC is to support, enhance, and preserve a person's function in order to achieve his or her best quality of QOL (Santiago-Palma & Payne, 2001), setting goals in PC can be problematic if the person and his or her care unit are not viewed holistically. Goals should therefore be tailored individually to each person and take into account his or her disease trajectory, current medical status, functional

limitations and presenting symptoms, and psychosocial status (Chen & Bradley, 2010; Jones & Bunnell, 2011).

In order for goals to be achievable with this patient group, it is preferable to set short-term goals due to patients' fluctuating functional performance levels and the uncertainty of time. Short-term goals should relate to the completion of activities that are meaningful to the patient and enable a person to live as normal a life as possible during this period (Jones & Bunnell, 2011). Regardless of the type of goal set, each goal should be continually reassessed. Frequent reassessment ensures that goals remain realistic regardless of disease progression or increased functional limitations. If it becomes evident during reassessment that goals are no longer realistic, discussion must occur with the patient or family member on how to best change or modify the goal to enhance the chance of the goal being met (Cheville, 2001; Jones & Bunnell, 2011).

It is also important to acknowledge that while goals may be initially set with the patient, the goals and wishes of the family members and caregivers are also relevant and have to be addressed. A meta-analysis of randomized trials found that involving the patient's family resulted in enhanced treatment outcomes for both the patient and the caregiver (Northouse, Katapodi, Song, Zhang, & Mood, 2010). For example, involving family and caregivers has been shown to facilitate the achievement of goals, improve QOL, and enhance effective discharge planning (Harding & Higginson, 2003; Northouse et al., 2010).

■ **Interventions.** Patients with palliative diagnoses will present with varying levels of physical limitations and differing symptoms. Each patient will have his or

her own needs, hopes, desires, fears, and goals that he or she needs to face prior to death, as well as differing support systems and anticipated life expectancy, and thus each person will require his or her own tailored rehabilitation intervention plan (Chang et al., 2007; Tester, 2008). Planning interventions in palliative rehabilitation should always occur with involvement of the patient and his or her family, with each patient being considered as an individual.

Nursing interventions in palliative rehabilitation that have been proven effective in increasing a patient's independence predominately revolve around symptom control and provision of psychosocial support to both the patient and his or her family. The most common nursing rehabilitation interventions in PC nursing are related to managing a patient's symptoms of pain, fatigue, and breathlessness (Qaseem et al., 2008; Rueda et al., 2004).

■ **Symptom Control.** Pain is a common symptom experienced by people with a palliative illness. It is estimated that up to 70% of all people with a palliative illness experience some form of pain regardless of their diagnosis (Chang et al., 2007; Dy, 2010). Pain has been found to have acute and chronic origins in people with cancer (Foley, 2004). Cherny and Portenoy (1994) suggest that acute pain is related to diagnostic or therapeutic interventions, anticancer treatments, and infections or complications, whereas chronic pain occurs from tumor infiltration into the nervous system or internal organs and from bony metastases (Cherny & Portenoy, 1994; Dy, 2010). Functionally, pain can affect a person's ability to mobilize, transfer, or participate in meaningful activities of daily living and engage in relationships (Chang et al., 2007; Foley, 2004).

A systematic review that looked at effective treatment strategies for pain found strong evidence to support the use of nonsteroidal anti-inflammatory drugs (NSAIDs), opioids, radionuclides, and radiotherapy to treat cancer pain, and weak evidence to support the prescription of opioids for noncancer pain in patients with a palliative illness (Lorenz et al., 2008). Nonpharmacological rehabilitative interventions found to be effective for pain relief include cognitive behavioral therapy and pain education (Abraham, 1998; Dy, 2010; Ferrell & Rivera, 1997).

Nurses have been proven to be essential for delivering pain education and evaluating its effectiveness for patients (Ferrell & Rivera, 1997). Numerous studies have proven the effectiveness of nurse-led pain management education in the reduction of pain levels (Ferrell, Rhiner, & Ferrell, 1993; Ferrell & Rivera, 1997; Oliver, Kravitz, Kaplan, & Meyers, 2001). Studies have demonstrated that effective pain management education should include both verbal

and written media (Ferrell et al., 1993; Ferrell & Rivera, 1997). Verbal education should address misconceptions and fears about pain treatments, explanation of the WHO pain control ladder, and identification of pain management goals, which in turn include discussing pain with the treating physician and developing strategies to meet these goals (Oliver et al., 2001). Written information should be given to complement the verbal information received, and should contain information on pain management, pain treatments, guidelines for discussing pain with the physician, free space to write down any questions or goals, and a pain scale (Oliver et al., 2001). Before completing pain management education, assessment of existing pain levels should occur to determine any changes in the patient's pain levels as a result of the intervention (Ferrell & Rivera, 1997).

Fatigue is a multidimensional symptom that is widely prevalent in people with a palliative illness; it and has been linked with anxiety-depression, pain, dyspnea, insomnia, anorexia, nausea, and drowsiness (Belchamber, 2004; Eyigor, 2010). These symptoms have a direct impact on a person's ability to engage with his or her daily life, often resulting in a reduced QOL (Belchamber, 2004; Eyigor, 2010). While there has been no formal consensus on a definition of fatigue, it is characterized by a prolonged lack of energy and a feeling of exhaustion that does not resolve with rest (Anderson, Dean, & Piech, 2010; Tester, 2008). However, unlike typical fatigue, it is not proportional to activity expenditure, and consists of physical, emotional, and cognitive elements (Saarik & Hartley, 2010). Interventions for fatigue are varied and can involve fatigue management strategies, psychological interventions, and exercise (Anderson et al., 2010; Belchamber, 2004; Tester, 2008). The goal of fatigue management in palliative rehabilitation is to assist the patient to reduce the effects of fatigue and to maximize the person's existing energy levels (Borneman, 2013).

General fatigue management strategies are often completed in conjunction with other members of the multidisciplinary team such as occupational therapists, dietitians, and physiotherapists. Occupational therapy strategies to manage fatigue include energy conservation education, task modification and pacing to ensure a balance of activity and rest, and distraction therapy (Kealey & McIntyre, 2005; Lowrie, 2006; Vockins, 2004). Dietitians focus on optimizing a person's nutritional intake and prevention of weight loss in order to reduce feelings of fatigue (Borneman, 2013; Lowrie, 2006; Saarik & Hartley, 2010). Exercise has been proven to be the most beneficial intervention for patients with cancer-related fatigue, regardless of their stage of disease (Kumar & Jim,



2010; Saarik & Hartley, 2010). Physiotherapists will tailor an exercise program to meet the patient's needs and stage of disease (Kumar & Jim, 2010). Exercise programs may include walking, resistive exercises, or a combination of exercises (Saarik & Hartley, 2010). Two meta-analyses have been conducted to look at the effect of exercise interventions on cancer-related fatigue (McMillan & Newhouse, 2011; Puetz & Herring, 2012). McMillan and Newhouse (2011) found that aerobic exercise has the most significant effect when compared to aerobic, resistance, and mixed training exercises in patients with breast or prostate cancer. Puetz and Herring (2012) found that exercise not only improved fatigue, but also increased a person's QOL and decreased depression and anxiety both during and after treatment.

Nurses can assist in the palliative rehabilitation process through thorough assessment of a patient's fatigue levels (Borneman, 2013). Assessment should include the use of a visual pain scale as well as discussion surrounding the impact of the fatigue on the patient's QOL and his or her ability to complete activities of daily living. Nurses play a role in empowering the patient and the family by educating them on fatigue management, pain control, proper nutrition and hydration, the importance of exercise, and energy conservation (Borneman, 2013).

Breathing difficulties are an issue for many patients with palliative illnesses, and tend to become more frequent as the person nears the EOL (Bausewein, Booth, Gysels, & Higginson, 2008). Breathing difficulties are most commonly present in patients with diagnoses such as lung cancer (including lung metastases to the chest region or obstruction of the airways or mediastinum); end-stage respiratory failure; end-stage cardiac failure; and neuromuscular diseases (Barton, English, Nabb, Rigby, & Johnson, 2010). Common symptoms of breathlessness include dyspnea, hemoptysis, obstruction, cough, and respiratory secretions (Bausewein et al., 2008; Chan, Sham, Tse, & Thorsen, 2005).

Remediating symptoms of breathlessness is important because they affect a person's well-being on physical, emotional, social, and functional levels (Bredin et al., 1999). For example, breathlessness can raise a person's fatigue levels, resulting in poor concentration, decreased appetite, pain, and memory loss (Chan et al., 2005). Emotionally, breathlessness can cause anxiety and fear, as patients panic because of their uncomfortable awareness of breathing (Belchamber, 2004). Functionally, breathlessness may limit a person's ability to complete his or her activities of daily living, resulting in the person moving less, or dependency while completing simple tasks such as showering and dressing. Breathlessness can also affect how frequently a person interacts with

others and the type of activities that he or she continues to pursue (Belchamber, 2004; Fialka-Moser, Crevenna, Korpan, & Quittan, 2003). The goal of palliative rehabilitation in a patient with breathlessness should be to decrease the symptoms that contribute to the person's breathlessness (Fialka-Moser et al., 2003).

Both pharmacological and nonpharmacological interventions have been proven to be effective for breathlessness (Bausewein et al., 2008; Chan et al., 2005; Lorenz et al., 2008; Rueda et al., 2004). The strongest evidence for pharmacological interventions for breathlessness is for opioid use for people with chronic obstructive pulmonary disease (COPD). However, a nursing-led nonpharmacological intervention found to be effective in reducing breathlessness, regardless of the stage of illness, was education on symptom control (Rueda et al., 2004).

A pilot study looked at the effectiveness of providing breathlessness interventions over one or three sessions (Barton et al., 2010). Twenty-two participants were randomized to receive either a single session or three sessions of education on activity pacing, anxiety management and relaxation, and diaphragmatic breathing. Education was given in person by either a physical therapist or a trained nurse; however, each participant also received a DVD and written material, as well as a telephone call from a research nurse at the conclusion of his or her final session. This study showed a reduction in perceived breathlessness, an increase in coping abilities, and satisfaction in care in the group who received three intervention sessions as opposed to the group who received a single session. While no statistical significance was found, due to the small number of participants and the high attrition rate, this study showed benefits to administering breathlessness interventions over three sessions rather than one session (Barton et al., 2010).

Exercise, diaphragmatic and pursed-lips breathing, and walking and stair-climbing exercises prescribed by physiotherapists have also been proven to be effective in the reduction of breathlessness symptoms (LeGrand, 2002; Lorenz et al., 2008; Syrett & Taylor, 2003). Occupational therapy interventions of task modification, positioning, home modification, and the prescription of bathroom and bedroom equipment has also been found to reduce symptoms of breathlessness for patients (Cooper, 2006; Fialka-Moser et al., 2003). While these types of interventions are typically prescribed by other health professionals, nurses play a role in encouraging patients to remain engaged in their activities of daily living and complete the intervention programs that have been set up by other health professionals.

### ■ Psychosocial Support for Patients and Families.

Psychological distress is common in patients with advanced illness, and has links to fatigue, pain, nausea, and breathlessness (Belchamber, 2004). At present, there is limited evidence to support the role of nurses in the provision of psychosocial support interventions with patients who have palliative illnesses (Rueda et al., 2004). However, one randomized controlled study by Chan, Richardson, and Richardson (2011) assessed the feasibility of running two 40-minute educational sessions combined with progressive muscle relaxation to patients with advanced lung cancer who were receiving palliative radiotherapy, when compared to standard care. Each education session was run in person by a registered nurse; participants were invited to discuss their related symptoms and self-care management and were given written information on the same. Results showed statistically significant changes in the reduction of anxiety, breathlessness, and fatigue in favor of the psychoeducational group over the control group who received standard care (Chan et al., 2011).

Nurses' role in rehabilitation includes liaising with the family (Long, Kneafsey, Ryan, & Berry, 2002). Through communication and rapport building with the family, the palliative rehabilitation nurse is able to provide information, give emotional support, and coordinate care for the family's loved one, thus enhancing a patient's rehabilitation process (Long et al., 2002). Studies have shown that health professionals, including nurses, should routinely assess a patient's family or caregivers' emotional, practical, and supportive needs while caring for a patient with a palliative illness (Qaseem et al., 2008).

However, the exact needs of the family and caregivers of people with a palliative illness have received little research attention. Few interventions have been directly aimed at caregivers, with most focused on patient outcomes (Northouse et al., 2010). However, caregivers' needs must be addressed for them to maintain optimal health and provide the best possible care to the patient. A meta-analysis of caregiver studies found that nursing interventions targeted at caregivers can have many positive effects (Northouse et al., 2010). Caregiver interventions were found to have a significant effect on reducing caregiver burden, improving coping abilities, increasing confidence as caregivers, reducing anxiety, and improving marital and family relationships (Northouse et al., 2010).

Nurses can reduce caregiver burden and improve coping abilities by providing education on the nature of the disease and treatment options for the patient; identifying caregivers' physical, emotional, and supportive needs; and problem solving and evaluating any negative reactions to caregiving (Derdiarian, 1989; Given et al.,

2006; McCorkle, Robinson, Nuamah, Lev, & Benoliel, 1998). A randomized controlled trial by McMillan et al. (2006) provided coping skills education to caregivers of people with cancer over three 1-hour sessions. Nurses taught a problem-solving method that assisted the caregiver to assess and manage patient symptoms by focusing on creativity, optimism, and respite care resources. Findings from this study showed an increase in caregiver QOL scores and a reduction in carer burden related to the patients' symptoms and caregiving tasks (McMillan et al., 2006).

Improving caregiving skills was seen to be an effective way to increase caregivers' confidence in caring for their loved ones (Mokuau, Braun, Wong, Higuchi, & Gotay, 2008). Given et al. (2006) completed a randomized controlled trial with the aim of lowering caregivers' reactions to chemotherapy symptoms and increasing caregivers' involvement in the symptom management of patients with cancer. This 10-week cognitive behavioral intervention was administered by registered nurses with oncology experience to both the patients and their caregivers. Results showed that caregivers who were given education strategies on symptom management, such as monitoring the effectiveness of pain relief medications for pain control, had significantly lower reactions to assisting patients with symptoms and also assisted with significantly fewer symptoms as the patients had improved in their symptom severity (Given et al., 2006).

A randomized controlled trial found that caregiver anxiety can be managed through the provision of telephone counseling and low-impact exercise (Badger, Segrin, Dorros, Meek, & Lopez, 2007). This intervention focused on both the patient with a cancer diagnosis and the patient's partner and was delivered by a psychiatric registered nurse with oncology expertise. The patient received a weekly telephone call for 6 weeks and was given cancer education and interpersonal counseling. While the patient was receiving his or her intervention, his or her partner received a biweekly phone call to discuss his or her own emotional well-being and relationship issues. Counseling for the partner addressed cancer education, social support, identification and management of depression and anxiety, and role transitions. A second group was given a self-directed 6-week exercise protocol, which focused on regular, low-impact exercise such as walking. These patients received a weekly phone call to monitor their progress and encourage them to exercise, while their partners received a biweekly call to encourage exercise and monitor their progress. At the conclusion of the 6 weeks, both the patient and his or her partner's anxiety symptoms had decreased significantly in both the interpersonal counseling and the exercise groups (Badger et al., 2007).



Finally, nurses have been found to play a role in maintaining marital satisfaction, providing family support, and improving couples communication in patients with cancer (Northouse et al., 2010). A secondary analysis of data collected from a previous randomized controlled trial looked at a standardized nursing intervention protocol aimed at improving the QOL for people who had a prostatectomy and their partners (McCorkle, Siefert, Dowd, Robinson, & Pickett, 2007). In the original study, each participant received a 9-minute home visit biweekly, and a weekly telephone call during the alternate week, for a total of 16 weeks. Interventions focused on educating the patient and his or her spouse on symptoms, symptom management, and caregiver-related skills, communication techniques, and intimacy expectations. Results showed that spouses reported significantly higher levels of depressive symptoms and distress relating to marital interactions than the patients. Patients reported significantly higher distress levels relating to sexual function than their spouses. Findings suggest that standardized nursing interventions focusing on symptom management and communication techniques may help patients and their spouses to develop realistic expectations and perceptions of their sexual functioning, as well as increasing their ability to discuss their expectations of each other (McCorkle et al., 2007).

■ **Outcome Measurement.** Health professionals are continually being asked to employ outcome measures to determine if they are providing effective interventions and relevant services for their client group (Bausewein, Daveson, Benalia, Simon, & Higginson, 2011). Outcome measures provide quantifiable evidence of the effectiveness of an intervention by

determining if there have been positive or negative health-related changes (which can be attributed to their health care) in a person's health status over time (Bausewein et al., 2011; Hearn & Higginson, 1997).

Measuring outcomes in PC is often difficult, as clients will continue to decline in their function or they may pass away before a reassessment of their abilities has been performed, confounding the observable effectiveness of the intervention (Pearson, Todd, & Fitcher, 2007). It has thus been suggested that outcome measurement in PC should focus on reflecting the values and goals of PC, which are to improve QOL before death, enhance symptom control, and provide support to the family, rather than on measuring functional gains or losses (Hearn & Higginson, 1997). Therefore, it is more appropriate to select an outcome measure that will reflect a meaningful outcome for the patient who is dying (Gail, 2006).

A review of the literature was unable to provide a consensus on which standardized outcome measures should be used in practice to measure changes in PC (Stiel et al., 2012). This was due to the wide scope of PC outcome measures currently being utilized in clinical practice and research (Table 9.3; Stiel et al., 2012). Findings suggested that outcome measures in PC were selected based on the need to measure a certain dimension or domain of care (Bausewein et al., 2011). Dimensions of care involve physical, social, psychological, or spiritual elements, which provide the health professional with more in-depth knowledge of the problem. For example, a dimension of care may rate the patient's perception of the severity of fatigue as it relates to his or her activities of daily living. Domains may involve the patient, family, and caregiver or multiple physical or psychosocial elements (Bausewein et al., 2011).

**TABLE 9.3 Examples of Outcome Measures for Use in Palliative Rehabilitation**

<b>Multidimensional outcome measures</b>	Palliative Care Outcome Scale (POS) Support Team Assessment Schedule (STAS) European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ-C30) Distress Thermometer Palliative Care Assessment Tool (PACA)
<b>Quality-of-life measures</b>	McGill Quality of Life Questionnaire (MGQOL) McMaster Quality of Life Scale (MQLS) Quality of Life Index WHO Quality of Life Assessment Instrument (WHOQOL) Quality of Life at the End of Life Measure (QUAL-E)
<b>Symptom assessments</b>	Edmonton Symptom Assessment Scale (ESAS) Memorial Symptom Assessment Scale (MSAS) Symptom Distress Scale (SDS) Problem Severity Scale POS-S Symptom List

(continued)

**TABLE 9.3** Examples of Outcome Measures for Use in Palliative Rehabilitation (continued)

<b>Functional status assessments</b>	Karnofsky Performance Scale (KPS) Australian Modified Karnofsky Scale (AKPS) Eastern Cooperative Oncology Group (ECOG) RUG-ADL Hospice Care Performance Inventory (HCPI)
<b>Caregiver assessments</b>	Family Satisfaction With Advanced Cancer Care for the Evaluation of Families' Satisfaction and Perception of Care (FamCare) Carer Coping Scale Carer Distress Thermometer Caregiver Quality of Life Index (CQOL-C)

When selecting an outcome measure for use, one should assess the dimensions of the domains that are appropriate for the client. For example, their need may relate to individual symptoms, their functional status, QOL, or their caregiver, or they may need an outcome measure that is multidimensional (Bausewein et al., 2011).

Regardless of which outcome measure is chosen and implemented, nurses should ensure that the measure has adequate validity and reliability and is responsive to change in the palliative population. Thought should also go into the timing of the measurements taking place (e.g., at the commencement of treatment), and the frequency of measurement, to ensure that each measurement point is long enough to elicit change.

## ■ CONCLUSION

A core concept in understanding the issue of QOL in PC is that the experience of incurable illness and dying, taking on a caregiver's role, grieving and death itself cannot be fully understood solely within a medical context (Byock et al., 2001; Howarth, 2007). The perspective of PC services is deeply founded upon notions of holistic care. Health promotion and rehabilitation are critical to maximizing an individual's function and well-being even in the face of life-threatening illness. Nurses play a key role in promoting the health of the patient and his or her family caregivers across the illness trajectory.

## CASE STUDY Conclusion

Jack was assessed as needing education about his illness, medications, and positioning; psychological support; a social worker to sort out finances and offer support to his family; an occupational therapist for home modification (hospital bed installed downstairs, bathroom changed to downstairs), equipment prescription (hospital bed, pressure care mattress, over-toilet seat, shower chair), and task modification/energy conservation education; and a physiotherapist for mobility aid and breathing exercises.

The goals of Jack's rehabilitation are:

- Increased independence in mobility, toileting, and self-care tasks
- Decreased caregiver burden
- Increased emotional support
- Education regarding the disease trajectory, symptoms, breathlessness, and so forth
- Assistance regarding financial concerns
- Increased feelings of control



## Evidence-Based Practice

### Level II Evidence: RCT, Non-Blinded, Parallel Group

Barton, R., English, A., Nabb, S., Rigby, A.S., & Johnson, M.J. (2010). A randomized trial of high vs. low intensity training in breathing techniques for breathless patients with malignant lung disease: A feasibility study. *Lung Cancer*, 70, 313–319.

#### Background

Breathlessness remains a refractory symptom in malignant lung disease. Breathing training is an effective, non-pharmacological intervention but it is unclear how this should be delivered.

#### Purpose

This feasibility study aimed to assess recruitment and retention, best end point and variability of breathlessness scores in order to calculate sample size for a future study.

#### Design

Single center, randomized controlled non-blinded parallel group feasibility study.

#### Results

22 patients were randomized over 12 months. Screening logs indicated this resulted, in part, from excluding patients who were receiving or who had recently received chemotherapy or radiotherapy. The most useful NRS scores for breathlessness severity were for “worst” and “average” over past 24hrs. From the variability data for “worst breathlessness”, a sample size of 270 should allow detection of a 30% improvement in area under the curve in the three-session group compared with single-session, (90% power;  $p = 0.05$ , two-tailed; 2:1 randomization single:three sessions) allowing 50% drop out at four weeks.

#### Conclusion

The follow-on study will test the hypothesis that three sessions of training improve breathlessness better than a single session.

### Level IV Evidence: Descriptive, Qualitative

Richardson, J. (2002). Health promotion in palliative care: The patients' perception of therapeutic interaction with the palliative nurse in the primary care setting. *Journal of Advanced Nursing*, 40(4), 373–487.

#### Background

Health promotion may seem to be of little relevance in palliative care and for patients within its remit, yet therapeutic nursing, and its core elements of holism, egalitarianism and a humanistic approach, accord with the philosophy of palliative care and are recognized as health promoting nursing practice.

#### Purpose

To identify and describe palliative patients' perception of factors within the interaction with the community palliative care nurse that enhance feelings of health and well-being, and to begin to define health promotion in relation to palliative nursing in the primary care setting.

#### Design

A qualitative methodology was used. Information was obtained from 12 patients by qualitative semi-structured interviews. Data were organized and analyzed using phenomenological analysis.

## Results

The humanistic, interpersonal interaction with the nurse and the professional relationship addressed both disease-related symptoms and a perception of improved psychological health and wellbeing. A combination of therapeutic nursing and a more traditional expert-led approach resulted in the promotion of an enhanced sense of physical and psychological health and well-being, and was an integral part of community palliative care nursing.

## Conclusion

This study provides a description of health promotion relevant to palliative nursing in the primary care setting, which identifies that for many patients, the practice of holistically therapeutic palliative nursing is the ideal.

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# Loss, Suffering, Bereavement, and Grief

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## KEY POINTS

- Loss and suffering are universal experiences that occur across the life span.
- Traditional grieving theories view the process in stages with closure or resolution; contemporary theories view the process as nonstaged, individual, and ongoing.
- Although culture and ethnicity may influence an individual's views on living with and dying from life-threatening illness, individuals must be recognized as unique and encouraged to grieve as best suits them.
- The nurse is on his or her own journey along with patients and their families and significant others who are facing living with and dying from life-threatening illness.
- Nursing presence is an important aspect that can enhance healing in others who are grieving.

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## CASE STUDY

Roberto Carballo, a 69-year-old widower, is hospitalized on a medical-surgical unit in a large West coast teaching hospital. Mr. Carballo is suffering from septicemia and a gangrenous lower right extremity (LRE) resulting from a 5-decade history of having diabetes mellitus (DM). It is felt by Mr. Carballo's physician that Mr. Carballo will not survive amputation of his gangrenous LRE, nor is he responding well to a number of different antibiotics. Mr. Carballo has stated that he thinks he is nearing his time and that he is ready to join his beloved wife Carmelita, who died 6 months earlier.

Mr. Carballo has three adult children: Isabella, a single 47-year-old bookkeeper; Kasandra, a 44-year-old mother of 7-year-old Teresa and 5-year-old Alberto; and Roberto Carballo, Jr. (Bob), a divorced 39-year-old navy captain. Mr. Carballo's two daughters live in the area and take turns staying at their father's bedside. The grandchildren visit Mr. Carballo briefly each day, are curious about "all the tubes in Lito" (Spanish nickname for "grandfather"), and ask many questions about what is happening to their grandfather. Bob is stationed in Guam, has no children, and is kept updated by Kasandra on their father's condition.

## LOSS AND SUFFERING

Like 7-year-old Teresa and 5-year-old Alberto, I was very moved by two deaths in my early childhood: my grandmother's and a little bird's. I was 6 years old. My sister and I were doing our nightly routine. My mother came into our room and sat down on my bed. Mom was crying. She had just received a phone call from "way far away" (my 6-year-old mind's concept of distance) that my grandmother had died. Although I only had seen my grandmother a few times in my young life, I felt very connected to her. I loved her very much, because I felt cherished by her. I also knew my mom and dad loved her greatly, and that Grammie had been sick for a long time. Mom answered our questions and prayed with my sister and me. After my mom and big sister left the room, I remember that I "talked to" Grammie from my bedroom window. I said, "I don't know if you can hear me, but I love you a lot and will miss you." I felt sad and cried. I waited, half expecting to hear an answer from her; it was okay when I did not. It was our little good-bye with one another. I felt secure that she was in Heaven and that Heaven seemed like a good place for her to be if she were dead and no longer on earth. I felt at peace.

The other striking memory related to death occurred at the same period of time. My sister and I were playing in one of our favorite pine-needle-laden spots on our farm. We came upon a dead robin. We were horror-struck to see this beautiful creature lifeless on the ground. We ran and got a dustpan and gently scooted the bird onto it with a little pine branch. We dug a hole, wrapped the bird in a paper towel, respectfully placed it in a shoebox, and laid the bird to rest in its grave. We read Scripture, sang a hymn, and prayed for the bird. I was very grateful I had an older sister who knew how to conduct a proper funeral service for this dear little creature. We were both sad and cried. That also was the first time I remember questioning if animals have souls and where they go when they die.

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Loss and suffering are major experiences along life's journey. How one learns to accept, adapt to, and advance through these experiences determines how the individual will move through life itself. Are loss and suffering perceived as natural, functional,

growth-promoting, and normal dimensions in and transitions through life, or are they perceived as unnatural, dysfunctional, harmful, and abnormal circumstances to be avoided?

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## CASE STUDY *Continued*

On Day 5, Mr. Carballo becomes unconscious. His physician approaches the daughters about a do-not-resuscitate (DNR) order. Isabella does not want their father "to suffer any longer" and wants to go forward with the DNR order. Kasandra informs Mr. Carballo's primary nurse Jake that she wants Mr. Carballo kept alive for as long as possible and thinks her sister just wants him to die. Kasandra indicates she has been in touch with their brother, Bob, and is trying to convince him to come "make things right with Dad so Dad can die in peace when it is his time." On Day 6, a feeding tube is inserted to provide nourishment for Mr. Carballo.

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## ■ LIVING WITH AND DYING FROM LIFE-THREATENING ILLNESS

“Losing, leaving, and letting go” are normal processes that help individuals grow (Viorst, 1987, p. 3). However, contemporary grief theorists suggest that grief may be an ongoing experience in which one connects with the lost relationship via memories, heritage, or spirit, rather than sever the relationship (Moules, Simonson, Fleischer, Prins, & Rev Bob Glasgow, 2007; Moules, Simonson, Prins, Angus, & Bell, 2004). Loss and suffering are inescapable dimensions of life. How an individual transitions through loss and suffering is what remains variable. When planning the patient’s care, it is important for the nurse to note how the patient with a life-threatening illness and his or her significant others view loss, suffering, and living with and dying from such an illness. It also is important for nurses to examine their own beliefs related to these life experiences. Developing awareness of and attending to each person’s perspective is key in formulating successful interventions.

Provision of nursing care takes place within a person’s cultural context. Having an awareness of a patient’s cultural background, as well as his or her usual cultural interventions, is both helpful and important. Variations within specific cultures exist, so it is important to discern with a patient and significant others what specific customs and rituals around death and grief are important and preferred (Choi & Lee, 2007; Clements et al., 2003; Mystakidou, Tsilika, Parpa, Katsouda, & Vlahos, 2003). Holloway (2006) considers death to be a leveler in the context of culture; death causes individuals to face the common humanity of mankind. However, nurses must explore the individual’s specific view of dying and death while considering the individual’s view of self within a given culture or ethnicity.

Narayanasamy (2006, p. 841) details an “ACCESS” model of transcultural nursing (see Table 10.1).

The living–dying interval often is a time of great uncertainty and questioning. Patients may question,

**TABLE 10.1** ACCESS Method of Transcultural Nursing

Assessment	Focus on cultural aspects of clients’ lifestyle, health beliefs, and health practices
Communication	Be aware of variations in verbal and nonverbal responses
Cultural negotiation and compromise	Become more aware of aspects of other people’s culture as well as understanding
Establishing respect and rapport	Requires a therapeutic relation that portrays genuine respect for clients’ cultural beliefs and values
Sensitivity	Deliver diverse culturally sensitive care to culturally diverse groups
Safety	Enable clients to derive a sense of cultural safety

Source: From Narayanasamy (2006).

Why? Why me? Why now? Patients often seek answers to questions related to the meaning of life, the meaning of suffering, the meaning of death, and the meaning of loss. This may be a time of opportunity for the patient to grow and sense a greater wholeness than ever before in spite of an acute awareness of loss, suffering, and grief. Patients living with and dying from a life-threatening illness need to focus on what they are able to do rather than on what they cannot do.

Grief is considered by clinicians in both traditional and contemporary views as work. Grief work involves cognitive and emotional realms. At the heart of grief is “excruciating sorrow,” and at the core of grief work is “spiritual comfort” and “spiritual healing” (Moules et al., 2007, p. 127).

## CASE STUDY *Continued*

Jake has been Mr. Carballo’s primary nurse for 5 of the 6 days he has been hospitalized so far. During that time, he has witnessed the tension that exists between the two daughters and that surrounds Mr. Carballo’s relationship with his son. Jake hopes silently that a DNR is not initiated because he wants Mr. Carballo’s son to come while his father is alive. Jake has not expressed his feelings to the sisters but soon realizes he is overidentifying with Roberto Carbello, Jr. Jake sets up an appointment to meet with his supervisor to process his feelings. Jake shares with his supervisor that he did not get an opportunity to reconcile with his own father before he died 2 years ago.

## The Nurse's Role

Nurses meet individuals across the life span and often at the crossroads of their suffering and loss. Regardless of the setting, nurses are in a unique position to help individuals and their significant others who may be in physical, emotional, social, and spiritual pain related to suffering and loss. The nurse has a broad-based background in providing competent nursing care to individuals across the health–illness continuum. The breadth and depth of each nurse's skills in the specific area of giving care to those living with and dying from terminal illness will be dependent upon numerous factors. Some of these include the nurse's personal beliefs and values, life experiences (professional/nonprofessional), level of comfort with death and dying, educational level, licensure, and interest in this area.

Every nurse must be committed to providing patients, either directly or indirectly, quality care at the end of life (EOL). Critical to helping the nurse fulfill this obligation is a degree of comfort in dealing with death and dying. Student nurses need experience and support coping with dying and deceased patients. One student nurse shared how traumatic it was for her during her senior preceptorship to be left alone while providing her first postmortem care; the staff member assisting her had to step out of the room temporarily. The student nurse expressed frustration with herself that she felt “frozen” and “scared” until the staff member returned. Processing this experience with her faculty member helped her.

Knowledge of the process of dying and the degree of comfort in dealing with others who are experiencing death and dying are two important areas in which the advanced practitioner's education, experience, and expertise will provide more depth in discerning the special needs of the patient. Furthermore, the advanced practice nurse's skill level is more appropriate for dealing with high-risk and complicated situations.

A number of endeavors have been supported to enhance EOL care and further education around death, grief, and bereavement. One project is the End of Life Nursing Education Consortium (ELNEC) funded by the Robert Wood Johnson Foundation. Nurses involved with the ELNEC project developed a curriculum to improve EOL nursing care. Nurses are taught interventions that assist patients and families experiencing loss, grief, death, and bereavement, particularly in relation to effective and supportive communication strategies (Matzo et al., 2003; Matzo & Sherman, 2006). To date, ELNEC has trained thousands of nurses across the United States. Its curriculum has been adapted for critical care, geriatrics, veterans, pediatrics, oncology,

and public hospitals—and has specialty courses for advanced practice registered nurse (APRN) and graduate nurses. The curriculum has been translated into many languages and is being taught in places such as Japan and Africa (American Association of Colleges of Nursing [AACN], 2013). With a growing body of evidence supporting its efficacy, ELNEC arguably is becoming the gold standard in EOL education for nurses.

Communication may be impaired or even unintelligible in the dying patient. In such circumstances, the nurse needs to inform the patient that the nurse is attempting to understand. It also is important for the nurse to convey an understanding of how difficult it must be for the patient to be unable to communicate and that the nurse will make every effort to meet the patient's needs.

Living with and dying from a life-threatening illness can thrust a patient into a sense of uncertainty. Each patient must be allowed to live and die in his or her own way. The nurse may assist patients to express what this way is and help them regain some semblance of control (Ferrell & Coyle, 2008). Nurses must be educated to promote holistic care, recognizing that quality-of-life (QOL) issues that are important to dying patients include finding peace of mind, having a voice and being heard, finding meaning, experiencing comfort, and seeking spiritual understanding (Ferrell & Coyle, 2008).

Fostering patterns that are health promoting and positive for individuals is the ideal in nursing care. Unhealthy patterns need to be identified and interventions provided to promote health and healing even as death approaches.

## ■ EXPERIENCE OF LOSS AND SUFFERING ACROSS THE LIFE SPAN

At birth, an infant is thrust or pulled into a new environment through expulsion and separation from the mother's womb. The infant has no control over this experience. A fairly traumatic transition takes place; one no longer is in the safe and warm environment that provided nourishment and protection during this critical developmental stage. The infant now has to adjust to a new home. This new environment includes the experiences of suffering and loss.

Nearing the 6th month, the infant usually develops an acute awareness of separation from the mother or mother figure. This state is referred to as separation anxiety. This keen awareness of loss may initiate a rudimentary development of death awareness (Backer, Hannon, & Gregg, 1994). This hypothesis is based on Bowlby's (1980) model of attachment between mother and infant and the infant's experience of



separation from the mother. As the individual continues to develop, suffering and loss continue to occur. Generally, this occurrence causes the individual to move from a dependent state to an interdependent state and then to an independent state. In some cases, usually due to more loss and suffering, the individual may return to a dependent or interdependent state prior to death. Thus, life often involves a rhythm of change, interfacing with suffering and loss, from the time an individual is born.

Children under the age of 2 years usually have a sense of separation but little understanding of the concept of death. For children between 2 and 5 years of age, death is seen as a transient state but not a permanent event.

Between 6 and 10 years of age, children begin to grasp the reality of death (McIntier, 1995). Adolescents conceptualize death in a way similar to adults; namely, they are mortal and will eventually die. As the adolescent comes to terms with his or her individuality and increasing independence, there is an increasing awareness of one's own mortality. Although death is considered a future event to adolescents and young adults, death anxiety is more evident than at earlier ages. Middle-aged adults and older adults are more aware and accepting of death. However, no assumptions can be made concerning any age group, and the previous remarks are generalizations. Each individual's response to death is unique (Rando, 1984; see Table 10.2 for developmental views of death).

## ■ THEORETICAL UNDERPINNINGS AND THEORIES ON DEATH AND DYING

Stage theory of grief, although widely accepted, has been empirically tested only recently (Maciejewski, Zhang, Block, & Prigerson, 2007). This longitudinal study consisted of 233 individuals experiencing grief after the loss of a family member to natural causes. The stages encompassing disbelief, yearning,

anger, depression, and acceptance attained peak values in the given sequence when rescaled but not in expected sequencing when examined for most frequently endorsed at initial checkpoints. An interesting finding was that the first four negative indicators all reached maximum values within a 6-month period (disbelief—1 month; yearning—4 months; anger—5 months; and depression—6 months). Acceptance increased throughout the entire 24-month observation period.

As will be reviewed, Engel (1964), Freud (1957), Glasser and Strauss (1965), Kubler-Ross (1969), and Lindemann (1944) developed classical work related to dying and death. Bowlby (1980), Pattison (1977), Rando (1984), and Worden (1991) broadened knowledge in the field with their work. More recent writings by Buckman (1993), Copp (1997), Corr (1992), Evans (1994), and Mallinson (1999) have challenged, as well as added to, previous theoretical information. New information relevant to theories on death and dying is expanding rapidly. Contemporary research on death and dying views the time frame for grief resolution in a less restrictive way than earlier writings. Although different in some ways, most of the authors demonstrate a similar thread and core knowledge related to grief work that is helpful to both the beginning clinician and the advanced practitioner.

Freud (1957) brought the concept of grief work to the forefront after examining his personal feelings and societal observations following the mass losses brought about by World War I. Freud saw grief as a necessary process to assist an individual in adapting to loss. He also felt an individual needed to free him- or herself from attachment to the “lost object.”

Lindemann (1944) studied bereavement in individuals who were survivors of the Coconut Grove Hotel fire in Boston (as well as their close relatives); patients who lost a relative while in treatment; relatives of members of the service; and relatives of patients who died while in the hospital. He determined that common physical symptoms, affective symptoms,

**TABLE 10.2** Developmental Views of Death

Age (Years)	Stage of Development	Task/Area of Resolution
Birth <2	Infancy	Sense of separation; no concept of death
2–5	Early childhood	Death is transient; is not a permanent state
6–10	Late childhood	Beginning awareness of the reality of death
11–25	Adolescence–young adulthood	Similar to adult view—realization of mortality and eventual death; death anxiety more evident; death perceived as a future event
26–65	Middle-aged and older adults	More aware and accepting of death

Source: Adapted from McIntier (1995) and Rando (1984).

behavioral manifestations, and physiological changes accompanied each grief experience. Lindemann also first alluded to anticipatory grief in relation to women anticipating the potential death of significant males in their lives during World War II.

Engel (1964) cited three stages through which one progresses in uncomplicated bereavement: shock and disbelief; developing awareness; and restitution and recovery. Engel pointed out that denial predominates initially and helps prevent the individual from being totally overwhelmed. During the second stage, the individual may express guilt and cry. Finally, thoughts and memories of the deceased are discussed and behaviors of the deceased may be displayed by the bereaved.

Glasser and Strauss (1965) examined different contexts related to caregivers and patients' relation to knowledge about a patient's dying. They suggested that there are four states of awareness related to dying: closed awareness, suspicion awareness, mutual pretense awareness, and open awareness. In the first context, closed awareness, caregivers are aware that the patient is dying but keep that information from the patient. In suspicion awareness, the caregivers know that the patient is dying, but the patient only suspects he or she is dying. The patient is ambivalent about wanting to know and not wanting to know that he or she is dying. In the mutual pretense context, both the caregiver and the patient act as though they do not know the patient is dying, but both know that the patient is. Within the context of open awareness, there is a sharing of knowledge, information, and communication about the patient's dying between the caregiver and the patient (Glasser & Strauss, 1965; Rando, 1984).

Kubler-Ross (1969) studied more than 200 patients diagnosed with terminal cancer. Her work was pivotal in theorizing that individuals move through (not necessarily sequentially) five phases when trying to cope with pending death. These five stages are denial and isolation, anger, bargaining, depression, and acceptance. In the denial and isolation phase, an individual experiences shock and disbelief. A comment such as "I don't believe this is happening" may be made. During the anger phase, the individual questions, "Why me?" Anger often is displaced. The individual may try to rationalize during the bargaining phase by pleading or regretting, "Yes, me, but..."; bargaining is an attempt to postpone death and extend life. It involves self-imposed deadlines. During the depression phase, the individual may express feelings of guilt or sadness, such as "Yes, this is happening to me." There often is an awareness of great loss for the patient. In the acceptance stage, the struggle is over. The individual has come to accept imminent death and is ready to let go and move on. A comment such as "My time is close; it's all right now" may be made.

Pattison (1977) was the first to focus on a model that examined the "living-dying interval." Pattison defined that interval as existing between knowing that death was imminent and the actual point of death. He incorporates three clinical phases within the living-dying interval: the acute crisis phase, the chronic living-dying phase, and the terminal phase. During the acute crisis phase, the patient is confronted with the knowledge that a process beyond the patient's control influences his or her death. The chronic living-dying phase involves an acute awareness of living and dying simultaneously. Finally, the terminal phase commences when the patient starts withdrawing from the outside world. There is an internal awareness that the patient must conserve energies for him-/herself.

Bowlby (1980) described four phases of bereavement: numbness; yearning and searching; disorganization and despair; and reorganization. His theory is based on an attachment model in which the child must separate from the mother. The process includes (a) shock and disbelief related to the loss (numbness); (b) protest involving an attempt to regain the lost object (yearning and searching); (c) an intense sense of despair in which the individual tries to regain the lost object (disorganization and despair); and (d) completion of the mourning when the individual stops searching and develops new relationships (reorganization; Evans, 1994).

Worden (1991) refers to four tasks of mourning: accepting the reality of the loss; experiencing the pain of grief; adjusting to an environment in which the deceased is not there; and emotionally relocating the deceased and moving on with life. Mourning may become maladaptive if an individual's response is to avoid, distort, amplify, or prolong grief (Kissane & Bloch, 2002).

Rando (1984) cites six processes of mourning or grief work: recognizing the loss; reacting to the separation; recollecting and reexperiencing the deceased and the relationship in a realistic way; relinquishing old attachments to the deceased and the assumptive world; readjusting to move adaptively in the new world without forgetting the old; and reinvesting. Rando (1984) considers that complicated grief may exist if there is compromise, distortion, or failure of one or more of the six "R" processes occurring after consideration of the amount of time since death.

As mentioned, Buckman (1993), Copp (1997), and Corr (1992) developed more contemporary theories. Corr expanded the theoretical premise of task work postulated by Pattison (1977) and Kalish (1979) to include four major areas of task work in coping with dying, specifically physical, psychological, social, and spiritual loss. Addressing physical tasks involves meeting bodily needs satisfactorily and minimizing the individual's physical distress. Working through



psychological tasks maximizes the individual's psychological security, autonomy, and richness of living. In order to meet social tasks, interpersonal attachments of significance must be sustained and enhanced in addition, individuals must be assisted to explore social implications of dying. Likewise, spiritual task work involves determining and affirming sources of spiritual energy that, in turn, stimulate hope.

Buckman (1993) promoted the concept that grief is more characteristic of the individual than of the individual's progression through particular grief stages. The second major point made by Buckman is that an individual's movement during the grieving process is dependent upon resolution of various issues related to emotions rather than changing from one emotion to another, as in Kubler-Ross's model. Additionally, Buckman addressed other responses to dying, such as fear of dying, guilt, hope, despair, and humor (Buckman, 1993).

Copp's (1997) work with dying individuals and the nurses caring for them examined two additional dimensions that seem to occur within the dying individual: readiness to die and a body-person split. Copp observed many direct and indirect actions between patients and nurses: protecting and letting go, watching and waiting, and holding on and letting go. Copp further noted a distinct reference by nurses and patients to the body as separate from the self in relation to patients who were nearing death. A dying individual's personal acceptance of imminent death and physical condition determined the individual's readiness to die. The states of readiness included the following: (a) person ready, body not ready; (b) person ready, body ready; (c) person not ready, body ready; and (d) person not ready, body not ready. One major thrust of Copp's (1998) work is that the dying experience impacts everyone who is involved with the dying patient.

Theories are emerging that demonstrate the ongoing process and complexity of reconstructing meaning for individuals who have experienced a loss versus traditional, linear, stage theories (Pilkington, 2008). These theories are supported through qualitative studies, such as those related to parents dealing with loss of an infant through sudden infant death syndrome (SIDS; Krueger, 2006).

Florczak (2008) incorporates Parse's (2007) human becoming theory in her contemporary conceptualization of grief. Florczak's views vary from traditional ones in that she asserts as follows: (a) the loss is maintained, not severed; (b) a changed meaning about the loss occurs; and (c) sorrow persists related to unfamiliar-familiar patterns being woven into one's life related to the loss (Florczak, 2008).

In contemporary grief theory, grief is seen as dynamic, individualized, pervasive, ongoing, and

normative (Cowles & Rodgers, 2000). Contemporary theorists address masculine and feminine differences in grieving (Baum, 2003; McCreight, 2004; Thomas, 2004).

As Pilkington (2006) points out, many of the studies done in relation to human becoming theory are qualitative. Thus, they are not generalizable. However, they provide knowledge for nurses to better understand the importance of presence and to better relate to those who are grieving. Although sorrow related to the loss may continue, the meaning attributed to the loss may change as the individual continues to journey through the process of separating-connecting (Florczak, 2008).

In recent years, Bonanno has challenged many assumptions regarding the way in which people react to bereavement and grief. Following subjects over long periods of time and utilizing sophisticated modeling techniques, Bonanno's research suggests that the most common reaction to grief is not prolonged distress or depression but a stable trajectory with minimal disruption of healthy functioning (Bonanno, Westphal, & Mancini, 2011). Termed *resilience*, this method of coping is often predicted by a number of personality traits present prior to the grief experience. Some of these traits include hardiness, self-enhancement, and a tendency toward positive emotions (Bonanno, 2004). Additionally, Bonanno rejects the notion that people grieve in stages or react to grief experiences in similar ways and instead reports that there is wide variability in response to grief.

## ■ DIMENSIONS OF LOSS, SUFFERING, GRIEF, AND BEREAVEMENT

### Definitions

■ **Loss.** Defined as being deprived of something or someone, loss can be actual, potential, physical, or symbolic. Loss related to health, function, roles, relationships, and life itself is the central focus of this book. Losses other than the death of the loved one are referred to as secondary losses (Rando, 1984).

Mitchell and Anderson (1983) describe six types of loss: materialistic, relational, intrapsychic, functional, role, and systemic. Material loss involves separation from a physical object or surroundings. In relationship loss, an individual no longer has the ability to relate to another individual. Intrapsychic loss impacts an individual's self-image through loss of what might have been, changed perceptions, lost emotions (i.e., faith, hope, or courage), or emotions

that result when a major task has been completed successfully. Functional loss occurs through bodily decline or deterioration in illness or aging. Role loss results when an individual changes or loses a customary role (e.g., healthy person to terminally ill person) or acquires a new role (e.g., patient). Systemic loss involves the loss of contact with customary behaviors or functions within a system, such as absence from a usual work environment or home environment.

Loss can be primary or secondary. Primary loss refers to the initial loss (whether of health for the patient or possibly loss of the patient through death for the significant others). Secondary losses stem from the initial loss. As a result of being diagnosed with a terminal illness, the patient also may experience secondary losses of roles, job, income, and so forth. Significant others may experience secondary losses of roles, income, their own health, and so forth.

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### CASE STUDY *Continued*

Mr. Carballo's family members and caregivers are experiencing "anticipatory grief," as they watch Mr. Carballo's condition decline. His gangrenous LRE is becoming much worse. He is not responding to any treatment attempts.

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■ **Suffering.** Suffering is defined as the bearing of pain or distress. Suffering impacts a patient's body, mind, and spirit. Cassell (1991) defines suffering as "the state of severe distress associated with events that threaten the intactness of person" (p. 33). Cassell recognizes the importance of human suffering within any of the human dimensions, such as body, mind, and spirit. He also advocates asking individuals about the presence or absence of suffering because suffering is a very individualized experience and may result from treatment as well as from the disease process or a number of other events. Ferrell and Coyle (2008) assert that relieving suffering is the crux of nurses' professional work.

According to Georgesen and Dungan (1996), the presence of pain compounds suffering and results in spiritual distress. Pain is a frequent companion of terminal illness. Suffering can be present with or without the presence of pain. Suffering, however, cannot be treated or managed like pain. Suffering is a personal experience. Framing suffering in a religious, philosophical, or personally meaningful perspective can help patients endure it better (Rando, 1984). Physical pain is associated with psychological, social, and spiritual distress; pain that continues without meaning results in suffering (Ferrell & Coyle, 2008).

Suffering can be acute or chronic. Acute suffering occurs when the patient is in crisis and confronted with an immediate loss. Chronic suffering results from the longer-term realization and impact of a loss that carries a great deal of significance for, and

meaning to, the patient. The patient with a terminal illness may experience only one type of suffering, both types at different times, or both simultaneously. Intervention involves trying to understand the patient's suffering and trying to help the patient cope effectively with suffering. Key to helping the suffering patient is attempting to understand the meaning of the suffering and attempting to comfort and sustain the individual through it.

Similar to chronic suffering is the middle-range nursing theory of chronic sorrow introduced by Eakes, Burke, and Hainsworth (1998). Chronic sorrow is viewed as normal in response to the recurrent experience of ongoing, significant loss that may be actual or symbolic or both. Major concepts within this theory relate to the following: losses, disparity between reality and idealism, trigger events or milestones, and an individual's internal and external means of managing recurring grief that accompanies chronic sorrow. One of the key antecedents to chronic sorrow, namely, disparity between the individual's current reality and idealized reality, is what differentiates chronic sorrow from chronic suffering. An individual experiencing chronic suffering does not necessarily face disparity with chronic suffering. Interventions are aimed at helping the patient with chronic sorrow acknowledge and bear his or her pain, with the goal of redefining the overwhelming scope and impact of a loss into more manageable proportions, thereby decreasing the impact of chronic sorrow on daily living (Rossheim & McAdams, 2010).



## CASE STUDY *Continued*

Mr. Carballo groans occasionally. His daughters Isabella and Kasandra ask Jake, the nurse, if Mr. Carballo is in a lot of pain. Jake assures them he will do a thorough pain assessment and ask for more pain medication if needed. Isabella tells Jake she cannot bear to see Mr. Carballo in physical pain and that she saw her mother suffer “a painful death at home when she had a heart attack.”

■ **Grief.** Grief is defined as deep or intense sorrow or distress, particularly arising from bereavement concerning someone to which a close bond was formed. Rando (1984) describes grief as a normal reaction to the perception of loss. Grief is generally a transitory, acute state in response to loss with the possibility that the individual's ability to function may be disrupted temporarily. In addition, the individual may be distracted, disoriented, distressed, or all of these (Mallinson, 1999). Feelings that may accompany grief include anger, shame, helplessness, sadness, guilt, despair, relief, peacefulness, calm, and release (McCall, 1999). Charleton (2003) asserts that stages of grieving might include any or all of the following: “distress, shock, denial, anger, feeling ‘low in spirits,’ depression, resignation, acceptance, resolution” (p. 671).

Common grief responses are listed (see Table 10.3). These responses may involve physical, psychological, and spiritual/sociocultural responses. They may have aspects that seem contradictory in nature. The impact of grief can be extensive and pervasive. Anticipatory grief, those feelings of grief experienced prior to an expected loss, generally assists individuals in working through depression related to the upcoming death, rehearsing of the death, adjusting to the consequences of the death, and having an increased concern for the terminally ill (Fulton & Fulton, 1971). Rando (1984) views anticipatory grief as also allowing for gradual absorption of the reality of the loss, helping resolve unfinished business, changing assumptions about life and identity, and making future plans.

**TABLE 10.3** Grief Responses

Physical	Psychological	Spiritual/Sociocultural	Dichotomous Nature
<ul style="list-style-type: none"> <li>■ Shortness of breath</li> <li>■ Insomnia</li> <li>■ Loss of appetite</li> <li>■ Loss of sleep</li> <li>■ Energy loss</li> <li>■ Greater susceptibility to illness</li> <li>■ Sighing</li> <li>■ Nervousness and restlessness</li> <li>■ Sensation of something in the throat</li> <li>■ Feelings of emptiness or heaviness<sup>a</sup></li> <li>■ Heart palpitations</li> <li>■ Crying</li> <li>■ Psychomotor retardation</li> <li>■ Decreased libido or hypersexuality</li> <li>■ Weight loss<sup>b</sup></li> </ul>	<ul style="list-style-type: none"> <li>■ Depression</li> <li>■ Anxiety</li> <li>■ Guilt</li> <li>■ Anger and hostility</li> <li>■ Anhedonia</li> <li>■ Self-reproach</li> <li>■ Low self-esteem</li> <li>■ Helplessness and hopelessness</li> <li>■ Sense of unreality</li> <li>■ Suspiciousness</li> <li>■ Interpersonal problems</li> <li>■ Imitation of the deceased's behaviors</li> <li>■ Idealization of the deceased</li> <li>■ Ambivalent feelings about the deceased<sup>a</sup></li> </ul>	<ul style="list-style-type: none"> <li>■ Spiritual pain and suffering</li> <li>■ Spiritual loneliness</li> <li>■ Fear of God, the unknown, and/or the future</li> <li>■ Feelings of failure and guilt</li> <li>■ Feelings of unfairness and anger</li> <li>■ Loss of transcendence</li> <li>■ Hopelessness<sup>a</sup></li> <li>■ Search for meaning</li> <li>■ A need for love and hope</li> <li>■ A sense of forgiveness<sup>b</sup></li> <li>■ Participation or lack of participation in formal religious group</li> <li>■ Views related to use of “extraordinary” life-prolonging measures</li> <li>■ Beliefs related to afterlife</li> <li>■ Handling of the body after death</li> <li>■ Rituals performed after death<sup>c</sup></li> </ul>	<ul style="list-style-type: none"> <li>■ Universal/individual</li> <li>■ Benign/malignant</li> <li>■ Life-giving/life-requiring</li> <li>■ Active/passive</li> <li>■ Internal/external</li> <li>■ State/process</li> <li>■ Heart/head</li> <li>■ Inarticulate/poetic</li> <li>■ Celebration/beravement<sup>a</sup></li> </ul>

Physical—<sup>a</sup>taken from Lindemann (1944); <sup>b</sup>taken from Rando (1984).

Psychological—<sup>a</sup>taken from Lindemann (1944).

Spiritual/sociocultural—<sup>a</sup>taken from Stuart and Sundeen (1991), p. 154; <sup>b</sup>taken from Pritchett and Lucas (1997, p. 203); <sup>c</sup>taken from Kazanowski (2013).

Dichotomous—<sup>a</sup>taken from Moules et al. (2007, p. 122)

Evans (1994) challenges the belief that anticipatory grief experienced prior to death is the same process as the conventional grief experienced in the postdeath period. Evans proposes use of the label “terminal response” to describe the process that occurs between diagnosis of terminal illness and death. Differences

noted between pre- and postdeath grieving include the following: (a) anticipatory grieving ends at the time of death, whereas conventional grieving can go on indefinitely; and (b) anticipatory grieving increases as death draws nearer, but conventional grieving usually diminishes in intensity with time.

### CASE STUDY *Continued*

Talking with his supervisor helped Jake deal with some of his unresolved grieving issues related to his own father’s death. When Jake goes home after his 3 to 11 p.m. shift on his sixth shift of providing care for Mr. Carballo, Jake takes out pictures of his father and him. He cries about the loss of his father for the first time since his father’s death.

Jake decides to make sure Mr. Carballo’s family members are offered resources that might help them deal with their father and grandfather’s pending death. He recalls how pained Isabella appeared the night before and suggests she talk with the spiritual care advisor connected with his unit. He also decides to talk with Kasandra about any needs she or her children might have in relation to Mr. Carballo’s care and pending death.

■ **Bereavement.** Bereavement is defined as the state or act of being deprived of a loved one. McCall (1999) describes bereavement as the “overall reaction to the loss of a close relationship” and sees it as a description of various “patterns, phrases, and/or stages that an individual goes through when grieving” (p. 42). Mallinson (1999) depicts bereavement as the long-term process of the survivor’s accommodating his or her life without the loved one. Bereavement is a major life event that can result in an individual’s having impaired health (Charleton, 2003).

*Mourning, grief, and bereavement* often are used interchangeably. Mourning often encompasses a sociocultural dimension and involves customs and rituals that are influenced by sociocultural and religious beliefs and values. Rando (1984) differentiates among the three in the following ways: (a) grief is the response to the perception of loss and is a transitional phase in the overall process of mourning; (b) mourning is the intrapsychic processes initiated by loss; and (c) bereavement is the state of having suffered a loss (pp. 15–16).

### CASE STUDY *Continued*

Jake decides that he is going to write a letter of reconciliation to his father, go to his father’s grave on his next day off, and read it to his father. He tells his supervisor the next day how helpful her suggestions to him were.

### ■ SIGNIFICANCE AND MEANING OF THE RELATIONSHIP TO LOSS AND SUFFERING

The intensity of loss for the dying patient and his or her significant others relates directly to each individual’s perceptions of how close the relationship is and how great the loss of this relationship will be. The significance of the relationship impacts how the individual will interpret the loss and the accompanying suffering. The meaning that the patient, significant others, and nurse assign to loss and suffering also

will determine how each individual faces the patient’s dying and death. Interpretation of loss and suffering is unique to each individual and to each individual’s particular circumstances.

Relationships fall into three categories: social, intimate, and therapeutic (Brady, 1997). Social relationships incorporate the everyday contacts individuals have, such as work colleagues and casual friends. Both individuals in this type of relationship are attempting to have their needs met. There is no particular goal within this relationship. Intimate relationships imply



commitment by both individuals to one another. Therapeutic relationships involve goal-directed interaction with the purpose of helping one individual obtain an anticipated outcome to meet an identified need and facilitate growth.

The degree of intimacy and involvement within a relationship is not necessarily dependent upon the relationship's being a long-term one versus a short-term one or a blood relationship versus a nonblood relationship. Many factors determine how an individual will view his or her relationship with another individual. Some of these factors include respect, responsibility, commitment, compatibility, values, biases, beliefs, and time.

The stage of growth and development of the individual with terminal illness influences his or her ability to cope with the loss, suffering, and grief related to terminal illness. The stage of growth and development of significant others and the nurse also determine their ability to cope with the loss, suffering, grief, and bereavement related to the patient with a terminal illness. In addition, the stages of growth and development for all three groups (patient, significant others, and nurse) significantly impact how each will deal with the other.

Two of the most difficult aspects of a terminal illness are the accompanying uncertainty and unpredictability. These two factors may stress the relationships between the patient, the significant others, and the nurse. For some individuals, not knowing what is going to happen to the patient and when it might happen are difficult and unbearable aspects of coping with the patient's terminal illness.

Balancing aspects of "getting through it" and "accepting that it will take time and a lot of hard work" were critical in a study involving 39 families who each had a child diagnosed with cancer (Woodgate & Degner, 2003, p. 117). In addition, support from the family unit was considered most important for helping maintain one's spirit and keeping the family together. Families wanted to share the entire experience of their children's having cancer and not focus on symptomatology.

Some terminal conditions, such as HIV/AIDS, may not be discussed by the patient or significant others who fear stigma or repercussions. In such situations, it is imperative that the nurse understand and be ready to assist the patient and significant others in sharing the pain associated with these conditions.

Nurses, patients, and caregivers assigned similar meaning to pain in a study of patients with cancer (Ferrell, Taylor, Sattler, Fowler, & Cheyney, 1993). Although both nurses and patients viewed pain as a challenge, nurses saw the challenge to eliminate pain, whereas patients saw the challenge to live with the pain in order to obtain vitality. Caregivers greatly

empathized with the patient's pain and experienced personal suffering and grief. Grief was triggered by pain, as it represented death to the caregivers.

Furthermore, an individual's view of change itself will help determine how that individual will accept loss and suffering related to his or her terminal illness. Has the individual's pattern been to welcome and embrace change or resist and fear change? The answer to that question can assist the nurse in implementing care that will help the patient and significant others to grow through the loss and suffering associated with the patient's terminal illness. Knowledge of change theory can help the advanced nurse facilitate acceptance of, and growth through, loss and suffering for the patient, significant others, and the nurse. Knowing the benefits and risks of change, change strategies, and resistance to change can help the nurse maximize the many changes within the patient's life.

### ■ ASSESSMENT—WHERE AM I (THE NURSE) ON THE JOURNEY?

In order to be an effective caregiver to the dying patient and the significant others, nurses must come to terms with their own mortality and views on dying and death. Death is an inevitable outcome of life for each individual. The death of a patient with a terminal illness forces the nurse to acknowledge that a cure cannot always be achieved. Fear related to death and dying is normal. Likewise, issues related to grief and bereavement during the death and dying process also are normal and even necessary for healthy adaptation to the preceding loss and suffering.

In American culture, individuals generally believe that explanations for dying always should be given. Furthermore, Americans feel that options to deal with the dying process always should be available (Kazanowski, 2013). This widely held belief impacts the nurse, as well as the patient and significant others, in relation to high expectations of cure, treatment, care, and avoidance of a painful death. This approach is considered by some to be the "medicalization of human mortality"; this approach has limitations, however, because it cannot address psychological and spiritual factors associated with the suffering related to dying (Kissane & Bloch, 2002, pp. 78–79). Furthermore, with an increasing number of states examining physician-assisted suicide or death with dignity laws, the nurse will be called upon to determine further how to participate and assist—or not—in this process.

Nurses are encouraged to maintain their composure when caring for patients. However, professionalism for the nurse within this context does not require that the nurse deny emotional engagement with the patient and

significant others during the dying process and bereavement period. It does require, however, that the nurse's needs be subordinate to the needs of the patient and significant others. Constructive self-disclosure of feelings by the nurse may role model to others a healthy process of acknowledging and resolving the suffering of loss. The nurse may or may not actually cry with the patient and significant others. If crying occurs, the nurse needs to be able to direct this situation into a meaningful and positive one for the patient and significant others. Empathy appropriately shared in this manner may well be described as a "therapeutic tear."

Lewis (1998) describes a strategy used to assist nursing students in working with patients and significant others who are experiencing loss and grieving. The learning activity is called *Culture and Loss: A Project of Self-Reflection*. Student nurses are requested to examine how their culture handles loss, to prepare a creative presentation for a small group of peers on how their culture responds to loss, and to describe to their class the meaning of their project and how it connects to their culture. Goals for implementing this strategy are identifying personal responses to loss; recognizing differing responses to loss and the influence of individual and cultural factors; and learning skills related to supporting individuals who are grieving.

Spencer (1994) examined which strategies were helpful to nurses in dealing with their own grieving. The most significant strategy noted was the nurse's informal network of peer group support. In addition, the nurses recommended formal group support and increased grief resolution training. When a team is involved, it is helpful to provide an opportunity for staff members to have open communication and to sustain and care for one another (Leichtling, 2004). There are numerous other health-promoting strategies to help the nurse cope with caring for dying patients. These include regular exercise, good nutrition, diversional activities, focus on caring rather than curing, emphasizing the positive dimensions of the nurse's role, and recalling positive experiences with families (Pritchett & Lucas, 1997).

Advances in technology have prolonged dying and death in our culture. As a result, advance directives have taken on greater significance in relation to EOL care. Studies have indicated that patients who have prepared advance directives select palliative care (PC) more frequently, are more accepting of death, and have less expensive care and less aggressive treatment (Danis, 1998).

There are incongruences between the ideal and reality in EOL care. First, clinicians are expected to be able to predict the expected time of death for a terminally ill patient; however, this involves a great deal of uncertainty. Goals of care may need to change quickly as the patient's condition changes or therapeutic trials fail. Second, it is expected that the patient's clinicians know the patient's wishes concerning dying and

death. In reality, organizational factors may impact the patient's care more than the patient's wishes during the EOL process. Third, it is thought that the patient's care is well coordinated. Often this is not the case because some intensive care facilities are staffed with their own primary care providers who may not know the patient admitted with a terminal illness. Therefore, it is important for the nurse to work closely with the patient and the significant others concerning the patient's priorities and wishes. Finally, the measurement of goals and outcomes may not be congruent. Measures of care for dying patients usually focus upon frequency of DNR orders and lengths of time a patient spends on life support or in a coma. It may be more important to patients and significant others to examine issues related to pain management and satisfaction with care (Danis, 1998).

Confronting death with a terminal illness is difficult, painful, and complex. Nurses need to be strong advocates for satisfactory pain management. Keeping abreast of the patient's treatment wishes (which may change during the dying process) and coordinating care between facilities and providers also are important. Additionally, nurses may need to coordinate EOL care through use of hospice programs or PC in various settings: hospital, nursing home, or community (Kazanowski, 2013).

## Personal Experiences With Death

Personal experiences with dying and death influence how nurses give care to those who are dying and their significant others. For example, examining personal experiences can help nurses understand their own fears and anxieties related to dying and death. Understanding the meaning and significance of relationships helps put the loss in perspective. The nurse's ability to articulate feelings regarding a good or bad death is important when working with individuals who are dying. Exploring individual values and biases can enhance the nurse's competence; this helps the nurse better understand an individual's health care attitudes and behaviors (Warren, 1999).

Kazanowski, Perrin, Potter, and Sheehan (2007) developed a course in which student nurses examine their personal losses in a progressive manner, both in terms of level of difficulty and level of disclosure. The intent of the course is to assist students in coping with the suffering of patients with whom they are working as well as the suffering they are experiencing themselves in witnessing such suffering. Ideas from the course have broadened to assist nurses in processing patient suffering and their own suffering in various settings and points in their professional journey (Perrin, Sheehan, Potter, & Kazanowski, 2012).



Offering one's presence to patients, families, and significant others affects nurses. The impact on a nurse researcher, supervisor, and two transcribers was examined in addition to data obtained from the original sample group of 38 pregnant women in a grounded theory study exploring their experiences after hearing they had a diagnosis of fetal abnormality (Lalor, Begley, & Devane, 2006). The three themes that emerged were as follows: bearing to watch, bearing to listen, and bearing to support. Painful stories cause strong emotional reactions to those interacting with such information (Lalor et al., 2006). Nurses identify sources of suffering for patients and offer their presence to help patients move through the suffering (Ferrell & Coyle, 2008).

Use the following exercises to help you expand your self-understanding in relation to loss and suffering, dying and death, and grief and bereavement.

### Self-Reflective Questions

- What experiences have you had with death? Describe your earliest memory of death. Was anything positive about it? Was anything negative about it? Have you experienced what you would call a "good death"? Have you experienced what you would describe as a "bad death"?
- Can you picture yourself helping someone who is dying? How? What do you have to offer that is special and unique?
- Relate what you believe happens when someone dies. What do you fear about death? What do you fear about your own death?
- Assume you have just received news that you have been diagnosed with a terminal illness. What would be the most difficult things for you to have to give up during this time?
- How do you feel about cultural attitudes or behaviors that may be different from your own?

### ■ ASSESSMENT—WHERE IS THE PATIENT ON THE JOURNEY? THE LIFE CYCLE CONTINUUM—ACROSS THE LIFE SPAN ON THE JOURNEY

Living with and dying from a terminal illness can be best understood within the context of a continuum. One generally does not remain on a fixed point along the continuum. Like one's view of health and illness, living with and dying from terminal illness is a dynamic and fluid experience in which the individual moves back and forth across the continuum.

Reactions to dying and death vary across the life span. They also are dependent upon physical, psychological, spiritual, and sociocultural factors that impact the individual's sense of wellness. Physiological

change can lead to a sequelae of loss: function, body image, self-esteem, sexuality, and role competence. Furthermore, interfacing of the various factors has the potential to result in grief over lost health (Talerico, 2003). The living–dying interval occurs from the time death is acknowledged as imminent to the point of the actual death. A difficult task during this period is continuing to treat the individual as still living; in other words, as a person and not just a patient. Tasks that the individual needs to attend to are arranging his or her affairs; coping with loss (loved ones and self); attending to future care needs; planning remaining time; confronting loss of self and identity; facing one's own death encounter; deciding whether to succumb to or resist the dying process; and struggling with the psychosocial problems of dying. Some of the issues for the individual during this period of time include treatment choices, remissions and exacerbations, expression of sexuality, financial pressures, employment concerns, struggle for control, and suffering (Rando, 1984).

Depending on level of maturity, the patient may be confronted with the meaning of life, relationship with God and others, and the reality of death (Georgesens & Dungan, 1996). In addition, the patient may face losses related to independence, control, work, physical comfort, a sense of normalcy, sexual activity, and usefulness when living with a life-threatening condition (Ferrell et al., 1993). For example, it may be difficult for older adults who have served as caregivers to receive care from another because of loss of independence. An aid to this transition of caregiving may be to enable older adults to focus on ways they can affirm the individuals now serving as caregivers to them (Talerico, 2003).

Once rapport has been developed, the nurse may suggest that the patient and the patient's significant others consider attending a support group. Support groups have been found to be particularly helpful for significant others facing traumatic (e.g., loss of a child) or stigmatized (e.g., AIDS) deaths, as well as for individuals who themselves are dying (Callanan & Kelley, 1992; Goodkin et al., 1999; McCreight, 2004; Rando, 1984; Vigil & Clements, 2003).

### Individual Needs

During the illness/dying trajectory, the nurse needs to assess the patient's immediate and specific needs. Certain simple pleasures may be more important to the patient than a nurse-perceived need for oxygen. For a peaceful death, a patient may need the comfort and joy that a treat, such as food or music, may represent. Asking the patient (or significant others if the patient is unable to respond) what the immediate and specific needs are may bring insight as to what intervention is needed to help the patient be more comfortable.

Maintaining some control is especially important during this time, as the patient may have had to relinquish control in many areas. Studies have demonstrated that physical and psychological outcomes can be linked to perceptions of control (Volker & Wu, 2011). Moreover, having control over pain is critical. Patients with a terminal illness and their significant others fear lack of pain control during EOL care (Danis, 1998; Ferrell & Coyle, 2008).

Having a sense of order and a sense of closure in personal affairs are important aspects to address with the patient also. Sharing what one needs to say to others, through direct contact (e.g., in person or phone) or indirect contact (e.g., written communication), may help the patient have a more peaceful death.

Sensitivity to the patient's leading in this area is critical.

### Areas of Assessment

Use the following questions to assess the patient on his or her journey living with and dying from a terminal illness in relation to loss and suffering, dying and death, and grief and bereavement.

- How do you view your illness?
- What is the meaning of your illness to you?
- What fears or concerns do you have regarding your illness?
- In what ways are you experiencing loss and suffering?
- Are there any unresolved issues or business matters that need to be resolved?
- Do you have any specific fears about dying and death in general? About your own dying and death?
- What concerns do you have for others now and after your death?
- What helps you maintain a sense of hope during difficult times?
- What specific needs do you have at this time?
- In what ways might I be most helpful to you in meeting those needs?

### ■ ASSESSMENT—WHERE ARE THE SIGNIFICANT OTHERS ON THE JOURNEY?

Healthy spouses of terminally ill cancer patients were studied (Siegel, Karus, Raveis, Christ, & Mesagno, 1996). Males were found to be more at risk for depressive symptoms than females if they were parents of school-aged children. Part of this could be due to their having less of a social network than females in general, and part may be due to their having to assume additional parenting responsibilities as the result of their spouse's illness and subsequent death. Overall adjustment was better for well spouses and inversely proportionate to

the number of children in the household. Work was perceived as both a stressor due to the demands of the job and as a stress buffer due to the potential emotional support, sense of control, and predictability it may provide for the significant other. Masculine and feminine differences have been explored more recently, as well, indicating that feminine grieving involves more talking, help seeking, and social involvement than masculine styles of grieving that involve solitude, self-medicating, and expression of grief through activities (Baum, 2003; McCreight, 2004; Thomas, 2004).

Elderly males have been found to be at increased risk for suicide after the death of a spouse, especially within the first year (Ajdacic-Gross et al., 2008). In general, older adults face multiple losses for numerous reasons including declining health with increasing age (Talerico, 2003).

Family often plays a central role in providing support of a patient diagnosed with a terminal illness. Such informal caring may involve considerable physical, psychological, and economic stresses on significant others (Candy, Jones, Drake, Leurent, & King, 2011). As a result, there is reciprocal suffering inherent in being a family member or significant other of a patient diagnosed with a terminal illness. This suffering results from the expectations and responsibilities placed upon the significant other to care for the patient, the mutual experience of intensified needs brought about by the patient's illness, and the often rapidly changing needs of both the patient and the significant other. QOL issues arise for the family members and significant others as well as for the patient (Sherman, 1998). In addition to the needs of the patient, nurses should assess the concerns of caregivers and consider that they may also benefit from additional support (Candy et al., 2011).

Koop and Strang (1997) reviewed a number of studies to determine correlates of greater satisfaction in families of patients with a terminal illness. They found higher satisfaction in families in which there had been psychosocial support from the nurse, fulfillment of basic needs, high frequency of home visits, support at night, connection to other services, visits to the bereaved caregiver, choices in treatments, privacy during hospitalizations, treatment of respiratory symptoms, the presence of professional caregivers (especially if the patient is at home), and participation in a hospice program.

There is interdependence between the patient, the significant others, and the nurse in relation to providing optimal care for the patient with a terminal illness. The nurse can maximize the positive aspects of this interdependence by recognizing and affirming the patient's significant others, incorporating them into the patient's care as desired by the patient, and assisting the significant others in their loss, suffering, and grief related to the patient's dying and death. Kissane



and Bloch (2002) recognized the influence of family in Reiss's (1990) study on renal disease, claiming, "This research highlights the potential influence of the family on both the course of illness and survival" (p. 26). Woodgate and Degner (2003) note in their research of children with cancer that, "It is important for those involved in the care to recognize that maintaining the family unit was equally important to families as was beating the child's cancer" (p. 117). In addition, the patient's significant others will experience bereavement issues once the patient dies. Research by Jordan and Neimeyer (2003) demonstrates that "With the help of family and friends, apparently most mourners are able to work through and integrate their losses relatively well" (p. 772).

How does one know when the patient is ready to die? Four types or stages of death occur, usually in the following order: social death, psychological death, biological death, and physiological death (Sudnow, 1967). Social death marks the narrowing of the patient's world, as he or she has known it. This is a highly individualized stage that is dependent upon the patient's level of involvement versus detachment in his or her social world. Psychological death is a death of the patient's personality. Relationships change. The patient withdraws and distances himself or herself from others. Terminal illness places demands that result in the patient's becoming regressed and dependent. Biological death involves the loss of consciousness and awareness on a self-sustaining basis; the patient may be on life supports at this point. Finally, physiological death occurs. All vital organs cease to function (Rando, 1984). At this point, a nurse or physician (depending upon state law) pronounces death. The moment of finality has arrived. Life as the patient and the significant others knew it for the patient has ceased.

## Relationships

Support from significant others can aid in decision making and acceptance of death for a patient with a terminal illness. Patients and their significant others may determine together if they want to pursue life-sustaining procedures or to forego them in light of the uncertainty and potential trauma that surround the situation. With the availability of advanced, and potentially life-extending, technology, patients and their significant others often seek the nurse's advice around treatment options at the EOL. The nurse can initiate conversations focused on the patient's expressed goals and values to help guide these decisions. This close communication is essential because as the needs of the patient at the EOL transition, the nurse can utilize these transition points to revisit with the patient and the patient's significant others their

prognosis, goals of care, and treatment options. It is especially important to maintain communication because these transition periods can be times of physical, psychological, and existential crisis for patients and significant others (Peerboom & Coyle, 2012).

Significant others who care for a terminally ill patient are faced with increased feelings of powerlessness, anger, and grief when the patient's pain is unrelieved (Ferrell & Coyle, 2008; Ferrell et al., 1993). When patients choose to spend the EOL at home, it is often the significant others who are directly responsible for the patients' care. It is important for the nurse to support, educate, and work collaboratively with the significant other to both control the pain of the patient and to reduce the distress that unrelieved pain causes the caregiver. Strategizing a pain management "game plan" with the significant other can help achieve both of these goals.

## Areas of Assessment

- Determine with significant others what they perceive as the patient's needs.
- Provide education in pain assessment and pain management strategies.
- Assess how the significant others feel they are doing and what degree of loss and suffering they are currently experiencing.
- What types of secondary losses are being experienced or anticipated as a result of the primary loss (i.e., anticipatory death or actual death of the patient)?
- Determine the level of emotional support needed.
- Ascertain if spiritual support is desired.
- Assure significant others that they are not an imposition to professionals who also are providing care for the patient.
- Identify available resources to help significant others care for the patient.
- Encourage significant others to grieve in whatever ways are best for them.

## Normal Grief

Grief is a normal response to loss. Grief may become manifest in feelings, physical sensations, cognition, and behaviors (see Table 10.3). Psychological, sociocultural, and physical factors influence the grief reaction. The nurse needs to assess which factors are influencing the significant others. Rando (1984, pp. 43–57) addresses these influences as follows:

Psychological factors:

- Significance of the loss
- Attachment level

- Family role of the deceased
- Individual coping behaviors, such as avoidance, distraction, preoccupation, impulsivity, rationalization, intellectualization, prayer, and connection with others
- Intelligence and maturity levels
- Previous experience with death and loss
- Conditioned sex roles
- Age of the individual grieving
- Age and characteristics of the deceased
- The death of a parent represents loss of the past
- The death of a spouse represents loss of the present
- The death of a child represents loss of the future and may be the most difficult death to handle
- Unattended business between the griever and the deceased
- Perception of fulfilled life for deceased
- Circumstances related to death including location, type, reason, and preparedness
- Timing of the death (is the death psychologically acceptable?)
- Perception of death's prevention
- Sudden or anticipated death
- Chronic versus acute illness
- Impact of anticipatory grief on the relationship with the dying patient
- Impact of secondary losses
- Additional stresses or crises

#### Social factors:

- Level, acceptance, timing, and duration of support
- Religious, sociocultural, ethnic, and philosophical backgrounds
- Bereaved's educational, economic, and occupational status
- Positive or negative funeral rituals

#### Physiological factors:

- Positive and negative impact of medications
- Need for nutrition, sleep and rest, exercise, and physical health

A way to distinguish between grief and depression is to note if the individual in question is able to experience pleasure. Grieving individuals generally can experience pleasure; depressed individuals often have difficulty experiencing pleasure and may lose morale and hope (Kissane & Bloch, 2002). There has been much controversy over the *DSM-5* inclusion of grief as a psychiatric disorder. What is clear is that bereavement can result in acutely debilitating symptoms; such symptoms usually

are temporary but may result in more chronic symptomatology (Shear et al., 2011).

## ■ CHILD'S EXPERIENCE OF LOSS

The death of a parent impacts a child greatly. Family life and daily routine are disrupted permanently. A child may have a depressed mood, cry, be sad or irritable, withdraw, or have sleep disturbances during the first 4 months after the loss of a parent. Physical, behavioral, and emotional responses occur immediately for young children. Although infants and toddlers are not at a developmental stage to be able to comprehend loss or death, they are distraught that someone important to them is absent (Hames, 2003). A child's reaction may be impacted by individual personality factors, sociocultural factors, the child's age, the child's history, the child's religious beliefs, family dynamics, family's socioeconomic status, sex of the child and the remaining parent, additional stress in the child's life, parental substitutes, nature of the death, and how the child was notified (Geis, Whittlesey, McDonald, Smith, & Pfefferbaum, 1998).

Children who have lost a parent, especially by suicide, are at increased risk of psychiatric problems. The most common psychiatric complaints in bereaved children are depressive symptoms. Regression may occur temporarily. Having a baseline of a child's behaviors is important when discerning if there is a serious problem. Suicide bereavement is compounded by the stigma and lack of social support oftentimes in such circumstances (Gray et al., 2011; Mitchell et al., 2007). Melhem, Porta, Shamseddeen, Walker Payne, and Brent (2011) report that one of the best predictors of a child's well-being after the death of a parent is the well-being of the surviving parent. For example, the risk of the child developing depression increases if the surviving parent is experiencing complicated grief after the death of his or her spouse.

Caregivers must recognize the importance of age in relation to a child's ability to experience loss and grief. Saldinger, Cain, and Porterfield (2003) note that children may have a very difficult experience with anticipatory grief if they are expected to demonstrate levels of "self-sacrifice" that exceed their "levels of maturity" (p. 175). The ELNEC curriculum provides a table of children's ages and expected grief reactions that can be valuable to caregivers (see Table 10.4).

Degree of attachment also impacts how a child will respond to the loss of a parent. Stroebe (2002) found that individuals who had a more secure attachment to the lost figure had a more fluid movement between loss and restoration orientations and experienced less complications with grieving.



**TABLE 10.4 Grief and Bereavement in Children**

<i>Characteristics of Age</i>	<i>View of Death and Response</i>	<i>What Helps</i>
<b>Birth to 6 Months</b>		
Basic needs must be met, cries if needs aren't met. Needs emotional and physical closeness of a consistent caregiver. Derives identity from caregiver. View of caregiver as source of comfort and all needs fulfillment	Has no concept of death. Experiences death like any other separation; no sense of "finality." Nonspecific expressions of distress (crying). Reacts to loss of caregiver. Reacts to caregiver's distress	Progressively disengage child from primary caregiver if possible. Introduce a new primary caregiver. Nurturing, comforting. Anticipate physical and emotional needs and provide them. Maintain routines
<b>6 Months to 2 Years</b>		
Begins to individuate. Remembers face of caregiver when absent. Demonstrates full range of emotions. Identifies caregiver as source of good feelings and interactions	May see death as reversible. Experiences bona fide grief. Grief response only to death of significant person in child's life. Screams, panics, withdraws, becomes disinterested in food, toys, activities. Reacts in concert with distress experienced by caregiver. No control over feelings and responses; anticipate regressive behavior	Needs continual support, comfort. Avoid separation from significant others. Close physical and emotional connections by significant others. Maintain daily structure and schedule of routine activities. Support caregiver to reduce distress and maintain a stable environment. Acknowledge sadness that loved one will not return—offer comfort
<b>2 Years to 5 Years</b>		
Egocentric cause-effect not understood. Developing conscience. Developing trust. Attributes life to objects. Feelings expressed mostly by behaviors. Can recall events from past	Sees death like sleep: reversible. Believes in magical causes. Has sense of loss. Curiosity, questioning. Anticipate regression, clinging. Aggressive behavior common. Worries about who will care for them	Remind that loved one will not return. Give realistic information, answer questions. Involve in "farewell" ceremonies. Encourage questions and expression of feelings. Keep home environment stable, structured. Help put words to feelings; reassure/comfort. Reassure child about who will take care of them; provide ways to remember loved one
<b>5 Years to 9 Years</b>		
Attributes life to things that move; may fear the dark. Begins to develop intellect. Begins to relate cause and effect; understands consequences. Literal, concrete. Decreasing fantasy life, increasing control of feelings	Personifies death as ghosts, "bogeyman." Interest in biological aspects of life and death. Begins to see death as irreversible. May see death as punishment; may feel responsible. Problems concentrating on tasks; may deny or hide feelings, vulnerability	Give clear and realistic information. Include child in funeral ceremonies if he or she chooses. Give permission to express feelings and provide opportunities; reduce guilt by providing factual information. Maintain structured schedule, individual and family activities; needs strong parent. Notify school of what is occurring, gentle confirmation, reassurance
<b>Preadolescent Through Teens</b>		
Individuation outside home. Identifies with peer group; needs family attachment. Understands life processes; can verbalize feelings. Physical maturation	Views death as permanent. Sense of own mortality; sense of future. Strong emotional reaction; may regress, revert to fantasy. May somaticize, intellectualize, morbid preoccupation	Unambiguous information. Provide opportunities to express self, feelings; encourage outside relationships with mentors. Provide tangible means to remember loved one; encourage self-expression, verbal and nonverbal. Dispel fears about physical concerns; educate about maturation; provide outlets for energy and strong feelings (recreation, sports, etc.); needs mentoring and direction

Source: Reprinted with permission from Fine, P. G. (1998). *The Hospice Companion*, 2nd ed. New York, NY: Oxford University Press.

## CASE STUDY *Continued*

Teresa, aged 7 years, and Alberto, aged 5 years, had been at their Lita's (Spanish nickname for grandmother) wake about 6 months earlier. They remembered that her body was "cold" and "hard" when they touched her. Both Teresa and Alberto put one of their favorite toys in the coffin to take with her in "her new home in Heaven." Teresa remembered how Lita used to take their faces in her hands and tell them how much she loved them. She was sad and cried at Lita's wake. Alberto did not seem to grasp totally what was happening but started to cry when he saw Teresa crying and had asked when Lita would wake up.

Children often experience separation anxiety after the death of a parent. Coming to terms with surviving in a world without the presence of the deceased parent can be traumatic for the child. Secondary to that trauma may be the additional stress of observing a surviving parent cope with the loss or the anticipated loss if such were the case (Saldinger et al., 2003). Nurses can help a dying parent communicate with children who will be left behind; this can enhance meaning and comfort to the dying by making a contribution to their child's journey with grief. Likewise, a surviving parent inadvertently becomes a role model for grieving to children left behind by a deceased parent (Hames, 2003).

If a child loses a sibling, other issues, such as guilt, ambivalence, denial, increased vulnerability, and fear for his own well-being, may arise. Parental response to surviving siblings helps determine the child's adjustment. Similar responses may occur for adolescents with possible reframing of the adolescent's self-concept, self-identity, and family role (Geis et al., 1998). Tasks that occur for all siblings of a deceased child, regardless of age, include grieving the deceased sibling, coping with family changes, realigning relationships, and attempting to understand the meaning of the tragedy within the family (Kiser, Ostojka, & Pruitt, 1998). Research related to the loss of a sibling through suicide indicated younger siblings living at home experience a more difficult time than either older siblings or parents; intervention resources frequently are focused upon parents (Dyregrov & Dyregrov, 2005).

### Areas of Assessment

- How is the child functioning socially according to his or her developmental level? What is the child's involvement in relationships, recreation, and routines?
- Is the child exhibiting any changed behaviors?
- What is the child's predominant mood (sad, withdrawn, hyperactive, angry)?

- How does the child express his or her suffering or "pain" related to the loss?
- What does the child feel might help make the "pain" better (besides the return of the lost loved one)?

### Family Caregiving—Parental Experience of Loss

Living with dying can tax a patient and his or her significant others economically, as well as physically, spiritually, and psychologically. Often the patient or his or her significant others lose work time due to the patient's care requirements. Additional expenses may arise with treatments, hospitalizations, or other hidden expenses, such as transportation, child care, out of home food purchases, lodging, and so forth. Dying patients often experience much stress because of the financial burdens that fall upon the significant others (Rando, 1984). If the nurse feels unprepared to counsel the patient and significant others in this area, it is imperative to refer them to someone who can.

The loss of a child often is devastating to the parents and to the family. Parents feel responsible for their child's health, well-being, and safety. In the case of a newborn with a serious condition, there is accompanying parental blame and guilt for the infant's condition. Parents must grieve the healthy, "normal" child they lost in addition to the anticipated death of the infant.

Parents usually do not expect their child to die. This is true even in the case of adult children who die before parents. As adults are living longer, it is now less certain that children will outlive their parents (White & Beach, 2012). Older adults may experience "survivor guilt, powerlessness, and loss of religious faith"; the deceased child may be idealized, which can complicate grief resolution (Talerico, 2003, p. 14).

Grief related to the loss of a child is apt to be severe and complicated. Anniversary events and developmental milestones for the deceased child



reopen the grief experience throughout the parents' lifetime (Kiser et al., 1998). Acknowledging that their lives have changed forever is part of the grief resolution that takes place for parents; however, recovery from the death of a child is a lifelong process (Geis et al., 1998). For the single parent, aloneness may be magnified (Backer et al., 1994). Controversy exists about parents' viewing prenatally deceased infants and stillborn infants; in general, viewing the body is thought to help with grieving (Haas, 2003). Nurses must be sensitive to family members' readiness and wishes related to viewing the body of their deceased loved one.

### Areas of Assessment

- How has your loved one's illness impacted your life?
- In what ways will you remember your child who died?
- What is the most significant type of suffering you are experiencing right now?
- What are your specific needs at this time and how can I help you meet them?

### GERONTOLOGIC GRIEF

Parker et al. (2002) have asserted that successful aging involves achieving competency in four distinct areas:

- Engaging in life actively
- Maximizing cognitive and physical function
- Preventing disease and disability
- Experiencing spirituality in relation to developmental processes

However, what happens when one does become ill, either physically or mentally, or acquires chronic illness and/or disability? Hardiness can assist older adults as they age with diagnoses, such as HIV; hardiness includes factors, such as control, commitment, and challenge (Vance, Burrage, Couch, & Raper, 2008). Obstacles may become perceived as opportunities. Although there are conflicting reports, more research is needed to determine if an association exists between hardiness and immunological responsiveness in adults with HIV (Vance et al., 2008).

Recognizing whether an older adult is grieving or depressed is important. Although an older adult may deny feeling sad or depressed, it is important to look for the following additional signs of depression, such as

- Complaints of unexplained aches and pains
- Expressions of hopelessness or helplessness

- Symptoms of anxiety
- Memory impairment
- Loss of pleasure
- Decreased movement
- Irritability
- Forgetful of meals, personal hygiene, or taking medications (Segal, Jaffe, Davies, & Smith, 2007)

### RISK FACTORS FOR COMPLICATED GRIEF

Predicting bereavement outcomes is difficult because the subjects are considered to be a vulnerable study population. A balance between the need for protection and the benefits of participation must be attained. Studies suggest that individual differences such as self-enhancing biases, attachment style, coping styles, belief systems, personal identity, and positive emotions can be predictors of well-being during bereavement. For example, those who tend to display more positive emotions prior to the loss of a loved one have lower levels of distress following the loss (Mancini & Bonanno, 2009). The persistence of what some perceive as negative emotions of grieving—namely, disbelief, yearning, anger, and depression—may be an additional predictor of the need for intervention (Maciejewski et al., 2007).

Although each individual's grieving is unique, the bereavement process may be functional or dysfunctional, adaptive or maladaptive. The length of time for grief resolution varies considerably between cultural groups and from person to person (Zisook & Shear, 2009). The majority of individuals experience uncomplicated grief after a loss; however, approximately 10% to 20% of bereaved individuals will experience the prolonged, debilitating phenomenon known as complicated grief (Claxton & Reynolds, 2012). These prolonged reactions range from exaggerated normal reactions to abnormal grief reactions. Furthermore, grief may be unresolved or compounded if a loss or losses occur within a community of individuals where the losses are minimized or ignored; this may result in further complications with subsequent losses (Talerico, 2003).

Backer and colleagues (1994) describe three basic types of complicated grief reactions: delayed, inhibited, and chronic grief. In delayed grief, the grief is triggered by the loss of someone or something else. There is minimal impact in this situation. For example, someone whose father has recently died may experience delayed grief related to the death of the individual's mother 10 years prior to the father's death. The individual has never experienced full grief

for the death of the mother until the death of the father. His death triggers the deeply felt but unexpressed loss of the mother. Inhibited grief occurs when an individual never grieves. It also may occur if the individual feels great distress related to a lost relationship. This type of grief becomes complicated if another condition develops related to the unfelt grief. Last, chronic grief exists when the grieving is unending, and the intense yearning for the lost relationship continues. A cause for this type of grief could be unspeakable deaths, such as those due to AIDS or suicide.

Rando (1984) addresses delayed, inhibited, and chronic grief reactions but also includes absent grief, conflicted grief, unanticipated grief, and abbreviated grief in her list of complicated grief types. Absent grief is characterized by a total lack of grief emotions and processes of mourning. Conflicted grief involves an amplification of the characteristics of normal grief partnered with a suppression of other manifestations of normal grief. Unanticipated grief takes place after an unexpected loss that the individual cannot grasp. Abbreviated grief is normal grief that lasts a short period of time because of swift replacement of the lost individual or lack of attachment to the lost individual. One study (Prigerson et al., 1997) identifies grief involving trauma and separation as traumatic grief and indicates that psychiatric sequelae, such as traumatic grief, puts bereaved individuals at risk for complicated grief.

Families grieve in unique ways. Family members all fill unique roles. A lost family member means the family must reassign the lost role. Likewise, families may distort circumstances through idealization, blame, anger, or despair. Families who do not share their grief may experience poor coping or breakdown (Kissane & Bloch, 2002).

There are a number of individuals at risk for complicated grief after the death of an individual with a terminal illness. Some of the best predictors are excessive dependency and insecure attachment styles, which suggest that the loss of a person who provides emotional stability may lead to an exacerbated grief reaction (Claxton & Reynolds, 2012). Others include those with a history of childhood abuse, insomnia, female gender, marital closeness, parents, those experiencing the loss of loved ones through unspeakable deaths, and those with a psychiatric history (Kristjanson, Lobb, Aoun, & Monterosso, 2006).

Work done by Pennebaker, Mayne, and Francis (1997) indicates that language usage can help to impact bereavement outcomes in a positive way. Encouraging individuals to talk about traumatic events forces a disorganized event and emotions to become more

organized, coherent, and insightful. Over time, the use of insight and causation words in relation to the event and its accompanying emotions helps cognitively reframe the experience that results in more adaptive outcomes.

Frank, Prigerson, Shear, and Reynolds (1997) postulate that individuals experiencing elongated periods of distress (for several months) and exhibiting criteria for major depressive episodes are undergoing traumatic grief reactions. They advocate treatment interventions that involve reexperiencing the moment of death, saying good-bye to the deceased while still retaining special memories of the person, and gradually being exposed to situations that the bereaved has avoided since the deceased's death. The outcome of this traumatic grief treatment has been reduced subjective distress. They do not advocate for pathologizing or treating brief periods of bereavement-related distress.

A number of factors were examined in a study attempting to predict depressive symptomatology in the postbereavement period (Kurtz, Kurtz, Given, & Given, 1997). Prebereavement depressive symptomatology scores, levels of support from friends, and caregiver optimism were most predictive of postbereavement depressive symptomatology. The link between prebereavement and postbereavement depressive symptomatology scores was anticipated. The role of optimism is important for nurses to capitalize on and strengthen when working with significant others. The connection between high social support in the prebereavement period from friends and postbereavement depressive symptomatology was strong. This phenomenon could be caused by altered or lost relationships due to the dying and death of the spouse. Possibly friends experience a social death before the physical death of the bereaved's spouse.

Poor bereavement recovery is apt to occur if the death is unexpected, untimely, or traumatic for the bereaved, such as with homicide or suicide (Kristjanson et al., 2006). Moreover, maladaptive grieving may occur if the significant other had an ambivalent or dependent relationship with the deceased, perceives his or her social networks as unsupportive, and is experiencing concurrent loss. Family coping styles that negatively impact outcomes are (a) hostile (high conflict, low cohesiveness, and poor expressiveness); (b) sullen (limited but less in comparison with the hostile group); and (c) intermediate (intermediate cohesiveness and low control and achievement orientation). Additional correlates for poor outcome include use of medications or alcohol, concern for self, level of contentment, and not viewing the deceased's body. Positive bereavement outcomes are more apt to occur in families who are



supportive (high cohesion) and resolve conflict well (Kissane, McKenzie, & Bloch, 1997).

In more dysfunctional grieving situations, the advanced nurse practitioner must treat symptoms of pathological grief. Three major symptom categories of pathological grief are intrusion, denial, and dysfunctional adaptation (Horowitz, Bonanno, & Holen, 1993). Spending long periods of time idealizing the memory of the deceased is a sign of an intrusive thought process. Living as if the deceased were still alive for more than 6 months is evidence of denial. Minimal dysfunction is evidenced in having difficulty making decisions, whereas major dysfunction is evidenced in more severe impairments. Such severe dysfunctional parameters involve extreme fatigue or somatic symptoms that last more than 1 month; inability to resume work, other interests, routines, and other responsibilities after more than 1 month; and reluctance to develop new relationships after 13 months of grieving (Lev & McCorkle, 1998, p. 147).

Use the following exercises to expand your understanding of helping the patient's significant others on their journey with the patient who is living with and dying from a terminal illness in relation to suffering and loss, death and dying, and grief and bereavement:

**Exercise I**—Discuss how you might feel and what you might do if you were the nurse who walked into a patient's room just as the patient has died and the family or significant others are there.

**Exercise II**—A family member who has been estranged from the dying patient on your floor is in the room as you come in to check on the patient who is unconscious. The family member says, "He wasn't a very good father. He abused my sister and me. I'll be glad when he's dead." How would you respond to this family member?

**Exercise III**—You are the advanced practice nurse heading up the first meeting of nursing staff since a patient on your floor died from cancer. What would be your objectives for the meeting?

## ■ CONTEXT OF CAREGIVING AND RELATED INTERVENTIONS

Working with the patient who is living with and dying from a terminal illness and that person's significant others requires compassion, skill, energy, sensitivity, and patience. Compassion promotes a positive connection among the nurse, the patient, and the significant others. Skill gives the nurse credibility in working with them. Energy, often in the form of providing hope

for the moment, moves the patient and significant others forward when they feel like giving up. Sensitivity enhances understanding and rapport in the relationships. Patience allows individuals the time needed to face and plan for an uncertain and unpredictable future.

The nurse attempts to help meet the needs of the patient and the significant others. Addressing immediate needs may take on greater significance with the patient experiencing a terminal illness than addressing either short- or long-term needs. Values, control issues, and goals of both the patient and significant others need to be taken into consideration, addressed directly, and handled tactfully and sensitively.

The nurse has a unique window into the patient's circumstances. Depending on the setting, nurses may provide 24-hour care. Even if nursing coverage is not for 24 direct-care hours, nursing care may be accessible for that period of time. Generally, it is the nurse who gets the most consistent, current, and constant view of what is actually happening with the patient and significant others. With few exceptions, the nurse usually is the most readily available and informed team player to help coordinate the patient's care.

Developing goals with the patient and family provides some stability and security during this time. It can empower the patient and the significant others to take an active role in planning the patient's remaining earthbound journey, uncertain and unpredictable as it may be. Furthermore, it helps set the stage for the continuing connection between the nurse and the patient's family in the bereavement period following the patient's death.

## Nurse

Nurses care for themselves by seeking support from colleagues, ensuring time for themselves by maintaining healthy boundaries with the patient and significant others, and tending to their own physical, emotional, sociocultural, and spiritual needs. After a patient's death, nurses may work through their grief by attending the memorial service or funeral of the deceased patient if this is deemed acceptable by the nurse's employing agency policy and the deceased patient's family. Sending a sympathy card to significant others, doing follow-up bereavement work with significant others, and reminiscing about the deceased patient with empathic colleagues usually help nurses in dealing with their own grief.

## CASE STUDY *Continued*

Jake met once more with his supervisor and felt better able to be objective again. Jake affirmed Isabella and Kasandra in their care and concern for their father and Kasandra in her concern for their brother. He suggested to Mr. Carballo's daughters that it might be helpful to meet with the unit's spiritual care advisor to help them as they traveled on this difficult journey of watching their father dying. Jake also suggested they meet with the medical ethics committee to explore the best ways to make decisions concerning their father's care. He also told them that he thought their bringing in pictures of Mr. and Mrs. Carballo had been meaningful to their father in providing care for Mr. Carballo. He asked if there was anything he could do for them and said he would be available to talk with them if they wished.

## Nursing Interventions

Nurses are accustomed to action-oriented, "doing for" interventions. However, when caring for the patient with a terminal illness, the nurse's role may be less action oriented and more presence oriented. Presence is being with a patient in an authentic relationship that promotes mutual respect, honesty, and dignity. Establishing presence requires self-awareness, openness, flexibility and willingness to embrace another person's situation—even when that situation involves suffering for which we can do nothing other than accompany the patient as he or she experiences it (Anderson, 2007; Lavoie, Blondeau, & De Koninck, 2008).

Given that so many American deaths occur in hospitals, the nurse is most apt to be with the patient and significant others at the exact time of death. Becoming comfortable with viewing the dying and death process, touching the deceased's body, talking with significant others about the death and their feelings, and dealing with the patient's death among staff are important aspects with which the nurse will be confronted.

The nurse's relationship with the patient will be critical in determining how she or he handles grief and bereavement in relation to the patient's dying and death. Was it a short-term nurse-patient relationship or did the nurse have a professional relationship with the patient for an extended period of time? In addition, how comfortable does the nurse feel sharing feelings, and how appropriate is it to share feelings with the patient? Nurses need to answer for themselves what the goal is of sharing their feelings and what the expected outcome is of doing so before proceeding.

Johns (2007) contends that reflection is a helpful practice to respond to a patient's suffering. He suggests that reflection should be structured and guided to maximize benefits and deepen attainment of the kind of health care provider one wants to be during a patient's suffering. He also encourages construction

of the story that is taking place to discover meaning and insight related to the total experience.

Level of intervention by the nurse will be based on professional skills, theoretical background, and clinical setting. The nurse will develop therapeutic relationships; ensure the patient's physical comfort to maintain function; explore the meaning of physical suffering and loss with the patient and significant others; reframe the patient's limitations to identify areas of value that will enhance the patient's QOL; encourage patient and significant others' attendance at support groups; and identify and maximize prior coping skills of the patient and the significant others. Advanced practice nurses will offer more intensive and extensive interventions for grieving and bereavement needs and be involved in conducting or participating in research studies. For example, the advanced practice nurse may prescribe various medications, offer individual or family counseling, lead a bereavement group, or conduct research on QOL and quality of dying outcomes.

## Patient

Each patient who is living with and dying from a terminal illness is unique. His or her experiences living with and dying from terminal illness also are unique. A critical factor in promoting good nursing care of this patient and significant others is affirming this uniqueness. Affirming the individual's growth and wholeness during this difficult living-dying interval is critical (Georgesens & Dungan, 1996; Talerico, 2003). Empowering patients to integrate the living-dying experience and optimize their QOL will affirm the patient further.

For example, the patient is affirmed when the nurse acknowledges the patient's level of acceptance of dying and death. The patient's acceptance or denial may seem selective at times. In reality, varying levels of acceptance or denial may serve an adaptive function in which only specific aspects of dying are tolerable at a given point in time. The patient is aided when the



nurse accepts and supports the patient's coping in this way to deal with the extensive and intensive challenges during the living–dying interval (Kastenbaum, 1997).

False reassurances prevent patients from accepting reality; the nurse must be honest and not foster false pretenses (Matzo et al., 2003).

Medical science has limitations, and often patients feel dehumanized during some medical procedures. In addition to addressing comfort needs, patients need assurance that their humanity will be respected and valued. The nursing profession has reawakened to the importance of integrating spiritual care within total patient care. Patients have indicated that their spiritual needs are best met through nurses' listening to, talking with, supporting religious practices of, and being with them (O'Neill & Kenny, 1998). Even in the midst of suffering through the loss of physical well-being, patients may sense spiritual well-being. Buckwalter (2003) refers to "moments of ministry" or "ministry of the moment" as those times when nurses or others assist patients in a "holy moment of connection," especially for someone who may be experiencing profound memory loss (p. 22). If a nurse feels inadequate or uncomfortable assisting dying patients in this area in any way, a pastoral care referral may be indicated. In addition, the patient may desire to have clergy closely involved even if the nurse is comfortable meeting the patient's spiritual needs.

Saying good-bye is painful for the patient with a terminal illness, for his or her significant others, and for the nurse. Discerning when (timing) and how (tone) to say and facilitate others' saying good-bye takes sensitivity (touch, emotional, and, physical) and skill (training/technique) on the nurse's part. This intervention can be illustrated as follows:

Discernment of readiness to facilitate  
good-byes = Nurse sensitivity (touch) + Skill  
(training/technique) + When (timing) + How (tone)

An important question to ask when caring for the patient who is dying from and living with a terminal illness is "What type of patient has the disease, rather than what type of disease does the patient have?" (Harris, 1991, p. 111). Respecting and affirming the patient as a unique and valuable human being will help promote wholeness during a time of brokenness. As the individual is faced with imminent death, he or she must reorient his or her life to adapt to this realization and the accompanying losses. Minimizing losses due to isolation, rejection, and loss of control can decrease the individual's suffering (Rando, 1984). Optimizing patients' strengths is essential in helping them achieve the QOL they would like to pursue in this living–dying interval.

Chronic sorrow is the distinct grief reaction that occurs when loss is not final but continues to be present in the life of the griever (Rossheim & McAdams,

2010). Chronic sorrow may be triggered if the individual senses a disparity with norms. For example, the individual may feel different from others. Situations such as hospitalization accentuate this discrepancy to the individual. Both patients and significant others may experience chronic sorrow.

Nurses can assist individuals with chronic sorrow by helping with internal and external management methods. Internal management methods consist of individualized coping interventions such as stress-relieving practices like journaling. External management methods are those provided by professionals to aid in effective coping such as professional counseling, pastoral care, or pharmaceutical interventions (Ahmann & Dokken, 2009). The nurse may advocate for a patient with a terminal illness by employing the following interventions: advancement of grief work, encouraging health-promoting strategies despite a compromised health state, making referrals, meeting with significant others, utilizing cognitive reframing of negative patterns, and engaging the patient in individual or group therapy to work through unresolved situations. The nurse may be asked to work with support staff and significant others to help them accept, support, and devise strategies to work with a patient or significant other who has a dysfunctional approach to suffering and loss.

However, the most meaningful "intervention" that may be provided to a patient with a terminal illness is the gift of presence. Presence validates one's existence amid the experience of suffering (Lavoie, Blondeau, & De Koninck, 2008).

## Family and/or Significant Others

The term "family" will be used to represent both family and significant others. The family of a patient dying from and living with a terminal illness experiences great turmoil and disequilibrium. Often, the illness becomes the focal point of family activity and organization. If the patient is a child and has siblings, the family struggles at maintaining life within the household as well as preparing for the death of one of its members. The child simultaneously may be growing in many ways while dying in others. Treatment programs and appointments may consume much of the family's energy, possibly for extended periods of time. Helping the family maintain a sense of normalcy and balance throughout this period will be an important task for the nurse. Keeping the family as involved as possible in the patient's care applies to the patient with a terminal illness of any age (Matzo et al., 2003; Rando, 1984).

The question of where the patient and family would like the anticipated death to occur must be answered. With shortened hospital stays, families have been forced to assume extended and at times

intensive care responsibilities for the dying patient in addition to their usual role expectations and demands. Helping the patient and family decide where and when care will take place becomes an important goal (Lev & McCorkle, 1998). The patient may wish to die at home, in a hospice setting, in a hospital, or in another setting. Assisting the patient and family to communicate what they each can handle at different stages of the patient's dying will be critical.

A family's response to the patient's death is as unique as the individuals making up the family constellation. Each family has its own management style in responding to the death of a member. Management styles include families that progress, are able to move forward as a family; accommodate, adapt to the loss and adjust; maintain, where family members are variable in their response; struggle, where the family is in conflict; and flounder, where the family is having difficulty both as individuals and as a unit (Wiegand, 2012). A family may seek or need to be referred for counseling if maladaptive symptoms develop. Family bereavement therapy involves assessing the circumstances related to the family member's death; the role of the deceased in the family before and after death; timing of the death in relation to family member's stage of growth and development; previous and current levels of family functioning; the context of the death; and the meaning assigned by the family to the death (Kiser et al., 1998, p. 97). There is little scientific evidence related to the impact of formal interventions with those bereaved; one reason for this may be that uncomplicated grieving resolves on its own (Jordan & Neimeyer, 2003). Jordan and Neimeyer further assert there is more evidence to support relational contexts of therapy (i.e., friends and family) over medical interventions (i.e., psychology or psychiatry) for those bereaved because those aspects promote hope and learning new coping skills.

However, the nurse must now focus attention on helping significant others begin the tasks of bereavement: accepting the reality of the loss, experiencing the pain of grief, adjusting to an environment without the deceased, and reinvesting energy into other relationships (Worden, 1991). Backer and colleagues (1994, p. 165) have identified guidelines for counseling the bereaved as follows:

1. Help actualize the loss by talking about the loss
2. Identify and express feelings related to the loss
3. Help the bereaved in decision making
4. Facilitate emotional withdrawal and development of new relationships
5. Provide time to grieve and be cognizant of holidays and anniversary dates

6. Reassure the bereaved that their behavior is normal and that they are not abnormal because of their feelings
7. Allow for individual differences in the bereavement process
8. Provide support
9. Examine individual defenses and coping styles (be aware of problems with alcohol or other substance abuse)
10. Identify pathological behaviors and refer to treatment

The length of time for intense grief to lessen varies from individual to individual. As long as the bereaved's grieving behavior does not interfere significantly with their physiological or psychosocial functioning, it is not considered abnormal. In general, intense responses to grief generally subside in about 6 to 12 months (Rando, 1984). Grieving, however, continues throughout the bereaved's life. The loss, in some cases, may be replaced but, in all cases, it is never recovered. Grief can inflict a woundedness of spirit, much different than a physical wound, that calls for the nurse to wait patiently versus debride quickly and that allows the body and soul to heal (Moules et al., 2007).

The living-dying interval comes to an end with the death of the patient, yet how does one know when grieving ends—or in a contemporary view, if grieving is moving forward—for the bereaved? Parkes and Weiss (1983) identified 10 major areas for assessment of recovery:

1. Functioning has returned to a level equal to or better than before bereavement.
2. Outstanding problems are being solved.
3. Acceptance of the loss has occurred.
4. Socialization is as effective as before the death.
5. The future is viewed positively and realistically.
6. General health is at prebereavement level.
7. Anxiety or depression levels are appropriate.
8. Guilt or anger levels are appropriate.
9. Self-esteem levels are appropriate.
10. Coping with future loss is feasible.

The process of bereavement differs from individual to individual. Some respond with minimal disruptions, some recover over time, while others experience a state of chronic distress (Bonanno et al., 2011). Some individuals' bereavement may occur in ways unfamiliar to the nurse. Through appropriate interventions, the nurse can help the bereaved adapt to their loss in a way that will foster their growth and wholeness as well. The nurse might determine with the bereaved what trajectory the individual may be on and adapt nursing interventions accordingly.



## ■ CONCLUSION

Living with and dying from a terminal illness results in many losses—for the patient, for the family, and for the nurse. Terminal illness can occur over an extended period of time or a brief period of time. The nurse functions as both facilitator and participant in this process. The nurse also can add objectivity while the patient and family resolve many feelings, issues, and decisions related to the living-dying experience.

This period of time frequently involves suffering in multiple dimensions. The nurse can utilize technical skills to alleviate certain attributes of the suffering, such as the patient's physical pain. When these technical skills are accompanied by the nurse's sensitivity, compassion, empathy, and presence, the patient and family are better equipped to face the other attributes of suffering as well. Thus, the nurse, as a caring professional, may contribute meaningfully to the health and wholeness of the patient and his or her family through one of life's most challenging and difficult transitions.

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## CASE STUDY *Conclusion*

On Day 10, Mr. Carballo went into cardiac arrest. Isabella and Kasandra were in the room at the time and called for help. There was no DNR recorded for Mr. Carballo at that time. He underwent cardiopulmonary resuscitation (CPR) and cardioversion. He sustained two fractured ribs and a punctured liver during that procedure. Mr. Carballo was placed on a respirator.

Isabella and Kasandra expressed guilt to Jake. Jake encouraged the daughters once again to see the medical ethics committee. Jake reported to his supervisor that he also felt guilty that he had not insisted that the daughters go to the medical ethics committee sooner. Jake's supervisor reminded Jake of patient/family choice in such matters and reminded him of the good care he was providing for Mr. Carballo and his family, including giving them constructive options for Mr. Carballo's care.

Isabella and Kasandra met with the medical ethics committee on Day 11. They concurred with the committee's recommendation to have a DNR order placed in Mr. Carballo's chart. They discussed the possibility of withdrawing Mr. Carballo's respirator but could not make a decision about that during the meeting.

Isabella and Kasandra also requested an appointment with the unit's spiritual advisor and met with her on Day 12. They worked on feelings of anger related to their brother Bob's decision not to come until after Mr. Carballo's death. They discussed their discomfort about withdrawing the respirator but were thinking they might do so the next day.

On Day 12, Isabella and Kasandra met at 8 a.m. in Mr. Carballo's room. They told him they loved him and that they did not want to see him suffer any more. They told him they hoped he would understand why they were going to withdraw his respirator. They each kissed him on the forehead and said a personal good-bye. They turned to go to the nurses' station, heard an alarm, looked up, and saw a straight line on the cardiac monitor. They immediately called for a nurse. Mr. Carballo was pronounced dead on Day 12 at 8:17 a.m. The daughters looked at each other, hugged one another, and cried.

Jake was off duty that day. One of his colleagues called him, but he did not receive the message on his home phone machine until later that night. He sat in his favorite chair and reflected on the care he had given Mr. Carballo and his family. In a few days, Jake was part of a medical ethics review of Mr. Carballo's care in terms of how the facility could handle such situations better in the future.

Roberto Carballo, Jr., wrote Jake a letter thanking him for the care he heard Jake had provided for his father and family members. He said he did not want to go into details but felt it was best that he did not see his father or his sisters before Mr. Carballo's death. He said he hoped Jake would understand.

Teresa and Alberto each selected another favorite toy that they placed in "Lito's" casket. They told each other that "Lito doesn't look like Lito, but he's with Lita in Heaven now."

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## Evidence-Based Practice

Moules, N. J., Simonson, K., Fleiszer, A. R., Prins, M., & Rev Bob Glasgow. (2007). The soul of sorrow work: Grief and therapeutic interventions with families. *Journal of Family Nursing*, 13(1), 117-141.

Q: What is the work clinicians do in helping families experiencing grief?

### Methods

**Data sources:** Hermeneutic interpretive inquiry by means of interviewing six participants. Interviews were transcribed verbatim and analyzed interpretively in order to achieve a collective hermeneutic understanding of the data.

**Study selection and assessment:** Three exemplars of practice clinicians and three willing family members with whom the clinicians had worked. The setting was the Calgary Health Region Grief Support Program, Calgary, Alberta, Canada. Two clinicians were female: one was male. All were White, whose experience ranged between 5 and 26 years. Educational background of the clinicians included a social worker with a bachelor's degree, a psychologist with a master's degree, and a clergyman. Family members were all female Whites ranging in age from 30 to 55 years with experience of losses from 2 to 8 years.

**Outcomes:** *Grief has an inarticulate and changing nature to it. Clinicians working with those bereaved do not follow models as much as they follow maps based upon experience and a willingness to journey "off the map" if necessary.*

### Main Results

All grief is complicated and falls in-between a number of areas (e.g., it is both universal/individual, active/passive, internal/external, etc.). Grief may involve struggle that may be identified by anger, guilt, and/or identity. Grief often is pathologized by society and forced into stages inaccurately. The core of grief and grief work is spiritual in nature, involves soul work, and is ongoing in nature.

### Conclusion

Grief work involves a "recollection of connections." Clinicians enhance healing in those grieving by journeying with them in their suffering and sorrow work.

### Commentary

Traditional and well-accepted grief work addresses specific stages of grieving, namely, denial, anger, bargaining, acceptance, and resolution. Different types of grieving in traditional framework include anticipatory, delayed, distorted, and complicated grieving.

In contrast, current nursing literature challenges stage theory of grief by asserting that grief is ongoing and that the meaning one attributes to loss changes constantly. Many of these assertions are based upon human becoming theory, science of unitary human beings, and the Neuman Systems Model (Pilkington, 2008). Floczak (2008) postulates that the sorrow of loss continues while the meaning of loss constantly changes.



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# Holistic Integrative Therapies in Palliative Care

## CHAPTER

### KEY POINTS

- Holism focuses on unity, mutuality, meaning, and the interrelationship of all beings, events, and things.
- People can grow and learn from illness and dying. Individuals can die healed.
- Holism is the theoretical and philosophical foundation for all alternative/complementary integrative healing modalities.
- Holistic integrative therapies can be used by the nurse, client/patient, and family. They are therapies of healing and empowerment.
- Relaxation is the basis for most holistic modalities.
- Imagination and imagery can play a powerful role in healing.
- Although there are many forms of meditation, all attempt to quiet the mind and focus one's attention inward.
- Sense therapies such as music (sound), aromas (smell), and touch (kinesthetics) have very potent natural healing properties that can adjust chemical or other imbalances with the body.
- Reminiscence and life review allow one to reintegrate past issues and experiences in the present to achieve a sense of meaning and ego integrity.
- Journal writing often helps those who cannot express verbally how they feel or what they are experiencing.
- Touch is essential to the quality of one's existence. It needs to be reintroduced as a significant modality in nursing practice.
- Herbs have many healing qualities but should be used knowledgeably.
- Homeopathy is a long-standing method of holistic medicine in which "like cures like" and remedies are tailored to the individual.
- Prayer is unique to each individual both in form and in content.
- There is a consciousness in dying where individuals become aware of their own deaths in phases.
- Self-care for health professionals who care for dying persons is imperative. Self-care areas include spiritual, emotional, physical, mental, and relationships.

## CASE STUDY

J. A., a 40-year-old male in the terminal stages of AIDS, was admitted to the hospital 1 week ago. This was his third hospitalization in 6 months. He was experiencing difficulty breathing, dehydration, extreme weakness, and fatigue. Because J. A. had lost so much weight, he was uncomfortable much of the time with muscle and joint aches. Additionally, J. A. was very anxious and found it difficult to sleep at night or rest during the day, increasing his discomfort and fatigue. He was fearful that any physical treatments or manipulation would exaggerate his pain, and he often became angry when the nurses administered morning and evening care.

J. A. was offered therapeutic touch (TT) treatments to see if it might be helpful in relaxing him. At first he refused, stating that he did not want to be touched. The nurse clarified that TT would not cause him any physical pain and that it did not in fact involve touching his body. She explained that it might be relaxing for him and might also help him to rest and sleep. The nurse suggested that, if J. A. was willing, she would do a 10-minute “trial” session to see if TT helped. After putting a sign on the door “Do not disturb for 15 minutes,” the nurse encouraged J. A. to breathe slowly and deeply and close his eyes. She then centered herself, breathing slowly and deeply, and set the intention for the wholeness and well-being of J. A. Working about 7 to 10 inches away from his body, she began to assess J. A.’s energy field to ascertain his energy flow and any blockages. She then passed her hands repeatedly through his field from head to toe to get the energy flowing and balance J. A.’s field. The nurse continued for about 5 minutes, noticing that J. A.’s muscles relaxed, his expression softened, and he became quiet.

This chapter introduces the reader to a variety of holistic modalities that are used in nursing practice today and can be used in palliative care (PC). The modalities are defined and shown where they are most useful. In addition, this chapter includes a section on exercises that can be used readily by nurses and incorporated into their practice. It also includes resources where more information on each of these modalities can be obtained. In the education of nurses, it is particularly important for nursing faculty to incorporate these healing modalities into the curriculum for both undergraduate and graduate-level students.

Holism focuses on unity, mutuality, meaning, and the interrelationship of all beings, events, and things. The words “heal” and “health” come from *haelan*, which means to be or become whole. Holism emphasizes the basic wholeness and integrity of the individual. It views the body, mind, emotion, and spirit as inseparable and interdependent. All behaviors, including health, illness, and dying, are manifestations of the life process of the whole person (Quinn, 2013).

Holistic nursing care draws on nursing knowledge, theories, expertise, and intuition, as nurses and clients become therapeutic partners in a shared evolving process toward healing. Holistic care:

- Believes that people can grow and learn from health, illness, and dying

- Promotes clients’ active participation in their own health care, wellness, and healing
- Uses appropriate interventions in the context of the client’s total needs
- Works to alleviate clients’ physical signs and symptoms
- Concentrates on the underlying meanings of symptoms and illness events and changes in the clients’ life patterns and perceptions (Mariano, 2013a)

Numerous modalities (Dossey & Keegan, 2013; Fontaine, 2011; Micozzi, 2011) are used in the provision of holistic care. Some of these that are particularly useful in end-of-life (EOL) care are discussed in this chapter. Nurses can practice holistic care in any setting where healing occurs.

## HEALTH CARE AND USE OF COMPLEMENTARY/ALTERNATIVE/INTEGRATIVE MODALITIES IN THE UNITED STATES

The American public is increasingly demanding health care that is compassionate and respectful, provides options, is economically feasible, and is grounded in holistic ideals. A shift is occurring in health care where people desire to be more actively involved in health decision making. They have expressed their



dissatisfaction with conventional (Western allopathic) medicine and are calling for a care system that encompasses health, quality of life (QOL), and relationship with their providers.

Barnes, Bloom, and Nahin (2008), in the most recent National Health Interview Survey, found that 38.3% of adults in the United States aged 18 years and older (almost 4 of 10 adults) and nearly 12% of children aged 17 years and younger (1 in 9 children) used some form of complementary and alternative medicine (CAM) within the previous 12 months. People who use CAM approaches seek ways to improve their health and well-being, attempt to relieve symptoms associated with chronic or even terminal illnesses or the side effects of conventional treatments, have a holistic health philosophy or desire a transformational experience that changes their worldview, and want greater control over their health. CAM provides individualized diagnosis and treatment of individuals; an emphasis on maximizing the body's inherent healing ability; and treatment of the "whole" person by addressing their physical, mental, and spiritual attributes.

Western medicine is proving wholly or partially ineffective for a significant proportion of the common chronic diseases. Furthermore, highly technological health care is too expensive to be universally affordable. Holistic care that promotes health is more cost effective and culturally acceptable to diverse and disparate populations whose belief systems are more congruent with whole system and holistic approaches to treatment. The use of alternative methods for economic and cultural reasons by these populations often outweighs their use of conventional treatments (Mariano, 2013b).

Barnes et al. (2008) found that CAM usage was positively associated with number of health conditions and number of doctor visits in the past 12 months. When worry about cost delayed the receipt of conventional medical care, adults were more likely to use CAM than when the cost of conventional care was not a worry. When unable to afford conventional medical care, adults were more likely to use CAM.

A Survey of Consumer Use of CAM by the AARP and National Center for Complementary and Alternative Medicine (AARP/NCCAM, 2011) found that people 50 years and older tend to be high users of CAM. Over one half of the respondents (53%) have used one or more CAM therapies. A significant aspect of this study was that among all respondents who saw a physician, only one third (33%) had discussed CAM with a physician and 67% did not discuss CAM with their doctor because of the following reasons:

- The physician never asked them (42%).
- The respondents did not know they should (30%).

- There was not enough time during the office visit (17%).
- They do not think the doctor knows the topic (17%).
- The doctor would have been dismissive or told them not to do it (12%).

In a 2007 AARP/NCCAM survey, nearly three fourths of respondents (74%) said that they take one or more prescription medications (AARP/NCCAM, 2007). Twenty percent of respondents reported currently taking more than five prescription medications. Three fourths (75%) of those currently taking one or more prescription medicines also take one or more over-the-counter medicines. Three fourths (75%) of the respondents who had used herbal products or dietary supplements reported that they currently take one or more prescription medicines.

It is clear that people aged 50 years and older are likely to be using CAM. It is also clear that this population is frequently using prescription medications. Common use of CAM as a complement to conventional medicine—and the high use of multiple prescription drugs—further underscores the need for health care providers and clients/patients/families to have an open dialogue to ensure safe and appropriate integrated health care. The lack of this dialogue points to a need to educate both consumers and health care providers about the importance of discussing the use of CAM, how to begin that dialogue, and the implications of not doing so.

The chronically and terminally ill consume more health care resources than the rest of the population. More than 75% of all health care spending in the United States currently is for the treatment of chronic disease and 25% of Medicare spending is for costs incurred during the last year of life (Kaiser Family Foundation, 2010). The great interest in CAM practices among the chronically ill, those with life-threatening conditions, and those at the end of their lives suggests that increased access to some services among these groups could have significant implications for the health care system.

With the number of older Americans expected to increase dramatically over the next 20 years, alternative strategies for dealing with the elderly population and end-of-life processes will be increasingly important in public policy. If evaluations show that some uses of CAM can lessen the need for more expensive conventional care in these populations, the economic implications for Medicare and Medicaid could be significant. If safe and effective CAM practices become more available to the general population, special and vulnerable populations should also have access

to these services, along with conventional health care. CAM would not be a replacement for conventional health care, but would be part of the treatment options available. In some cases, CAM practices may be an equal or superior option. CAM offers the possibility of a new paradigm of integrated health care that could affect the affordability, accessibility, and delivery of health care services for millions of Americans. (Mariano, 2013 b, p. 89)

## ■ HEALING AND DYING

Healing the dying sounds like an oxymoron....But to heal is not necessarily to cure....To heal is to bring various levels of oneself—cellular, physical, intrapersonal, interpersonal, societal, spiritual, perhaps even cosmic—into new relationship with each other. (Olson, 2001, p. 3)

The nurse must assess the relationship of the dying individual with self, others, and a higher power, and provide appropriate interventions to assist in the development or maintenance of new or right relationships.

“Dying healed means that a person has finished the business of life, said goodbyes, and reached life’s goals. An individual knows who he is, and has a sense of integration of self and life” (Olson, 2001, p. 3). He or she realizes that one’s life was unique and one’s death matters to someone. One looks inward and realizes that life’s difficulties have created a certain wisdom. Significant others have had time to grieve and plan for changes, and comfort and peace are attained. Control of the dying process is maintained as long as possible by the individual and as much as possible as the person is willing. Dying is seen as a stage of life. It is part of a larger philosophy and perception in which both life and death have meaning.

As mentioned previously, healing the dying necessitates regard for relationships and connectedness. We speak of transcendence when implying a sense of connectedness between self and a greater reality. Self-transcendence integrates self with past and future, giving meaning to the present. It reflects concern for others and/or for meaning (Olson & Keegan, 2013). Many of the integrative modalities described in this chapter facilitate self-transcendence. As noted by Olson and Keegan (2013), positive outcomes for the self-transcendent person, even when nearing death, include less depression, neglect, and hopelessness; a greater sense of well-being and ability to cope with grief and death; and the ability to live and find

meaning in the present and connect with a higher power.

This caring relationship emphasizes quality rather than length of life. Healing the dying includes PC, and focuses on relationships of all kinds. There is the provision for opportunities and choices where the dying person can live life to its fullest, and at some point comfortably forgive, let go, release, and experience a peaceful death.

The nurse is in a partnership with the dying client, sharing rather than denying the experience. The focus of nursing care is on providing sacred space and the milieu for a calm and peaceful death. The nurse works with the client to foster hope and cultivate an appreciation of the seemingly irrelevant things in life. Learning to appreciate simple occurrences such as a sunset or the joys of life can cultivate a more positive view of life and one’s present experience. Enhancing avenues of support, whether professional, social (family and friends), or support groups, can often facilitate grieving and increase a sense of meaning in illness. Developing unrecognized inner strengths and resources is of great importance to the person who is dying or grieving.

The Chinese symbol for crisis indicates that crisis can be a challenge but simultaneously offers an opportunity for growth and a different perspective. The Greek word for crisis (*krisis*) signifies a “turning point.” Grief can serve as a building block for personal growth and healing. Asking the dying person about spiritual needs gives the client an occasion to verbalize unmet needs. All of this requires skill, knowledge, compassion, caring, anticipation, and organization on the part of the nurse as well as a willingness to face one’s own impermanence and mortality. It also necessitates caring for oneself.

## ■ SPECIFIC HOLISTIC HEALING MODALITIES

Holism is the theoretical and philosophical foundation for alternative/complementary integrative healing modalities. Numerous kinds of these modalities are used in health care today. This chapter will cover only a few of those that are most useful in EOL care. Many of these modalities can be used effectively by the nurse as well as the client/patient, for example, centering, relaxation, imagery, meditation, prayer, herbology, and homeopathy. Others are described in use with clients/patients, such as sense therapies, reminiscence and life review, touch, and Reiki. In addition to their calming influence and physiological benefits, these techniques also may alter the perception of pain. Another valuable aspect of these modalities is that their use can empower clients and families. When clients learn to heal themselves, they



are empowered. When they learn these techniques, they can do it themselves, which oftentimes gives them a sense of control (Mariano, 2013a). And when families are taught to use these modalities, they feel as if they are contributing something positive to the care of their loved one.

## Centering

Centering is a process by which one quiets the mind and focuses one's thoughts. It calms the mind and allows the practitioner to access innermost resources that are powerful forces in healing. Krieger (1997) notes that

Being on-center does not mean being still, immobile, rigid...In centering, we are quiet and "listen" to another language. Our attention goes to the heart region, where we find our own center of peace and know it as an attribute of our true self. We find that this sense of deep serenity is reminiscent to the truer peace we find in untrammelled nature and, with a thrill of personal discovery, realize that it is through such profound natural experiences that we can be at-one with the universe. (p. 22)

Centering is a shift in consciousness, an integrated sense of being. It is "a calm and focused sense of self-relatedness that can be thought of as a place of inner being, a place of quietude within oneself where one feels integrated and focused" (Jackson & Latini, 2013, p. 417). Bodily movements become quieted, and yet one is in an actively conscious state. One feels a unique stillness and peace. There is a sense of inner equilibrium and well-being. Perception deepens, and one is less aware of the chaos of the moment, the day, and the mind's chatter. Practice in the act of centering (closing eyes, quieting one's mind and activities, focusing on one's center or inner peace) leads to intuition and inner wisdom (Krieger, 2002).

By remaining "on-center," the nurse is able to convey to the client an awareness, a sensitivity, an empathy, and a deep sense of peace and regard that often creates a relaxation response in the client. One must give oneself permission to center, as the environment is always calling us to be present for it rather than for ourselves. But when one is centered and personally present, compassion becomes real, and this state is needed for those who would facilitate healing. One important exercise that the nurse can practice is to center before entering into each client encounter—detaching from any prior encounter, and to approach each client with awareness and with, as Carl Rogers says, "unconditional positive regard" (Laurant & Shlien, 1984).

## Creating Intention

Creating intention affects the mental, emotional, and physical realms. It is a powerful way to establish an optimal milieu for a caring–healing interaction.

Examine the following intention: "I am here for the greater good of this person. I set aside my own concerns and worries and am fully present to the person here and now." With this intention the nurse is consciously setting aside his or her own concerns and focusing on the patient; s/he has set into motion the dynamic that this interaction will be "for the greater good of this person"; and s/he is making a conscious decision to be fully present. The nurse, through this intention, creates an environment that promotes and sustains a caring–healing interaction. (Thornton & Mariano, 2013, p. 625)

## Relaxation

Relaxation is a state in which there is an absence of physical, mental, and emotional tension. A pleasant sensation and the lack of stressful or uncomfortable thoughts also accompany relaxation. It is often referred to as the opposite of the fight-or-flight or freeze response.

Relaxation allows the body/mind to quiet and focus inward. One can retreat mentally from one's surroundings, still thoughts, relax muscles, and maintain a state of relaxation, attaining the benefits of decreased tension, anxiety, and pain. Regardless of the approach (use of meditation, yoga, muscle and breathing exercises, hypnosis, prayer, and other forms of stress management), the end result of the relaxation response is a movement of the person toward calmness, balance, and healing. The guidelines for relaxation are found in Exhibit 11.1.

Relaxation techniques are the basis of many holistic modalities. Relaxation has three aims: (a) as a prevention to protect body organs from unnecessary stress and wear; (b) as a treatment to alleviate stress in numerous conditions, for example, hypertension, tension headache, insomnia, asthma, immune deficiency, panic, pain; and (c) as a coping skill to calm the mind and to help thinking to become clearer and more effective (Pestka, Bee, & Evans, 2010; Rodgers & Micozzi, 2011). Positive information in memory also becomes more accessible when a person is relaxed.

There are numerous benefits to the relaxed state, including lowered blood pressure, decreased heart rate, increased body temperature, decreased anxiety associated with painful situations, easing of muscle tension pain such as in contractures, a general sense of

### Exhibit 11.1

#### Guidelines for Relaxation

- Be familiar with the relaxation exercise before introducing it to the client.
- Encourage use of familiar relaxation techniques that the client knows.
- Assess the client's level of tension, level of readiness to learn to relax, pain, anxiety, fear, and perception of reality or history of depersonalization.
- Ask the client what it means for him or her to be relaxed.
- Assess the client's ability to remain comfortably in one position for 10 to 20 minutes.
- Decrease as much environmental stimuli as possible.
- Assist the client to develop a positive expectation of what is to occur.
- Describe the potential benefits of relaxation and enlist cooperation.
- Reduce the opportunity for self-blame if the session does not go as expected.
- Have the client close his or her eyes.
- Use a tone of voice that is quiet and calm, conversational at first, and decreasing in volume as the session goes on.
- Use either tapes or a live voice. Music can provide background if desired.
- Guide the client through a basic breathing exercise (see "Exercises" section).
- Phrase all suggestions in a positive form, for example, "Let go of your tension," "Feel the tightness *melting* away," "Loosen and soften your muscles," "Allow the tension to *drift* away."
- Clients may experience a release of emotion as they relax, such as tears, vomiting, or faster and more shallow breathing. Gently ask if the client can put words to those feelings. Allow time for expression before continuing.
- At the completion of the session, bring the client gradually back to reality by having the client take deep breaths, move the hands and feet, and stretch if able.
- Have the client evaluate the experience.
- Engage the client's cooperation in continuing practice until the next session.

intense calm, decreased symptoms of depression and stress, and decreasing fatigue. Other benefits include helping the client to sleep, increasing the effects of medications, improvements in side effects of cancer therapy (decreased nausea, vomiting, and anxiety) and AIDS therapy, assisting in preparation for surgery or other treatments, and helping to dissociate from pain (Anselmo, 2013; Freeman, 2008; Payne,

2005). In addition to the therapeutic benefits, relaxation techniques also give clients a sense of control by enabling them to bring about certain psychological and mental responses by themselves.

Anselmo (2013), Davis, Eshelman, and McKay (2008), and Payne (2005) provide excellent guidelines for the nurse in preparing the client for relaxation and actual scripts to guide one through various relaxation exercises. Exhibit 11.1 includes guidelines or key points for relaxation.

A basic breathing exercise and relaxation exercise that can be used with the client or by the nurse are found in the "Exercises" section at the end of this chapter.

### Imagery

Imagining is a powerful technique of focusing and directing the imagination. One uses all the senses—vision, sound, smell, taste, movement, position, and touch. Imagery influences an individual's attitudes, feelings, behaviors, and anxiety, which can either lead to a sense of hopelessness or promote a perception of well-being that assists in changing opinions about disease, treatment, and healing potential. "Imagery [is the] internal experience of memories, dreams, fantasies, and visions—sometimes involving one, several, or all the senses that serve as the bridge for connecting body, mind, and spirit" (Schaub & Burt, 2013, p. 363). Imagery can affect people physically, emotionally, mentally, and biochemically, and the body and mind respond as if the event is actually occurring.

Guided imagery and interactive guided imagery (having the client directly interact with the image) are techniques to access the imagination through a guide. There are numerous types of imagery:

- Receptive imagery (inner knowing or "bubble-up" images)
- Active imagery (a focus on the conscious formation of an image)
- Correct biological imagery (recognizing the impact of negative images on physiology and creating positive correct biological images)
- Symbolic imagery (images emerging from both the unconscious and conscious that shape attitudes, belief systems, and cultural experiences, often mythic symbols)
- Process imagery (a step-by-step rehearsal of any procedure, treatment, surgery, or other event prior to its occurrence)
- End-state imagery (rehearsal of an image of being in a final, healed state)
- General healing imagery (images that have a personal healing significance such as a wise person, an animal, the sun, etc.)



- Packaged imagery (another person's images such as commercial tapes)
- Customized imagery (images specific to an individual)

Guided imagery has many applications in EOL care, including relaxation, stress reduction, pain relief, symptom management, grief work, and assisting clients to comprehend meaning in their illness experience (Fitzgerald & Langevin, 2010; Fontaine, 2011). It is useful not only in mobilizing latent, innate healing abilities of the client by intensifying the impact of healing messages that the autonomic nervous system sends to the immune system and other bodily functions, but also in the self-care of the nurse. It has been found helpful in relieving chronic pain and headaches, stimulating healing, tolerating medical procedures, exploring emotions that may have caused illness, understanding symptoms, solving difficult problems, enhancing self-esteem and self-confidence, envisioning and planning for the future, and listening to one's inner advisor.

It is usually helpful for the nurse to have training in the use of interactive guided imagery because of possibly overwhelming effects with this type of imagery. Otherwise, as Schaub and Burt (2013) note, imagery scripts are more effective when one learns the speaking skills of voice modulation, specific word emphasis, and the use of pauses. Guidelines for the nurse to use in teaching the client the imagery process are presented in Exhibit 11.2.

Basic imagery exercises that nurses can use with clients are under the Exercises section at the end of this chapter.

## Meditation

Meditation is a quiet turning inward. It is the practice of focusing one's attention internally to achieve clearer consciousness and inner stillness. There are numerous methods and schools of meditation, all having an individual interpretation of the practice. However, all methods believe in emptying the mind and letting go of the mind's chatter that preoccupies us.

Meditation, which originated in the Eastern tradition and is integral to Hinduism, Taoism, and Buddhism, is both a state of mind and a method. The state is one where the mind is quiet and listening to itself. The practitioner is relaxed but alert. The method involves the focusing of attention on something such as the breath, an image, a word, or action such as tai chi or qigong. There is a sustained concentration but it should be effortless.

The objective of meditation is to detach from external events as well as one's own mental activity. Rather than examining thoughts that may enter the

### Exhibit 11.2

#### Guidelines to Imagery

- Have the client relax. Help the client to identify the problem or goal of imagery.
- Develop a basic understanding of the physiology involved in the healing process. Begin with a few minutes of relaxation, meditation, or paying attention to the breath exercise.
- Assist the client to develop images of
  - The problem
  - Inner healing resources (beliefs, coping strategies, etc.)
  - External healing resources (medications, treatments, family, etc.)
  - End with images of the desired state of well-being

mind, the person disregards them and allows them to drift away. There is no criticism or judgment, but an attitude of a beginner's mind: a mind that is open and receptive, clear of attachment to any thoughts. The body is relaxed and the mind is emptied of all thought except awareness of the image, word, or breath. "Passive concentration" keeps the meditator in a state of awareness and alertness rather than drowsiness, and intently focused on the present moment. There should be no blame, guilt, or recrimination if the meditator loses focus or if the mind wanders; one is instructed simply to return the mind to its original focus. Reentry into the normal waking state should be gentle and relaxed. Meditation requires practice on a regular schedule, usually once or twice daily to achieve maximal results.

There are various reasons for practicing meditation: to find peace, achieve awareness and enlightenment, find oneself, experience true reality, and enhance a sense of well-being. Research has demonstrated that relaxed forms of meditation decrease heart rate and blood pressure, increase breathing volume while decreasing the number of breaths per minute, increase peripheral blood flow, improve immune function, decrease anxiety, decrease insomnia, and decrease skeletal muscle tension, epinephrine level, gastric acidity, motility, anxiety, depression, traumatic stress, and alcohol and drug consumption (Anselmo, 2013; Fontaine, 2011; Freeman, 2008; Gauding, 2005; Krietzer & Reilly-Spong, 2010). It is believed that meditation activates the right cerebral hemisphere and the parasympathetic nervous system, thereby quieting the nerves and allowing intuitive, wordless thinking to occur. In addition to

physiological benefits, the advantages of meditation cited by Payne (2005) are listed in Exhibit 11.3.

A simple meditation that can be practiced by the nurse or with a client is in the Exercises section at the end of this chapter.

## Sense Therapies

Sense therapies use the senses to treat physical and psychological problems and to adjust chemical or other imbalances within the body. These can include behavioral vision therapy, eye movement, desensitization, flower remedies, hydrotherapy, and light therapy. Three therapies will be explored under sense therapies: music therapy, music thanatology, and aromatherapy.

■ **Music Therapy.** Morris (2009) defines music therapy as the “behavioral science concerned with the systematic application of music to produce relaxation and desired changes in emotions, behavior, and physiology” (p. 327). The elements of music, sound, rhythm, hearing, melody, harmony, and movement are part of people’s primary experiences. Listening to, creating, or moving to music assists people in improving, changing, or better integrating aspects of themselves. Music has a power that cannot be expressed in verbal language.

There are references to the therapeutic powers of music in philosophy, art, and literature throughout the ages (Ingersoll & Schaper, 2013). Music is used in healing ceremonies throughout the world. Our own experiences demonstrate the psychological effect that music has on us. Despite varying musical tastes, certain types of music create specific moods: for example, a march, ominous music, lively music at sports

events, quiet and relaxing music in waiting rooms, or a mother’s singing and rocking her baby in times of distress.

Music therapy can reduce biopsychological stress, pain, anxiety, and isolation. It assists clients in reaching a deep state of relaxation, developing self-awareness and creativity, improving learning, clarifying personal values, and coping with a variety of psychophysiological problems. It also provides clients with integrated body/mind episodes and encourages them to become active participants in their own healing. Appropriate music produces the relaxation response, often removing a client’s inner restlessness and quieting ceaseless thinking. It is used as a healing technique to quiet the mind and bring about inner relaxation (Morris, 2009). Research has demonstrated that music reduces acute and chronic pain, is beneficial in treating or managing dementia symptoms, provides distraction, reduces agitated behaviors in elderly individuals, decreases the intensity of depression, reduces pain and nausea, and increases QOL and spiritual well-being (Fontaine, 2011; Ingersoll & Schaper, 2013).

Because music therapy focuses on process and not on outcome, one need not have any musical skills or talents to derive benefits. Clients can be induced to a relaxed state through breathing, suggestive imagery, or a relaxation exercise. Music selected by the client or the nurse is played, and the client is invited to explore images, sensations, emotions, memories, and visions brought on by the music. No one type of music works well for all individuals in all situations. A variety of soothing selections (popular, new age, classical, country, opera, folk, jazz, choral hymns, etc.) should be available because one cannot always predict a client’s particular preference or response to the music. Often the client experiences an altered state of consciousness, which is usually very relaxing. After the listening, the client is brought back to reality to discuss the experience. In some instances, the client chooses the music and moves to the music. The nurse should assess the factors described in Exhibit 11.4 in preparing to use music therapy (Chlan, 2010; Morris, 2009).

Music has the greatest effect when the client is appropriately prepared. Find a quiet environment and have the client assume a comfortable position. Suggest that the client maintain a passive attitude, neither forcing nor resisting the experience, and remind the client to focus all concentration on the music.

■ **Music Thanatology.** Music thanatology, developed by Schroeder-Sheker (1994, 2005) and Hollis (2010), is a relatively new field that addresses the needs of the dying by assisting the client in completing the transition between life and death. Specially trained therapists, using harp, voice, and chanting, assist the client in leaving during the last hours of life by reinforcing peace,

### Exhibit 11.3

#### Advantages of Meditation

- A better understanding of the self and increased receptivity to insights arising from one’s deeper being. Practicing meditation can bring the experience of self for the dying, where the individual may attain calm and often a sense of purpose
- A new sense of relaxation and inner peace
- A clearer mind and improved concentration
- More harmony with and within the self
- As a result of the detachment, an acceptance that many unpleasant emotional responses are short-lived sensations created by one’s thoughts
- An emphasis on living in the present and valuing the here and now



## Exhibit 11.4

### Assessment of Music Therapy

- The client's music history and music preferences
- The client's identification of music that make the client happy, excited, sad, or relaxed
- The client's identification of music that is distasteful and that makes the client tense
- Assessment of the importance of music in the client's life
- The frequency of music playing in the client's life
- Previous participation in relaxation/imagery techniques combined with music
- The client's mood—this will determine the type of music to be played

acceptance, and a calm anticipation of death. Schroeder-Sheker (1994) describes music thanatology as a

palliative medical modality employing prescriptive music to tend the complex physical and spiritual needs of the dying...music thanatology is concerned with the possibility of a blessed death and the gift that conscious dying can bring to the fullness of life. (p. 83)

This music is live (not taped), dynamic, and prescriptive. It is individual to each patient and each death, much like childbirth. According to Schroeder-Sheker (2005), music thanatology has been found to be most effective in deaths from cancer, AIDS, burns, and slowly degenerative diseases.

Schroeder-Sheker (1994) identifies six foundational assumptions of music thanatology:

1. It recognizes dying as a spiritual process and as an opportunity for growth.
2. The musical deathbed vigil, often called "musical-sacramental-midwifery," is a contemplative practice requiring serious inner work and integration of the physical, emotional, mental, and spiritual aspects of the caregiver.
3. Death is not an enemy and it is not a failure; it is a critical chapter of human biography.
4. The way in which each person dies is equally important as the way in which that person lived. Beauty, reverence, dignity, and intimacy are central to life and especially so for death. The infirm music can bring things to the surface in a nonthreatening way or serve the role of meditation. Music is a flow, weaving body, soul, and spirit together.
5. This work is a vocation, not merely a career. It requires clear intention and attention at each deathbed vigil.

6. Death and dying should be returned to the human, personal realm rather than denying or ignoring loss and leave-taking and thus reducing them to legal or corporate medical matters.

Music thanatology focuses on music for the dying versus music for the living. The dying person should not spend energy, only receive energy.

The entire surface of the skin can become an extension of the ear, thus enabling the patient to absorb infirm music, creating the possibility for even deeper emotional, mental, and spiritual reception....The sole focus is to help the person move toward completion and to unbind from anything that prevents, impedes, or clouds a tranquil passage. (Schroeder-Sheker, 1994, pp. 93–94)

■ **Aromatherapy.** Aromatherapy is an offshoot of herbal medicine in which aromatic plant extracts are inhaled or applied to the skin as a means of treating illness and promoting physical, psychological, and spiritual benefits as well as positive changes in mood and outlook (Buckle, 2013). Though aromatherapy and herbal medicine use many of the same plants, in aromatherapy the plants are distilled into oils of exceptional potency (Halcon, 2010).

The advantage of these oils comes from their influence on the limbic system, which coordinates mind and body activity. This system is very sensitive to odors and encodes them into associations and memories, which when awakened alter basic physical functions such as heart rate, blood pressure, breathing, and hormone level. When these oils are rubbed into the skin or inhaled, they set off a reaction leading to rapid and significant alterations in memory, heart rate, and other bodily mechanisms. Some boost energy, some promote relaxation, and others have pharmaceutical effects. However, no treatment should ever involve more than a few drops of oil.

There are hundreds of plants used for aromatherapy (Buckle, 2013; Davis, 2005; Fontaine, 2011; Harris, 2011; Price & Price, 2011). Some of the more common ones that are useful in the care of the dying include chamomile, which is used to overcome anxiety, anger, tension, stress, and insomnia; lavender, for exhaustion, depression, and stress; marjoram, used for those who are physically debilitated; neroli, for countering depression, anxiety, nervous tension, and fearfulness; peppermint and rosewood for treating nausea; and chamomile, camphor, fennel, lavender, peppermint, and rose for relieving vomiting. Aromatherapy also is used in the relief of pain (lavender, capsicum, bergamot, chamomile, rose, ginger, rosemary, lemongrass, sage, and camphor). It is most useful in the enhancement of mood, increasing

vitality, and relaxation. These plants and oils can be found in natural or health food stores.

## Reminiscence and Life Review

Life review or reminiscence therapy is the remembering of significant past events that enable one to reintegrate past issues and experiences in the present for the purpose of achieving a sense of meaning and ego integrity. The concept has been most frequently used with elderly individuals but is just as effective with those nearing the EOL. Reminiscence is a natural phenomenon. It is the process of recounting past events to someone else or it can be a more complex process of transpersonal focusing and inward reflection. The level of complexity depends on the wish of the client and the training of the nurse. Life review can be oral, including audio and video recordings, or written. Journal and letter writing can also be useful techniques in life review. Photographs and personal items often provide the opportunity for reminiscence and give information about the client that assists the nurse in providing personal and meaningful care.

Life review is a process of unfolding and emerging and therefore cannot be hurried. A life review can be one or many sessions. Olson and Keegan (2013) and Haight and Haight (2007) provide a guide for a structured life review that usually includes six to eight sessions:

- Use open-ended questions. Ask about childhood and earliest memories and be sure to be supportive if the client recalls sad events.
- Again using open-ended questions, proceed through the client's life history by asking about adolescence, family and home, adulthood, and later life.
- Have a summary session inquiring about the following: "Generally, what kind of life do you think you have had? What would you do over again?"

To promote the process, the nurse should encourage the client to express himself or herself, involve significant others, assure confidentiality of the information, be sure the client has sufficient physical strength and a desire for sharing, listen carefully, use touch as appropriate, and allow the client periods of silence to reflect. Life review provides integration, a feeling that this life was individual and unique. The client may verbalize sadness as well as achievement, but the objective is to allow a person to see the meaning in his or her life.

## Journal Writing

Keeping a log or journal is a very effective healing technique to use for individuals who are experiencing life-threatening illness and during the grieving

process. It allows the person to express his or her innermost feelings and thoughts without fear of criticism. It is often helpful for those who are uncomfortable or unable to articulate how they feel or what they are going through. Writing can also assist the person to make new connections and reframe past experiences. The healing emanates from the actual writing and expression, and not from an analysis of the content of the journal. The writing may be totally private or shared with others. Many clients do not think of this technique, and the nurse may suggest it. Levin and Reich (2013) and Snyder (2010a) offer some suggested topics for journal writing:

- Special thoughts of the dying person or about the deceased
- Feelings that were never expressed
- Saying good-bye
- Ways that grief or dying has helped one grow
- Lessons learned from life that one wants to share
- Positive aspects of the past, present, and future
- Transitions
- Fears about treatment/outcomes

There are numerous topics for journal writing, or the client can just write thoughts and feelings as they occur. The individual may find comfort in writing when difficult times occur, for example, unanticipated news about a diagnosis or prognosis, dealing with family members, or writing to God, a loved one, or one's disease. Often the journal becomes one's own record of grieving. It often serves as a chronicle of personal growth, insights, and wisdom gleaned from the experience of dying or loss.

## Touch

In the later stages of life, individuals are often deprived of tender and nurturing physical contact such as being touched in a way that is healing, nourishing, relaxing, and pleasurable. Touch is essential to one's quality of existence. It provides comfort, warmth, and renewed vitality—a sense of security and assurance that we are not alone. Reasons for the lack of touch of the dying include fear, discomfort, stereotypes about dying people, and a sense of one's own vulnerability. However, the benefits of touch on individuals are many. There is an increase of circulation and mobility (e.g., range of motion or hand grasp), a decrease in pain, increase in vitality, increase in physical functioning, the experience of being nurtured and cared for, a boost in self-esteem, increased motivation to receive and give attention to self and others, energy and emotional release, a sense memory triggering a relaxation response, relief from loneliness



and isolation, decreased feelings of abandonment and deprivation, verbal interaction, and calming reassurance and support (Goldschmidt & van Meines, 2012; Rose, 2009). It often induces much-needed sleep. In this day of technological care, touch may be the one caring tool to help a client feel better.

There are many forms of touch considered to be holistic/integrative modalities (Coughlin & DeLany, 2011; Fontaine, 2011; Jackson & Latini, 2013; Micozzi, 2011; Rose, 2009; Snyder & Lundquist, 2010). These include, but are not limited to, the following:

- **Acupressure**—The application of pressure, using fingers, thumbs, palms, or elbows, to specific sites along the body's energy meridians to stimulate, disperse, and regulate the body's healing energy for the purpose of relieving tension and reestablishing the flow of energy along the meridian lines.
- **Body therapy**—A general term used for approaches (e.g., Alexander technique, chiropractic, Rolfing, shiatsu, Feldenkrais) that use hands-on techniques to manipulate and balance the musculoskeletal system to facilitate healing, increase energy, relieve pain, and promote relaxation and well-being.
- **Reflexology**—The application of pressure to specific reflex areas on the feet or hands that correspond to other parts of the body in order to locate and correct problems in the body.
- **Massage**—The practice of kneading or otherwise manipulating a person's muscles and other soft tissue with the intent of inducing physical and psychological relaxation, improving circulation, relieving pain and sore muscles, and improving the individual's well-being. Procedural massage is done to diagnose, monitor, or treat the illness itself, focusing on the end result of curing the illness or preventing further complications. In the past, massage has been one of nurses' most important interventions for pain reduction, comfort, tension release, prevention of atrophy of muscles and stiffness of joints, and inducing sleep. A back massage has left many a patient refreshed and feeling cared for. It would behoove us in nursing to reintroduce massage into our practice armamentarium.

Therapeutic Touch (TT) was developed by Dolores Krieger and Dora Kunz. This is a specific modality of centering intention while the practitioner moves the hands through the client's energy field for the purpose of assessment and treatment. It is based on the philosophy that universal life energy flows through and around us, and any interruption in this free flow of energy leads to illness. The goal is to balance and repattern the body's energy so that it flows most efficiently to promote health and prevent disease. The TT practitioner scans the client's energy flow,

replenishing it where necessary, releasing congestion, removing obstructions, and restoring order and balance in the ill system. This approach is also an effective complementary care approach for facilitation of the body's natural restorative processes, thereby accelerating healing, promoting relaxation, reducing pain and anxiety, and treating chronic conditions.

According to Macrae (1987), a well-known TT practitioner,

Since therapeutic touch is an interaction, it has the potential to heal the practitioner as well as the patient... You can also use the principles of TT to assist in healing yourself... the use of mental imagery can facilitate both the energy transfer and the rebalancing of the [practitioner's] field. If you have pain or discomfort somewhere: (1) Sit quietly and center yourself; (2) visualize the healing energy (as light, if you wish) coming down from above and flowing through you; (3) visualize the energy clearing away the pain or discomfort (as light shines through a dark area). (pp. 79–80)

Compassionate touch, developed by Nelson (1994) specifically for hands-on care given to those who are elderly, ill, or dying, is described as

a gentle, sensitive, and nonintrusive program of massage, attentive touch, and supportive comfort care for those individuals who are temporarily or permanently less active.... It also includes individuals of any age who are actively beginning the mysterious life transition that we call death. (p. 1)

Compassionate touch is a hands-on technique stemming not from the hands but from the heart. It combines massage and attentive touch with active listening, reflective communication, relaxation, imagery, and breathing awareness exercises. It focuses on not only the physical condition of the client but also on the psychosocial, emotional, and spiritual needs as well.

According to Nelson (1994),

compassion for another implies a feeling of unconditional regard for that other; it also implies a genuine, sincere interest in that person's well-being. The compassionate heart shares in, and is affected by the suffering of another.... The compassionate individual is able to put aside his or her own concerns for a time in order to give attention to someone else. Some say compassion is love in action. (p. 1)

Compassionate touch is not something we give; it is a way of being. It is a way of providing contact, reassurance, relief, and comfort for those who may

be frightened, depressed, out of control, abandoned, overwhelmed, confused, or in despair. It is a means of relating to others rather than a prescribed set of techniques to be practiced on others. It is a spontaneous event of relationship that unfolds moment to moment. Compassionate touch can be administered by anyone who feels inspired to reach out toward a fellow human being in need.

Reiki is based on Buddhist teachings, using hands-on touch to support and intensify energy in the physical, emotional, intellectual, and spiritual areas. Universal and personal energy are aligned and balanced by applying gentle hands-on touch to energy pathways of the body. Those who use Reiki attribute it with reducing stress and stress-related illnesses, including acute and chronic conditions; helping in debilitating disease because it bolsters the immune system by increasing energy; and contributing to an overall sense of well-being in the client (Jackson & Latini, 2013; Ringdahl, 2010).

The philosophy of Reiki contends that a person is vitalized by an essential energy that comes from the universal life force. Everyone has access to this life force, and one becomes ill when the energy flow is interrupted or stopped. Opening pathways for energy flow is the prime objective of Reiki. Learners of Reiki must themselves receive an attunement by an expert Reiki master in an initiation ceremony so that they are attuned to the energy transfer process.

Reiki bodywork is not massage. The touch is gentle and aims not to manipulate tissue, but rather to transmit universal life force to the client. The practitioner uses both hands, palms down, fingers held together, and proceeds in a pattern over the client's body. Each positioning of the hands is maintained for 3 to 5 minutes without any movement of the fingers or change in the initial gentle touch. During these hand placements, the universal life force flows through the practitioner to the client to balance the client's energy where necessary (Ringdahl, 2010).

Reiki bodywork is very individualized, and the client's perception of the energy transfer is unique to each person. Most find it rejuvenating and relaxing. The effects may be felt immediately or several days later. Following attunement/initiation of the caregiver, Reiki can be used as a method of self-healing as well as caring for others. As can be seen, numerous holistic healing modalities can be used during EOL care.

## Herbology

Herbology is also known as *phytotherapy* or *phyto-medicine*. Herbal remedies have been used in various cultures for centuries and are increasingly popular in

the United States as health products and medicines. In fact, herbal use is the fastest growing category of alternative/complementary therapy in the United States. Sierpina, Gerik, Miryala, and Micozzi (2011) define herbs as plants or plant parts (bark, fruit, flower, leaves, stem, root, or seed) that are used in fresh, dried, or extracted form for food, medicine, or promoting, maintaining, or restoring health. Herbs are prepared in many forms: tinctures, extracts, capsules, tablets, lozenges, teas, juices, vapor treatments, poultices, compresses, salves, liniments, and bath products (Springhouse Corporation, 2005).

Herbs are classified based on their effects as follows (Gladstar, 2012; Gruenwald, 2009; Skidmore-Roth, 2009):

- Adaptogenic herbs (which increase the body's resistance to illness)
- Anti-inflammatory herbs
- Antimicrobial herbs
- Antispasmodic herbs
- Astringent herbs (which are applied externally)
- Bitter herbs to increase the secretion of digestive juices, stimulate appetite, and promote liver detoxification
- Carminative herbs (aromatic oils) to soothe the lining of the gastrointestinal (GI) tract and reduce gas, inflammation, and pain
- Demulcent herbs to soothe and protect inflamed and irritated tissue and mucous membranes
- Diuretic herbs
- Expectorant herbs
- Hepatic herbs to tone the liver and increase the production of hepatocytes
- Hypotensive herbs
- Laxative herbs
- Nervine herbs to strengthen and restore, ease anxiety and tension, and stimulate nerve activity
- Stimulating herbs to stimulate physiologic and metabolic activities
- Tonic herbs, which enliven and invigorate by promoting the "vital force," which is key to health and longevity
- Pain-relieving herbs

Although herbs are natural substances and overall risk seems to be low, they cannot be used indiscriminately. Herbs are medicinal and may have serious side effects and interactions with prescription drugs. Additionally, there is a lack of regulation of commercial herbal products in the United States and lack of standardized dosage ranges and preparations. Yet, so many Americans choose to take herbal remedies because they are much less costly than prescription drugs, their access is virtually unlimited and unrestricted, they are effective, and many people are



becoming disenchanted with traditional health care. However, before taking any herbal remedy, one must know what it does, how to use it, and the possible adverse effects.

Many clients may hesitate to inform their health care provider that they are using herbs. It is therefore important for the nurse to assess clients' use of herbs and advise them accordingly. Several researchers offer the following guidelines regarding herbal therapy (Fontaine, 2011; Plontikoff, 2010; Sierpina et al., 2011; Skidmore-Roth, 2009):

1. Encourage the client to disclose use of herbal treatments and obtain a history of herb use as complete as possible, including all products taken, amounts, and brand names. If the client is seeing a herbalist, report any prescription drugs.
2. Determine if the client is using herbal remedies instead of, or as an adjunct to, conventional treatment. Is the herb being used to treat a specific condition or for general health?
3. Inform the client of various benefits, risks, and side effects of the herbal remedy, and any potentially serious adverse reactions that may occur when herbs are used with other drugs or substances the client is using. Labels on the products should contain information about product ingredients and use. Recommend standardized herbs.
4. Warn elderly clients, pregnant women, children, and those with known adverse drug reactions, allergies, chronic skin rashes, or preexisting liver disease that they have an increased risk of adverse effects from herbal medicines.
5. Advise the client to notice any unusual symptoms and to report these to the health provider immediately.
6. Advise the client not to take herbal products for serious medical conditions unless they are used under the care of a well-trained health care provider. Urge clients to take only the recommended dosages of herbal remedies.
7. Advise the client to be informed of reputable herbal companies and careful about products sold through magazines, brochures, and the Internet.
8. Tell the client to see a health provider well-trained in herbology when using herbal remedies. Health food store clerks are salespersons, not trained practitioners.
9. Keep a referral list of knowledgeable herbologists.

The field of herbology is expanding at an enormous rate and many books are now available for the nurse to refer to in the care of clients. It is important that the nurse become informed about herbs because increasingly our clients will be coming to us while concurrently using herbal remedies.

## Homeopathy

"Homeopathy" comes from the Greek words *homeo*, which means similar, and *pathos*, which means disease or suffering (Boiron Group, 2009). It is based on the law of similars, or like cures like, where stimulating the natural healing properties in the body cures a disease or alleviates a symptom (Freeman, 2008). In other words, when a substance identical to what would produce the symptoms of the disease is introduced into the body in very small or minute doses, it stimulates the person's healing energy. This is very different from what Hahnemann (the father of homeopathy) called allopathy, from the Greek words *allos*, meaning different, and *pathein* or *pathos*, meaning disease or suffering (Weiner, 1998).

The philosophy of homeopathy strongly contends that health and disease are a holistic phenomenon and the individual must be considered from a body, mind, and spirit perspective; that there is an inherent capacity in all living things to respond to illness in a self-curative way; that there is an "unknowability" about certain disease processes; and that rather than focusing on the disease, treatment may begin with the symptom but the client is treated as a whole and as an individual rather than as a diagnosis with common symptoms. Treatment is individualized and tailored to the uniqueness of each person.

Homeopathic remedies are prepared from natural substances—plant, animal, and mineral. The use of micro doses, that is, highly diluted doses, ensures the minimization of toxicity and side effects. Homeopathic medicines are available in various dosage forms: pellets, tablets, liquids, suppositories, and ointments. The U.S. Food and Drug Administration (FDA) recognizes homeopathic remedies as official drugs and regulates the manufacturing, labeling, and dispensing of homeopathic remedies. Simple homeopathic medications of low potencies are available over the counter; however, dilutions for more complicated and chronic conditions are available only from a homeopathic practitioner. Homeopathic remedies are safe, economical, simple to administer, mild in action, and have very few serious or prolonged adverse effects (Carlston, 2011).

Homeopathic remedies are valuable for a number of symptoms: arnica (marked muscle soreness and acute pain); hypericum (nerve pain, shooting pain); bryonia (trauma, pain on movement); bellis perennis (muscle injury from surgery); ipecacuanha (nausea and vomiting); aconite (fear and shock); calendula (bleeding, preventing infection, increasing granulation); chamomilla (irritability, sensitivity); belladonna (fever); and nux vomica (insomnia; Cummings & Ullman, 2010; Wauters, 2007).

## Prayer

Whatever holistic/complementary therapy we use may not be as important as how we use it. Providing safe space where healing can occur is what is most important—and that means using ourselves as an instrument of healing. Clients with life-threatening illness often question “Why?” and may need support in their desire to connect with something larger and outside of themselves. Focusing on them as spiritual beings allows them to explore the meaning and purpose of their illness and can bring comfort, often alleviating pain (Dossey, 1996, 1998; Wright, 2005). Burkhardt and Nagai-Jacobson (2013) offer a number of useful guides and instruments to facilitate spiritual assessment.

As O’Brien (2010) notes, prayer is as unique as the individual who is praying. Whether it is of petition, adoration, reparation, or thanksgiving, both the form and the content may vary greatly. Prayer is a simple act of turning our attention to the sacred. Depending on one’s beliefs, this can be the God of whatever religion or culture, a higher power, or the ultimate reality. Prayer can be active or passive, involve words, or be wordless. It can involve asking something for oneself or another, expressing repentance for wrongdoing and asking for forgiveness, giving praise and honor, summoning the presence of the Almighty, or offering gratitude (O’Brien, 2003; Snyder, 2010b). Many forms of prayer are meditative in nature and have the benefits of meditation previously discussed in the section on meditation. Others are intercessory, an active form of prayer that seeks an outcome through intentionality where we ask for healing for another or ourselves. This also can be done at a distance, which is referred to as nonlocal healing (Dossey, 1998). Clients also can benefit from prayerful listening to sacred music or sounds, writing or art, or expressing their intent toward the sacred through some body movement or posture (Taylor, 2003).

Prayer is often an important solace to clients who are ill; however, illness may create a barrier to prayer. In those instances, nurses’ prayers for and with the client can be a meaningful spiritual intervention as long as permission is obtained when possible. The nurse should assess the client to ascertain if prayer is desired and then follow the client’s expressed wish. Taylor (2003) suggests some assessment questions that the nurse can use:

- “How important or helpful is prayer to you?”
- “Would praying together now be comforting?”
- “What type of prayer would be helpful or comforting to you now?”
- “What helps or hinders you as you pray?”

- “How has your illness affected the way you pray or think about prayer?”
- “Have your prayers changed since you became sick?”
- “Do you find it harder to pray sometimes? How do you deal with that?”
- “Have your beliefs about prayer been challenged or changed by illness?”
- “At times like this, some start thinking about if and how their prayers ‘get answered.’ Have you thought about this?” (p. 182)

A few minutes spent on assessing and possibly praying with a client can often lower a client’s anxiety or assist the nurse’s understanding of how prayer facilitates the client’s coping.

## ■ THE HEALING JOURNEY AT THE EOL

Individuals become aware of their own deaths in phases, and this awareness can lead to consciousness in dying. Olson and Keegan (2013) and Olson (1997) identify some tasks for dying consciously, specifically,

1. *Live fully* until death comes. Direct or participate in treatment decisions, determinations about the kinds of care, and other decisions until you are comfortable with accepting the assistance of others.
2. *Plan* to say good-bye to family and friends, finish things you wanted to do, make final decisions, regarding the last will and testament, the estate, organ donation, and so forth. Consider what an ideal death would be like. Who do you want with you, or do you want to be alone? Who are the important people in your life and have you told them? Are there certain rituals you want at your death, for example, a memorial service, cremation? What kind of ceremony do you want? Are there certain treasures that you want particular people to have? Are there particular prayers, poems, or music you want read or played?
3. *Participate* in emotional and spiritual tasks such as forgiving yourself and others, feeling that life mattered and the world is different because you were here, and knowing and accepting love as one changes. Forgiving yourself and others necessitates recognizing that we are responsible for what we are holding onto; confessing one’s story to self and others, looking for the good points in ourselves and others; making amends where possible; looking to a higher power for help; and considering what we have learned. Forgiving others and ourselves helps one recognize unconditional love and connect more with the source of our joy instead of focusing on loss, sadness, and pain.



Unconditional love helps release one from fear and anxiety.

4. *Rehearse* the dying process. Through an awareness of dying, learn to diminish the fear of death and to “let go of this life” when it is time to do so. Imagery, relaxation, meditation, and prayer scripts on learning forgiveness, becoming peaceful, letting go, opening the heart, forgiving self and others, releasing pain and grief, conscious dying, moving into the light, and closure, can facilitate the detachment from pain and grief, the establishment of comfort and peace, and the achievement of closure. Olson and Keegan (2013) is an excellent source for some of these scripts. However, the nurse should have some practice experience prior to their use with clients.

### ■ BENEFITS OF HOLISTIC INTEGRATIVE THERAPIES

Nurses can make a critical difference in ensuring that clients receiving PC obtain maximum benefit at minimum risk when they integrate complementary/alternative modalities and conventional therapies. Clients benefit because of the following:

- Holistic therapies build on the body’s capabilities and are aimed toward strengthening the body’s own defenses and healing abilities so that it can do for itself. Strengthened and healthy defenses offer relief that exceeds symptom management.
- Holistic integrative therapies view people holistically, realizing that they are complex combinations of unique bodies, minds, emotion, and spirits. CAM considers this interconnectedness, as it assesses and addresses the physical, mental, emotional, environmental, and spiritual aspects of the person. Healing practices are tailored to the individual. This is especially important for PC where each person is experiencing a unique dying process. As a result, questions, emotional problems, socioeconomic concerns, and spiritual issues that affect health can be shared. Learning about the total person facilitates addressing needs holistically. Whole-person practices offer attentive and customized healing measures.
- Holistic therapies empower clients and families. People are taught about self-care practices, guided in using them, and assisted in exploring obstacles that could stand in the way of doing so. Also, family members and caregivers can be taught simple holistic techniques to use with their loved ones and themselves, thereby empowering the caregivers/family to participate in their loved one’s care and reduce their own stress.

- Most holistic therapies are safer and gentler than conventional therapies. A variety of physical and mental changes, combined with the high volume and nature of medications used in terminal phases of illness, carry many risks for dying clients. Although there are conditions for which drugs provide remarkable benefit, there are other conditions that can be managed and improved through lower risk CAM approaches.

With the many benefits that can be derived from using complementary/alternative therapies and a holistic approach, nurses can best assist those in the dying process by integrating CAM with conventional therapies. This requires that nurses understand the intended and safe use of various CAM therapies, educate clients/families in appropriate CAM use, and prepare themselves to offer selected CAM therapies as part of their practice.

### ■ SELF-CARE FOR THE HEALER

Working with the dying and their families can create much stress for the nurse. It is sometimes referred to as “death overload.” Olson (1997) notes that caregivers of dying persons often reexamine their own belief systems and may suffer an existential crisis of faith. Health professionals grieve the loss of their clients, and when the losses come too quickly, they may not complete the grieving process before the next death. This may lead to feelings of guilt, anger, irritability, frustration, helplessness, inadequacy, sleeplessness, and depression. Problems may arise in interaction with clients, family members, and other staff. Olson (1997) further notes the consequences when staff are not dealing well with the deaths of clients (p. 207):

- Avoiding patients/families
- Poor clinical judgment
- Unrealistic expectations
- Staff absences
- Outbursts of anger
- Lack of anticipatory planning
- Staff conflict
- Scapegoating
- Interprofessional power struggles
- Staff fatigue
- Ambivalence toward patients/families

These problems can affect an individual or an entire team. Therefore, it is imperative that health professionals learn self-care techniques. In discussing bereavement care and the role of nurse healers, Roach and Nieto (1997) identify five self-care areas

and questions that need to be explored when working with the dying and their families:

1. Spiritual self-care—Is spirituality important in my life? What is my relationship with God or a higher power? Why am I here and what is my purpose? What is my relationship to the universe?
2. Emotional self-care—Can I identify my emotions? How do I deal with them? Am I usually in control? Can I discuss my emotions? Am I open to others and do I respect the feelings of others or do I jump to conclusions? When do my emotions get out of control?
3. Physical self-care—What areas of my lifestyle are unhealthy or do I have a healthy lifestyle? What can I do to improve my lifestyle?
4. Mental self-care—Am I knowledgeable and do I continually increase my knowledge? Am I satisfied with the status quo or am I open to new ideas? What am I doing to stimulate my mind?
5. Relationships self-care—Am I open and honest with myself and others? Do I have satisfying relationships with others? Am I willing to accept the thoughts and feelings of others even though they are different from my own or am I judgmental? Must I have all the control or can I share it? Do I have a balance among work, home, and leisure? (pp. 171–175)

Worden (1982) identified four tasks of mourning that are equally applicable to staff. Accepting the reality of the loss, although painful, is necessary for healing to occur. It may sometimes feel as if the nurse in EOL care is in chronic grieving because of the number of dying clients. But denying the emotional pain, especially of a favored patient, only slows or inhibits the healing process from occurring.

Although more obvious in the significant others, experiencing the pain of the loss also occurs in the staff, including anger, depression, and guilt. Healing support of each other involves encouraging the expression of feelings and emotions such as sadness, anger, guilt, resentment, and pain. Validating the normalcy of the feelings and emotions is also important. One should identify coping strategies that might work or are not working; forgive oneself and others; and remember shared experiences with the deceased client.

Rediscovering meaning is a period of yearning, searching, and discovery. One yearns for the lost person(s) or assumed state of ordinariness, searches for some type of normalcy to reenter the everyday living or working situation, and then discovers the meaning of the loss or losses. Meaning to each of us is individual, unique, and personal. But if one can find meaning, one seems to adjust more easily. Some find

meaning in religion, some in support or supportive groups, and some in going inward. Some may never find the answer to the questions “Why did they have to die?” or “Why am I surrounded by so much death?” However, even if these questions are not answered, one may find a new meaning to life—to the present and to the future.

Reinvesting in life or work is somewhat like hope (Roach & Nieto, 1997). One realizes that there is a purpose to this type of work, that the future can be full and good. There is a letting go of remorse and fear of the future, a sense of empowerment, and a sense of one’s place in the world. With letting go, the nurse is free to remember the meaningful times with clients and the lessons learned. Although many techniques described above help in reinvesting in work, it also is useful for one to engage in an area of interest outside of work: enroll in a class, take a trip, do special things for oneself, or review one’s job goals and setting. Reinvesting in work does not necessarily mean that everything is solved; however, it can be the motivation for growth. This growth can be expressed as feeling more intensely, empathizing more completely, caring more fully, and developing more sensitivity to and compassion for others.

As noted earlier, those who care for the terminally ill are at risk for stress associated with many losses. There is also opportunity for a career leading to joy, a sense of personal and professional proficiency, and a capability of living life to the fullest. Olson (1997) identifies three aspects of developing growth when working with the dying. Identifying one’s motivation for practicing EOL care is important. Is it unresolved personal issues; a professional challenge beyond the physical that involves a search for meaning and peace; a desire to witness the growth of each individual as one comes to terms with mortality and the nature of life; a spiritual calling; a joy in physical care that involves a variety of techniques including complementary modalities such as breathing, TT, and relaxation? Whatever the motivation, exploring this question leads the nurse in EOL care to a certain insight and wisdom.

Coping techniques include those strategies used to change the negative effects of stress (Mariano, 2007). It can be forgiving self and others, and maintaining health through good nutrition, weight control, regular exercise, adequate sleep, and sufficient resources to maintain oneself in a healthy state. Other kinds of physical activities include massage, diaphragmatic breathing, and distraction. Time needs to be scheduled so that the staff can focus on themselves. An example of diaphragmatic breathing is found in the Exercises section of this chapter. Those who use this technique regularly can do so on cue, even at the bedside of a dying patient. Distraction includes humor, a



massage break, having lunch out, or a day off. One needs these distractions to rest and refresh one's spirit. Scheduling things that are not reminders of patients, death, or dying are important aspects in addition to grieving and remembering.

Hill (2011) offers many tools and techniques for transforming oneself and impacting one's practice through the art of self-care or replenishing one's body, mind, and spirit.

The road you take to self-care creates an endless journey to learning and self-awareness. Self-awareness... allows us to see ourselves and the world differently. This is what allows us to live and nurse from the highest point of our consciousness. (Hill, 2011, p. xvi)

Developing the spiritual self includes knowing that one's life has meaning and confronting one's mortality. These are key aspects in caring for the dying and their significant others. "*Healing the dying* means healing oneself by forming connections with the Universe and all that it is. It means a path one can count on, a way one travels with confidence" (Olson, 2001, p. 252). Searching for meaning necessitates learning to listen, quieting the mind's chatter, hearing the whisper of the inner self, and connecting to one's spirituality. A sense of connection with meaningfulness and purpose can be with an organized religion, with a group, or on the path of an inner process. There are many ways to develop an ability to listen to the inner self: meditation, creating an environment that supports peace, for example, nature or sound; reading literature about the development of a spiritual path; setting a regular time to practice; keeping a journal; sharing one's spiritual journey with like-minded people; and enjoying life. Whatever the technique, there is a growing sense of unity and purpose in being. One belongs here; one has a mission and a purpose.

### A COMMENTARY ON EVIDENCE-BASED PRACTICE RESEARCH AND HOLISTIC INTEGRATIVE THERAPIES

There is a great need for an evidence base to establish the effectiveness and efficacy of holistic/integrative therapies, and research in this area will become increasingly important in the future. However, according to Hyman (2006), there are two fundamental problems with using randomized control clinical trials (RCT) to study holistic healing modalities. The first is that holistic healing modalities are often part of a system, a philosophical approach that is centered on facilitating and promoting balance and health in the body, rather than ameliorating a particular symptom. In an RCT, the holistic/healing modality often is examined out of

context, and, consequently, the results often do not indicate the accurate effectiveness of these treatments. Second, most outcome measures used in the scientific community today are based on tangible physical/mental or disease symptomatology. One of the formidable tasks for nurses will be to identify and describe outcomes of holistic/integrative therapies such as healing, well-being, and harmony to develop instruments to measure these outcomes. In addition, methodologies need to be expanded to capture the wholeness of the individual's experience because the philosophy of these therapies rests on a paradigm of wholeness.

There is presently much discussion about what method is most appropriate for the study of holistic phenomena. Evidence-based medicine (EBM) often falls short in the clinical context of patients with chronic complex illnesses. EBM tends to concentrate on research methodology and reduces clinical practice to the technical implementation of research findings. Clinical practice most often employs multiple interventions that do not add up to an evidence-based approach based on a single intervention. Clinical research fails to focus on the combined outcome of multiple interventions because of the complexity, cost, and absence of effective tools for studying such approaches.

Researchers are being challenged to look at alternative philosophies of science and research methods that are compatible with investigations of humanistic and holistic occurrences. We need to study phenomena by exploring the context in which they occur and the meaning of patterns that evolve. Also needed are approaches to intervention studies, which are more holistic, taking into consideration the interactive nature of the body-mind-emotion-spirit-environment. Rather than isolating the effects of one part of an intervention, we need more comprehensive interventions and more sensitive instruments that measure the interactive nature of each client's biological, psychological, emotional, spiritual, sociological, and environmental patterns. Researchers must begin to look at whole practices and whole systems, which typify whole-person treatment. Comprehensive comparative outcome studies are needed to ascertain the usefulness, indications, and contraindications of integrative therapies. And researchers must also evaluate these interventions for their usefulness in promoting wellness as well as preventing illness (Mariano, 2008).

The Institute of Medicine (IOM) report titled *Complementary and Alternative Medicine in the United States* (IOM, 2005) and participants at the "IOM Summit on Integrative Medicine and the Health of the Public" strongly emphasized that investigations of CAM (holistic/healing) practices entail a moral commitment of openness to diverse interpretations of health and healing, a commitment to finding innovative

ways of obtaining evidence, and an expansion of the knowledge base, relevant and appropriate to practice. One way to honor social pluralism is in the recognition of medical pluralism, meaning the broad differences in preferences and values expressed through the public's prevalent use of CAM modalities. The proper attitude is one of skepticism about any claim that conventional biomedical research and practice exhaustively account for the human experiences of health and healing.

The nature of many holistic phenomena presents a challenge to their "scientific" exploration and understanding. Because of the nonempirical effects of some healing therapies, how do we ascertain the effectiveness of some therapies when we presently can only measure the physical, emotional, or psychological parameters? How do we know something is useful to the client when there is no biophysical change and yet the client reports positive evaluations of these interventions? How do we know something works? How do we measure existential peace, or well-being, or openheartedness, or spiritual truth and connection, or psychic power? How do we measure transcendence or the universal life force? Do we need to measure their things? Are practice, theory, and research partly based on

faith and mystery? Answers to these questions are beyond the scope of this discussion; however, other ways of knowing such as intuition, esthetic and personal knowing, and unknowing as a way of knowing must be given credibility in the research world focusing on healing and holistic/integrative therapies (Mariano, 2008).

## ■ CONCLUSION

This chapter has presented some of the more common alternative/complementary/integrative healing modalities that are and can be used by nurses and by students of nursing. It should be noted that centering, relaxation, imagery, meditation, reminiscence and life review, and journal writing are basic and can be practiced by nurses and students with little or no experience. The sense therapies, touch therapies, and Reiki bodywork necessitate further study, which are offered through a few master's degree programs and workshops. Whenever one learns these therapies, it is imperative that nurses practicing EOL care be familiar with healing modalities and their beneficial effects for clients during the dying process.

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## CASE STUDY Conclusion

Following the TT treatment, J. A. fell asleep. He told the nurse later that this was the most rested he felt since coming to the hospital and with rest that maybe he could deal better with his pain. The staff decided that J. A. would receive a TT treatment each morning and evening during his hospitalization.

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## EXERCISES

### ■ PASSIVE RELAXATION<sup>1</sup>

Procedure for participants who are lying down:

- With your eyes closed, let your attention focus on your breathing...notice how gentle, slow, and regular it is becoming...imagine each breath out carrying your tensions away, leaving you more relaxed than you were before...if you want to, take one deep breath...then allow your breathing to settle into its own rhythm...easy, calm, and even...and forget about it.
- I'm going to ask you to take a trip around the body, checking that all the muscle groups are as relaxed as possible and letting go any tension that might still remain.

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<sup>1</sup> From Payne, R. (2005). *Relaxation techniques: A practical handbook for the health care professional*. Copyright 2005 by Churchill Livingstone. Reprinted with permission.



If outside thoughts creep in, hold them in a bubble and let them flow away. I'll begin with the feet.

- Bring your attention to your toes...are they lying still? If they are curled or stretched out in some way not entirely comfortable, wiggle them gently. As they come to rest, feel all the tension leaving them...feel them sinking down, heavy and motionless.
- Let your feet roll out at the ankles. This is the most relaxed position for them. Let all the tension flow out of them...enjoy the sensation of just letting them go.
- Moving on to the lower legs: Feel the tension leaving the calf muscles and the shins. As the tension goes, so they feel heavier...so they feel warm and pleasantly tingling.
- The thighs next: to be fully relaxed they need to be slightly rolling outwards...feel the relaxing effect of this position...make sure you have released all tension, and feel your thighs resting heavily on the surface you are resting on.
- Focus for a moment on the sensation of sagging heaviness throughout your legs...let the muscles shed their last remaining hint of tension and settle into a deep relaxation. And now, think of your hips. Let them settle into the surface you are lying on...recognize any tension that lingers in the muscles...then relax it away...let it go on relaxing a bit further than you thought possible.
- Settle your spine into the rug or mattress...become aware of how it is resting on a surface. Let it sink down, making contact whenever it wants to...all tension draining out of it.
- Let your abdominal muscles lose their tension. Let them go soft and loose. Feel them spreading as they give their last vestige of tension...notice how your relaxed abdomen rises and falls with your breathing...rises as the air is drawn in and falls as the air is expelled...abdominal breathing is relaxed breathing.
- Move up to your chest and shoulders, to muscles that are prone to carry tension...feel them letting go...feel them spreading...feel them easing into the surface, limp and heavy...feel them drooping down toward your feet...imagine them shedding their burdens...and as the space between your shoulders and your neck opens out, imagine your neck a bit longer than it was before.
- Now, direct your thoughts to the muscles of your left arm. Check that it lies limply on a surface. Notice the feeling of relaxation and allow this feeling to sweep down to your wrist and hand. Think of the fingers, are they curved and still?...neither drawn up nor stretched out...neither opened nor closed, but gently resting...totally relaxed. As you breathe out, let the arm relax a little bit more...let it lie heavy and loose...so heavy and loose that if someone were to pick it up, then let it go, it would flop down again like the arm of a rag doll.
- Repeat the last paragraph with the muscles of the right arm.
- Your neck muscles have no need to work with your head supported, so let them go...enjoy the feeling of letting go in muscles that work so hard the rest of the time to keep your head upright. If you find any tension in the neck, release it and let this process of releasing continue, even below the surface...feel how pleasant it is when you let go the tension in these muscles.
- Bring your attention now to your face, to the many small muscles whose job it is to manage your expressions. At the moment there's no need to have any expression at all on your face, so allow your muscles to feel relaxed...imagine how your face is when you are asleep...calm and motionless.
- Now, think about the jaw...and as you do, allow it to drop slightly so that your teeth are separated...feel it relaxing with your lips gently touching. Check that your tongue is still, and lying in the middle of your mouth, soft and shapeless. Relax your throat so that all tension leaves it and the muscles feel smooth and resting.
- With no expression on your face, your cheeks are relaxed and soft. If you think of your nose, it is just to register the passage of cool air traveling up your nostrils while the warmer air passes down...breathe tension out with the warm air...breathe stillness in with cool air.
- Check that your forehead is smooth...not furrowed in any direction...and as you release its remaining tension, imagine it being a little higher and a little wider than it

was before...continue this feeling into your scalp and behind your ears...feel a sense of calm as you do this.

- Let your thoughts focus on your eyes as they lie behind gently closed lids. Think of them resting in their sockets, floating, rather than fixed...and as they come to rest, so do your thoughts.
- Spend a few minutes continuing to relax, deepening the effect of the above sequences...
- You now have relaxed all the major muscle groups in your body. Think about them now as a whole...a totally relaxed whole...soothed by your gentle breathing rhythm, feel the peacefulness of this idea...
- Images may drift in and out of your mind...see them as thoughts passing through. Feel yourself letting go of them. Say to yourself, "I am feeling calm, I am feeling peaceful." Let your mind conjure up a sense of contentment.

## ■ IMAGERY

The instructor picks one of the following: a sunny beach, a river bank, or a scented garden. If trainees suffer from hay fever, the first item is the best choice. Imagery is best used after a short relaxation exercise.

### A Sunny Beach

- See yourself lying on the hot sand of a sunny beach within an enclosed bay. It is sheltered from storms and protected from ocean currents. It is safe. You watch the light dancing on the water; you smell the sea air as it fills your nostrils; you hear the gulls calling above the sound of waves; you feel the warm sun on your skin. The grains of dry sand run through your fingers, forming little bumps and hollows beneath your hand.

### A River Bank

- Imagine you are lying in the soft, juicy long grass of early summer. You are in a green meadow that rolls down to the river. Scents rise up from the wildflowers, sweeping over you in waves. The sun is warm, but a gentle breeze softens its intensity. Closing your eyes, you become aware of the sound of water flowing, of birds calling, and of leaves rustling.

### A Scented Garden

- Picture yourself lying on a newly mown lawn with the sun beating down on the moist cuttings, drawing out their fragrance. Reach out and feel the coolness of the damp grass. Through your half-closed eyelids you can see the tops of the trees swaying against the sky. Light breezes carry the scent of honeysuckle.

Following one of these short passages of visualization, trainees can relax for a few minutes, before the session is brought to an end.

## ■ RELAXATION<sup>2</sup>

I would like you to be as comfortable as you possibly can. Take a couple of deep breaths. Inhale deeply. Exhale very slowly and very completely. Focus on your breathing. Again, inhale very deeply and exhale very slowly. Become aware of your ability to relax your

<sup>2</sup> From Roach, S., & Nieto, B. (1997). *Healing and the grief process*. Copyright 1997 by Delmar Publications.



muscles. Allow every muscle in your body to be as relaxed as possible, starting with the feet. Allow the feet to become very, very comfortable. Relax the feet completely. As the muscles relax, you may notice a tingling sensation in the soles and toes of the feet. This simply indicates that the muscles are relaxing.

Be aware as this sensation of relaxation begins to move upward from the feet to the ankles. This sensation of relaxation flows from the ankles to the calves of the legs. The muscles of the calves release the tension and relax. The calves become very comfortable as the tension is released.

This comfortable, relaxed sensation moves from the calves to the upper legs and thighs. These muscles also relax and become very comfortable. Feel the muscles on the sides of the legs, the outside of the legs, the inner legs, and on the top of the legs as they become very comfortable and relaxed.

The sensation of relaxation moves up toward the buttocks and toward the pelvic area. Occasionally you may feel a muscle twitch. This is just another sign that relaxation is occurring. The tension of the muscles of the buttocks, pelvic area, and the lower abdomen is released. The internal organs relax and the muscles that surround them feel completely tension free.

The sensation of relaxation moves up the body to the upper abdomen, to the chest, and from the lower back toward the upper back. The muscles are relaxing from the chest and the upper back to the shoulders.

This relaxation extends to the neck and the throat. Feel the tension draining from the back of the neck. Tension is draining away from the back of the neck and the back of the head. As tension drains away, a sense of relaxation settles in. These feelings are so comfortable and so pleasant. Feel the muscles of the throat, the jaw, and across the bridge of the nose relaxing.

The tension in the arms is released, and these muscles feel relaxed. Relaxation spreads to the hands and the fingers as the tension is released.

From the feet, to the head, to the arms, to the fingertips, the whole body is completely and totally relaxed. Take a few moments to savor this comfortable state of total relaxation of body and mind.

■ **Closure.** Allow time for the client to appreciate this restful state of complete relaxation. After a few minutes, instruct the client to bring his or her attention back to the present. At times, the nurse may want to count slowly from 1 to 10 as the client progressively returns to a more wakeful state.

## ■ MEDITATION<sup>3</sup>

### Using a Mantra

1. Select a word to focus on. It can be a neutral word, such as “one,” or a Sanskrit mantra such as “Om Shanti,” “Sri Ram,” “So-Hum.” It could also be a word or phrase that has some special significance within your personal belief system. In his recent book, *Beyond the Relaxation Response*, Benson describes how a word or phrase of special personal significance (such as “I am at peace” or “Let go, let God”) deepens the effects of meditation.
2. Repeat this word or phrase, ideally on each exhalation.
3. As any thoughts come to mind, just let them pass over and through you, and gently bring your attention back to the repetitive word or phrase.

<sup>3</sup> From Edmund J. Bourne, 1995, *The anxiety and phobia workbook* (2nd Ed.). Copyright 1995 by New Harbinger Publications, Inc. All rights reserved.

## Counting Breaths

1. As you sit quietly, focus on the inflow and outflow of your breath. Each time you breathe out, count the breath. You can count up to 10 and start over again, or keep counting as high as you like, or you can use Benson's method of repeating "one" on each exhalation.
2. Each time your focus wanders, bring it back to your breathing and counting. If you get caught in an internal monologue or fantasy, don't worry about it or judge yourself. Just relax and return to the count again.
3. If you lose track of the count, start over at 1 or at a round number like 50 or 100.
4. After practicing breath-counting meditation for a while, you may want to let go of the counting and just focus on the inflow and outflow of your breathing.

Whichever form of meditation you try, you might want to start out with short periods of 5 to 10 minutes and gradually lengthen them to 20 to 30 minutes over a period of two to three weeks. Most people find that it takes persistent and disciplined effort over a period of several months to become proficient at meditating. Even though meditation is the most demanding of relaxation techniques to learn, it is for many people the most rewarding. Research has found that among all relaxation techniques, meditation is the one that people are most likely to persist in doing regularly.

If you are truly interested in establishing a meditation practice, you may want to find a class, group, or teacher to study with. This will make it easier for you to continue your practice.

## ■ SCRIPT FOR BREATHING FOR RELAXATION AND HEALTH<sup>4</sup>

- Close your eyes...Focus your mind on your breath...Just follow the air as it goes in...and as it goes out.
- Feel it as it comes in...and as it goes out...If your mind begins to wander, just bring it back to your breath.
- Feel your stomach rise...your ribs expand...and your collarbone rise...Breathe in naturally and slowly.
- On your next exhalation, release all the air from your lungs without straining...Let it all go...Let it all out...Prepare your lungs to receive fresh oxygen.
- Now take in a full, deep breath and let the air go to the bottom of your lungs...Feel your stomach rise...your chest expand, and the collarbone area fill.
- Now empty your lungs from top to bottom...Let all the air out...Compress your stomach to squeeze out all the stale air and carbon dioxide. Squeeze out every bit of air...Let it all go.
- Take in another deep breath...As you breathe in, your diaphragm expands and massages all the internal organs in the abdominal region...aiding your digestion.
- Breathe out...Relax...Feel the knots in your stomach untie...Let go.
- Breathe in...Your diaphragm is stimulating your vagus nerve, slowing down the beating of your heart...relaxing you.
- Breathe out...Let it all go...Relax...Relax more and more...Breathing heals you...calms you...soothes you.
- Breathe in again, fully and completely. Oxygen is entering your bloodstream, nourishing all your organs and cells...protecting you.
- Breathe out...Release all the poisons and toxins with your breath...Your breathing is cleansing you...healing you.
- Breathe in.
- Now imagine exhaling confusion...and inhaling clarity.

<sup>4</sup> From Julie T. Lusk, *30 Scripts for relaxation, imagery and inner healing*, Vol. 1. Copyright 1992 by Julie T. Lusk. Vols. 1 and 2 are available from Whole Persons Associates, 210 W. Michigan, Duluth, Minnesota 55802, 800-247-6789. Julie T. Lusk is also the author of *Refreshing Journeys*, a relaxation audiotape available from Whole Persons Associates, and *Desktop Yoga*, available from Perigee Books, 800-631-8751.



- Imagine exhaling darkness...and inhaling light.
- Imagine exhaling hatred...and inhaling love.
- Exhaling anxiety...and inhaling peace.
- Exhaling selfishness...and inhaling generosity.
- Exhaling guilt...and inhaling forgiveness.
- Exhaling weakness...and inhaling courage.
- Breathe in through your nose and sigh out through your mouth. Let the air stay out of your lungs as long as it is comfortable, and then take another breath.
- Let your breath return to its normal and natural pace. Continue to breathe in slowly, smoothly, and deeply...Your breathing is steady, easy, silent.
- Each time you exhale...allow yourself to feel peaceful...calm...and completely relaxed...If your mind wanders, bring your attention back to your breath.
- Stretch and open your eyes, feeling refreshed and rejuvenated, alert, and fully alive.

*Repeat the above instructions until everyone is alert.*

### ■ GENERAL GUIDED IMAGERY TECHNIQUE<sup>5</sup>

1. Achieving a relaxed state
  - A. Find a comfortable sitting or reclining position (not lying down).
  - B. Uncross any extremities.
  - C. Close your eyes or focus on one spot or object in the room.
  - D. Focus on breathing with abdominal muscles—being aware of the breath as it enters through your nose and leaves through your mouth. With your next breath let the exhalation be longer and notice how the inhalation that follows is deeper. And as you notice that, let your body become even more relaxed. Continue to breathe deeply, gradually letting the exhalation become twice as long as the inhalation.
  - E. Bring your mind back to thinking of your breathing and your relaxed body if your thoughts roam.
2. Specific suggestions for imagery
  - A. Picture a place you enjoy and where you feel good.
  - B. Notice what you see—hear—taste—smell—and feel.
  - C. Let yourself enjoy being in this place.
  - D. Imagine yourself the way you want to be—(describe the desired goal specifically).
  - E. Imagine what steps you will need to take to be the way you want to be.
  - F. Practice these steps now—in this place where you feel good.
  - G. What is the first thing you are doing to help you be the way you want to be?
  - H. What will you do next?
  - I. When you reach your goal of the way you want to be—notice how you feel.
3. Summarize process and reinforce practice
  - A. Remember that you can return to this place, this feeling, and this way of being anytime you want.
  - B. You can feel this way again by focusing on your breathing, relaxing, and imagining yourself in your special place.
  - C. Come back to this place and envision yourself the way you want to be every day.
4. Return to present
  - A. Be aware again of the favorite place.
  - B. Bring your focus back to your breathing.
  - C. Become aware of the room you are in (drawing attention to the temperature, sounds, or lights).
  - D. You will feel relaxed and refreshed and be ready to resume your activities.
  - E. You may open your eyes when you are ready.

<sup>5</sup> From Linquist, R., & Snyder, M. (2014). *Complementary and Alternative Therapies in Nursing*. New York, NY: Springer Publishing.

## Imagery: Finding One's Special Place<sup>6</sup>

Begin by placing your body in a comfortable position, arms and legs uncrossed, your back well supported. Now take three deep breaths, and during each breath relax even more. Let the exhalation be a letting go kind of breath, letting go of tension. With each breath, take in what you need and with each exhalation, release anything you don't need. Bring your attention to the top of your head. Feel your scalp relax and let your brow soften and smooth out. Allow the muscles around your eyes to relax. And let any tension flow out through your cheeks as you exhale. Suggest that your jaw relax. Imagine a wave of relaxation flowing down your shoulders, into your arms, elbows, and forearms, all the way into your hands and fingers. Now focus on your chest, releasing any tension around your heart or lungs, relax the muscles around your ribs. Wrap that relaxation around your back and let a wave of relaxation travel down the spine. Allow the muscles along the spine to lengthen and release. Soften and relax the buttocks and pelvis. Let the belly be very soft so that the breath moves easily down into the abdomen. Invite the legs to join in the relaxation now, as it moves through the thighs, knees, calves, ankles, and feet. Let any last bit of tension or tightness drain out through your feet or toes. When you feel relaxed and comfortable, let me know with a nod of your head. As your body remains relaxed and comfortable, imagine yourself in a very special place, somewhere that is full of natural beauty, safety, and peace. It may be a place you have been to before or it may be a place you want to create in your imagination. Take some time and let yourself be drawn to one place that is just right for you today. Let me know when you are present there (wait for response). Describe what it is like there. What do you see? Are there any smells? Are there any sounds? What is the temperature like? Where are you in this special place? How do you feel here? Take some time to do whatever you would like to do here, to relax or do some activity. Feel free to do whatever you want. This is your place (pause 3–4 minutes).

In a few moments, it will be time to come back into a waking state. Know that you can return to this place again anytime you want. Now gently bring yourself back, letting the images fade but keeping with you this relaxed and peaceful feeling. Remember what has been important about this experience. Become aware of the current time and place. Begin to move your body, take a deep breath, open your eyes, and feel relaxed and awake.

At this point, the guide can take a few minutes to allow the person to share his or her experience.

## Imagery in Oncology<sup>7</sup>

Many people live their lives in dread and fear of cancer and its treatment. Many nurses find it beneficial to work with the client's negative images and beliefs.

Some nurses have reported making tapes (there are also some available commercially) in which the client is encouraged to imagine chemotherapy or radiation therapy as something positive. Some clients prefer to view it as beams of energy or light.

The practitioner might ask "How do you imagine the chemotherapy?" Despite the response, the nurse can be helpful in supporting the transformation of the images into something beneficial and positive. "Imagine the medicine going into exactly the cells that most need it. The side effects will be minimal." There are a great variety of techniques and applications that enhance the healing journey through the experience of cancer.

### ■ QUICK USES OF IMAGERY IN THE CLINICAL SETTING

■ **Intravenous Therapy.** When a patient is receiving IV fluids, he or she can envision fluid flowing to every part of the body, removing toxins and flushing them out. The patient can see nutrients providing nourishment to every cell.

<sup>6</sup> From Shames, K. (1996). *Creative imagery in nursing*. Copyright 1996 by Delmar Publications.

<sup>7</sup> Ibid.



■ **Pain Medications.** Similarly, the patient can enhance the benefits of pain medication by envisioning its soothing effects as it travels through the bloodstream, sedating any irritated areas and bringing a deep sense of relief throughout. It is suggested that relaxation be used at the first sign of discomfort; focus the patient on the breath. Imagine the body releasing its natural medicine to all areas that are tense or uncomfortable. If pain begins to interfere with activity or rest, ask for medication before becoming so uncomfortable that it would be difficult to work with relaxation and the following imagery:

Imagine the pain medication to be exactly the strength it needs to be. See, feel, or sense the muscles around the painful area softening and relaxing as you breathe into the discomfort. See or feel the pain medication moving to that area, numbing the pain as if it had deposited a layer of frost.

Imagine a dial registering a number from 1 to 10 that represents your pain now. See the number come down to your tolerance level. Allow an image to form of a special, quiet, restful place and allow yourself to be there as you rest.

■ **Antibiotics.** Some patients like to imagine their antibiotic medication in the bloodstream as hunters stalking their prey. They can envision that the medication stays where the most protection is needed, particularly around burns or incisions, ready to pounce. If more medication is needed, there is an endless supply in the imagination.

■ **Anticoagulants.** Likewise, clients using anticoagulants can envision their blood becoming thinner, flowing to exactly the right places to prevent clotting. They can see the medication as extraordinarily efficient and relish watching as it does its magic.

■ **Oxygen.** As you take a deep breath, send nourishing healing oxygen into every cell of your lungs, expanding each cell like a balloon. As you exhale, imagine letting the balloons completely deflate and blow any tension or toxins that remain in the body out into the air. Continue doing this slowly for a few minutes, watching the balloons expand and contract.

■ **Healing Image.** Imagine little workers repairing the muscles and bones while they are resting, allowing the healing process to begin. See the bone rich in calcium, and see little bone cells growing like coral, increasing in number and density.

■ **Ideal Images.** Many clients continue to envision their healing process long after the crises have passed. One way to do this is to imagine themselves in three or six months. They can imagine themselves exactly as they would wish to be. They can observe how they look, how they walk, and their facial expressions. They might imagine themselves running or swimming, looking healthy and happy.

It is also a good practice for nurses to see themselves as they want to be. Focus on the image; how does it feel to be whole? Many nurses find that using imagery supports their patients totally and empowers them in their work. According to one nurse, after incorporating imagery frequently, “I finally felt as if I were making a difference.”

## ■ DIAPHRAGMATIC BREATHING

Diaphragmatic breathing is a useful technique for relaxing and beginning the centering process. Consciously realizing the path each inhalation takes through the respiratory passages, and inhaling so that the abdomen and lungs expand, allowing each breath to move to the bottom of the respiratory tree by moving the diaphragm downward and outward moves the whole person toward feeling more relaxed. As the slow, long exhalation occurs, a person feels shoulders moving downward and tensions slowly leaving the body. To help with stress at work, a nurse should practice diaphragmatic breathing at home, in either a supine or sitting position. Putting one's hand on the abdomen is an easy way to know if the abdomen is involved in the breath, or if shallow, tense breaths are a pattern. Once a pattern of abdominal breathing is the norm, the nurse can think of phrases such as, “I can feel this way whenever I take a deep breath and cross my fingers.” Connecting the relaxed feeling to the physical act of crossing fingers (or another physical cue) helps the body remember how it feels to relax. A nurse who regularly practices

this technique will have the ability to break the cycle of stress and muscle tension in just a few seconds, even at the bedside of a patient. The pattern is as follows:

- Recognize the feeling of tension;
- Take an abdominal breath—on inhalation the stomach expands; and
- On exhalation the stomach contracts—allow the shoulders to sag and experience the relaxation during the exhalation.

This technique, or pattern, is useful by itself to help relax for a few minutes or to lead to more profound states of relaxation.

## ■ RESOURCES

Academy for Guided Imagery  
10780 Santa Monica Blvd., Suite 290, Los Angeles, CA 90025  
(800) 726-2070  
[www.academyforguidedimagery.com](http://www.academyforguidedimagery.com)

American Herbalist Guild  
141 Nob Hill Road, Cheshire, CT 06410  
(203) 272-6731  
[www.americanherbalistguild.com](http://www.americanherbalistguild.com)

American Holistic Nurses Association  
100 SE 9th Street, Suite 3A, Topeka, KA 66612  
(800) 278-2462  
[www.ahna.org](http://www.ahna.org)

American Institute of Homeopathy  
801 N. Fairfax Street, Suite 306, Alexandria, VA 22314;  
(888) 445-9988  
[www.homeopathyusna.org](http://www.homeopathyusna.org)  
American Massage Therapy Association  
500 Davis Street, Suite 900, Evanston, IL 60201  
(877) 905-2700  
[www.amtamassage.org](http://www.amtamassage.org)

American Meditation Institute  
60 Garner Road, Averill Park, New York, NY 12018  
(518) 674-8714  
[www.americanneditation.org](http://www.americanneditation.org)

American Music Therapy Association  
8455 Colesville Road, Suite 1000, Silver Springs, MD 20910  
(301) 589-3300  
[www.musictherapy.org](http://www.musictherapy.org)  
American Psychological Association  
750 First Street NE, Washington, DC 20002-4242  
(800) 374-2721

Association for Applied Psychophysiology and Biofeedback  
Biofeedback Certification Institute of America, 10200 W. 44th Avenue, Suite 304, Wheat  
Ridge, CO 80003  
(303) 422-8436  
[www.aapb.org](http://www.aapb.org)  
[www.bcia.org](http://www.bcia.org)



Center for Mindfulness in Medicine, Health Care and Society  
 University of Massachusetts Medical Center, 419 Belmond Avenue, Worcester, MA 01604  
[www.mindfulnessstapes.com](http://www.mindfulnessstapes.com)

Compassionate Touch  
 20 Swan Court, Walnut Creek, CA 94596  
 (510) 935-3906

Contemplative Outreach, Ltd. [centering prayer]  
 P.O. Box 737, 10 Park Place, Suite 2B, Butler, NJ 07405  
 (973) 838-3384  
 E-mail: [office@coutreach.org](mailto:office@coutreach.org)  
[www.centeringprayer.com/cntrgpryr.htm](http://www.centeringprayer.com/cntrgpryr.htm)

Healing Touch International  
 445 Union Blvd., Lakewood, CO 80228  
 (303) 989-7982  
[www.healingtouch.net](http://www.healingtouch.net)

International Center for Reiki Training  
 21421 Hilltop Street, Suite 28, Southfield, MI 48034  
 (800) 332-8112  
[www.reki.org](http://www.reki.org)

Maharishi Foundation USA 1100 N.  
 4th Street, Suite 128, Fairfield, IA 52556

Maharishi Vedic School [TM program]  
 636 Michigan Avenue, Chicago, IL 60605  
 (312) 431-0110  
[www.maharishi.org](http://www.maharishi.org)  
[www.maharishi-medical.com](http://www.maharishi-medical.com)

National Association for Holistic Aromatherapy  
 3327 W. Indian Trail Road, Spokane, WA 99208  
 (509) 325-3419  
[www.naha.org](http://www.naha.org)

National Association of Music Therapy (NAMT)  
 8455 Colesville Road, Suite 930, Silver Spring, MD 20910  
 (301) 589-3300  
[www.musictherapy.org](http://www.musictherapy.org)

National Association of Nurse Massage Therapists  
 28 Lowry Drive, P.O. Box 232, West Milton, OH 45383  
 (800) 262-4017  
[www.nanmt.org](http://www.nanmt.org)

National Center for Complementary and Alternative Medicine (NCCAM)  
 P.O. Box 7923, Gaithersburg, MD 20898  
 (888) 644-6226  
<http://nccam.nih.gov>

National Certification Commission for Acupuncture and Oriental Medicine (NCCAOM)  
 11 Canal Center Plaza, Suite 300, Alexandria, VA 22314  
 (703) 548-9004  
[www.nccaom.org](http://www.nccaom.org)

Nurse Healers—Professional Associates International [Therapeutic Touch]  
 P.O. Box 419, Craryville, NY 12521  
 (877) 326-4724  
[www.therapeutic-touch.org](http://www.therapeutic-touch.org)

Transcendental Meditation  
 (888) 532-7686  
 Transcendental Meditation Program (888)LEARN TM  
[www.tm.org](http://www.tm.org)

Maharishi Foundation USA  
 1100 N. 4th Street, Suite 128, Fairfield, IA 52556

## Evidence-Based Practice

Lengacher, C. et al. (2012). A pilot study evaluating the effect of mindfulness-based stress reduction on psychological status, physical status, salivary cortisol, and interleukin-6 among advanced-stage cancer patients and their caregivers. *Journal of Holistic Nursing*, 30(3), 170–185.

### Purpose

To investigate whether a mindfulness-based stress reduction program for cancer (MBSR-C) improved psychological and physical symptoms, quality of life (QOL), and stress markers among advanced-stage cancer patients and caregivers.

### Design

A pilot within-subject design was used.

### Method

Patients previously diagnosed with advanced-stage breast, colon, lung, or prostate cancer and on treatment were recruited from the Moffitt Cancer Center and Research Institute. Twenty-six patient-caregiver dyads completed a modified 6-week, self-study MBSR-C program based on the Kabat-Zinn model. Psychological and physical symptoms and QOL were compared pre- and post-MBSR-C sessions. Salivary cortisol and interleukin-6 were assessed pre- and post-MBSR-C session at 1, 3, and 6 weeks.

### Findings

Following the 6-week MBSR program, patients showed improvements in stress and anxiety ( $p < .05$ ); caregivers' psychological and QOL also improved but were not statistically significant. Both patients and caregivers had decreases in cortisol at Weeks 1 and 3 ( $p < .05$ ) but not at Week 6. Similar to cortisol levels at Week 6, salivary interleukin-6 levels were lower overall (before/after an MBSR-C session), compared with Week 1 for patients and caregivers.

### Conclusions

MBSR-C may be a beneficial intervention for reducing stress, anxiety, cortisol levels, and symptoms in advanced-stage cancer patients and may also benefit caregivers.



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# Physical Aspects of Dying

## SECTION

Up until this last week, Candy has been relatively independent with her activities of daily living. She was having occasional right-sided chest pain, which she rated as a “3” in intensity, but was relieved by two Percocets. In the past week, the pain increased in frequency and intensity, and she had dyspnea at rest. During the past 3 days, Candy became very weak, with no appetite, and she spent most of her time sitting in her recliner chair. Because of her increase in symptoms, I called her daily and visited her every other day. She was extremely lethargic and her husband told me that she became very short of breath on ambulation to the bathroom.

Lethargy and loss of appetite in a person with advanced cancer are common physical symptoms associated with the process of dying. The fact that she was having an increase in symptoms of pain and dyspnea was further evidence that she was nearing death. I called her doctor and asked for a standing order for liquid morphine and Ativan. I showed Candy and Ron how to administer 5 mg of the morphine in her cheek and recommended repeating the medication dose in 15 minutes if it was not effective and to take the prescribed rescue dose if she experienced heightened pain or shortness of breath.

Today was the first time in the year that I have known Candy that she mentioned dying. I held her hand while she cried and told me how surprised she was that the end was coming so quickly. I suppose these things are surprising when it is clear that the disease will not be cured. Candy asked me to promise her that she would not suffer at the end; it was such a poignant moment. As I hugged her, I told her I would be with her until the end. With the support of members of the hospice/palliative care (PC) team, Candy’s pain and symptoms were alleviated, and the emotional and spiritual needs of Candy and her family were being addressed.

When I arrived at Candy’s house today, I saw that her level of consciousness had significantly declined. She had not had any oral intake for 2 days and was only responding occasionally to her name. Her skin was cool and starting to become mottled. Ron said he had given Candy four rescue doses of 10 mg of morphine since yesterday. She appeared comfortable and peaceful, with no evidence of grimacing or restlessness, which may indicate pain. Candy did not appear to have difficulty breathing, but her breaths were slow and shallow, and there was a rattle in the back of her throat. I explained that this noise was from secretions in the back of her throat but that it is usually not distressing to the patient.

I told him that Candy was actively dying and held him as he cried. I suggested to Ron that he get the children if he wanted them to be with her as she died. They came in and crawled into the bed with their mom and lay in her arms for the last time. Ron put his arms around them all, as they prayed together. I was thinking what a good

job Candy had done with her kids that they were so comfortable to be with her during this time; I do not know where Ron got his strength to support his family in this way. The love and faith were almost palpable. I stayed at the foot of her bed and did Reiki on Candy's feet, something she had always liked me to do during my visits. She opened her eyes, looked at each of us, stopped breathing, and died.

Ron held the children and told them what had happened. Fortunately, there were family and friends in the house to be with the children, as Ron stayed with me to bathe Candy's body. He wanted to do this final act for her because she never liked to leave the house looking "messy." He talked to her as we prepared her to leave her home for the last time.

As I reflect on this nursing experience, I realize the importance of our relationship that we developed over time. This family allowed me to care for them at one of the most vulnerable times of their lives. I learned so much from Candy about life, living, and ultimately about dying. These are gifts given to us by our patients at the end of life. PC nursing transcends traditional caregiving experiences. In a very intimate way, nurses cojourney with their patients and families experiencing life-threatening illness and helping them to live as fully as possible until death. With the knowledge and skills to alleviate the physical, emotional, social, and spiritual pain and suffering, and by bearing witness to the precious moments of life as patients and their family say their last good-bye and express eternal love, nurses experience the joy and rewards of hospice/PC nursing. Through competent and compassionate care at the end of life, nurses can make a difference in the quality of life (QOL) and quality of dying for their patients and their families.



# Cancer

## CHAPTER

### KEY POINTS

- Cancer affects all ages.
- The overall incidence and prevalence of cancer has increased with individuals living with cancer as a chronic illness.
- Treatment options have improved survival rates, decreased toxicity, and provided palliation.
- Symptoms associated with the disease and the toxicities of treatment require a commitment to an interprofessional model of care across health care settings.
- Palliative care (PC) focuses on the physical, psychosocial, and spiritual needs of the cancer patient and family as well as bereavement needs of families.

### CASE STUDY

Mr. J. is a 42-year-old White male who was diagnosed with Stage IV T3 N2 M1 colon cancer in May 2010. He underwent a right hemicolectomy and multiagent chemotherapy of erlotinib and FOLFOX. His past medical/surgical history was unremarkable. Current medications include oxycodone 5 mg p.o. every 2 hours as needed for pain and ondansetron 8 mg p.o. every 6 hours as needed for nausea and vomiting. He was being cared for at a comprehensive cancer center.

Physical examination at the time of chemotherapy initiation revealed a slightly overweight White male in no acute distress. Vital signs: afebrile, pulse 76 beats/min, with a regular rate and rhythm, respirations 16 breaths/min, and blood pressure of 126/82. Cardiac exam, S1, S2, Nos. S3 or S4, no murmurs, no edema, pulses 2+ throughout, no bruits. Lungs clear to auscultation. Abdominal examination revealed soft, nontender abdomen, well-healed surgical scar, bowel sounds present in all four quadrants, no organomegaly, and no palpable masses or lymphadenopathy. The musculoskeletal examination was unremarkable. The neurological system was grossly intact.

Mr. J. worked as a tool and die maker and lives in the area with his wife of 5 years. He has a child aged 3 years and four stepchildren to whom he is very attached. His first wife's ex-husband died 4 years ago from cancer after their divorce. Mrs. J. has a strong

religious practice in the Roman Catholic faith; however, Mr. J. is struggling with his spirituality and has no religious affiliation.

Questions that the nurse should consider are as follows:

1. What is the best PC practice model for Mr. J.'s plan of care?
  2. What are the benefits and burdens of continued chemotherapy treatment for Mr. J.?
  3. What support is needed to help Mr. J. and his family cope with his diagnosis, treatment, disease progression, and loss, grief, and bereavement?
  4. How can the nurse support Mr. J. during his spiritual crisis?
- 

Cancer is a devastating diagnosis that many individuals still associate with death. Upon initial diagnosis, individuals embark on a treatment journey that is overwhelming with medical jargon, new health care providers, unknown outcomes, and fluctuations of hope amid the distressing effects of the disease and its treatment. Although people are living longer with cancer, and some cancers can be considered chronic in nature, living with cancer can provoke anxiety and a loss of control for the patient and family. Individuals living with cancer rely on family or chosen support people to assist them for physician office visits and treatment, help to decipher and absorb disease and treatment information, and provide physical and emotional support for treatment and possibly end-of-life (EOL) care. Oncology health care providers work with a heterogeneous patient population attempting to provide the patient and family with clear communication, the most effective treatment options, and a healthy balance of hope for the future.

Despite continuous improvement in treatment efficacy and survival outcomes, cancer remains the second leading cause of death for both genders and throughout the life span. Adult cancer is second to heart disease while pediatric cancer is second to accidental death in most age groups through adolescence (Aldridge & Roesch, 2007; Djulbegovic et al., 2008; Wolfe, Friebert, & Hilden, 2002). The American Cancer Society (ACS, 2014) estimated 1.6 million new cases of all cancer sites. However, a new cancer diagnosis is no longer synonymous with a limited life expectancy, and could possibly mean a future navigating the health care system over the extended survival period. Historically, PC for cancer patients was mainly contained within hospice care. Now, cancer specialists are incorporating the precepts of PC and an interprofessional approach to patient care. Due to medical and nursing certifying boards regulating the specialty of palliative medicine and PC, the increasing number of health care professionals certified in PC offers more options for the supportive care of cancer patients actively involved in curative treatment, receiving expensive physiological supportive treatment, and

eventually facing imminent death (Gelfman, Meier, & Morrison, 2008; Griffin, Koch, Nelson, & Cooley, 2007; Kuebler, Lynn, & Von Rohen, 2005).

For the majority of 20th-century patients, cancer was more likely to be diagnosed in a later stage, treatment was largely ineffective, and death usually resulted within a few months. Today, roughly half of all cancer patients will die of their disease (Kuebler et al., 2005). The care of cancer patients has evolved in the last 20 years not only as a result of changes in treatment efficacy but also due to the interprofessional model of support currently offered. Health care consumers prefer honest and more complete information pertaining to diagnosis, prognosis, symptom burden, and survival benefits related to treatment. As a result, health care professionals are learning more compassionate communication skills and recognizing the importance of shared decision making with the patient, family, or family of choice (Kuebler et al., 2005; Surbone, 2008). Throughout the various stages of cancer, the needs of the patient and family are complex, requiring special attention to physical, psychological, social, and spiritual distress. Arrangements for an appropriate care setting and adequate caregiving support throughout treatment and at the EOL requires knowledge of specialized treatment providers, available alternatives, and an experience-based understanding of how best to match the needs of the patient and family living with cancer (Griffin et al., 2007). Even though many cancer specialists are experienced in EOL care and consider it germane to their practice, the specialty of PC is emerging as an interprofessional specialty with strong support for patient, family, and the clinicians involved in cancer management. Evidence suggests that PC teams assisting in cancer care improve patient care and reduce costs to the family and health care system by cultivating an equal exchange of information matching the goals of the patient with treatments offered (Gelfman et al., 2008). In addition, PC teams support the clinicians working so closely with a patient population living with a life-threatening disease by providing emotional and educational



support. Where multiple clinicians representing different specialties are involved, PC teams provide the hub of communication and specialized spiritual and bereavement support of patients, families, and clinicians that cancer care requires. PC should be integrated into every cancer patient's treatment, including those pursuing curative or life-prolonging therapies, and whether or not PC specialist teams are available, cancer treatment teams should receive education in the essentials of PC (Griffin et al., 2007).

Future implications for cancer care will include supporting patients through complex treatments offered in a variety of treatment locations and supporting late effects of treatment as seen with survivorship. Young and old, it is important to note that the stage of growth and development, familial support, physiological stamina, psychological reserve, and community resources all present significant consideration for the treatment of adults and children living with cancer (Aldridge & Roesch, 2007; Matsuyama, Reddy, & Smith, 2006). The National Collaborating Centre for Cancer (NCC-C, 2005) has issued guidelines standardizing care services for children and young people with cancer in England and Wales. Key recommendations include the following: (a) Care for children and young adults up to 19 years of age should be provided in age-appropriate facilities; (b) children and young adults must have access to treatment-specific clinical expertise; (c) all aspects of cancer care for children and young adults should be provided by appropriately trained staff; and (d) children, young adults, and their families should be supported by expert health care providers to coordinate care across the continuum of disease providing age and culture appropriate information.

## ■ INCIDENCE AND PREVALENCE

### Pediatric and Younger Adult

It is estimated that roughly 11,630 children under the age of 15 years in the United States will be diagnosed with some form of cancer in 2014. Even though childhood cancers are rare, representing less than 1% of all new cancer diagnoses, this is an increase in prevalence in the past 20 years. Due to considerable advances in treatment, and high rates of clinical trial participation, 80% of those children could experience a long-term remission representing a 30% increase in the 5-year survival rate between the 1970s and late 1990s and 68% decline in mortality from 1969 to 2009 (ACS, 2013; Aldridge & Roesch, 2007). The sites of cancers that occur in children contrast greatly from those

affecting adults. Leukemias (acute myelogenous and acute lymphocytic) account for approximately 31% of all childhood cancers; brain and nervous system cancers make up about 25% of childhood cancers; while neuroblastoma is the most commonly occurring (6% of all childhood cancer types) solid tumor outside of the central nervous system. Despite advances in early detection and treatment, an estimated 1,310 children will die from cancer in 2013 (ACS, 2013; Aldridge & Roesch, 2007).

### Adult

According to the ACS (2014), the most frequently diagnosed adult cancer cases, considering all sites, are female breast, prostate, lung, and colorectal. These four most commonly occurring cancers will be the physiological focus of this chapter. It is estimated that over 240,000 adult Americans will be diagnosed with lung cancer in 2014, and over 160,000 adult Americans will die of the disease within that same year. Estimated incident rates for new female breast cancer and prostate cases trail lung cancer rates closely, while colorectal cases affecting both genders could affect over 10,000 individuals in the United States. The total 2014 estimated cancer death rate representing all sites could reach 580,720 individuals in the United States, which represents an 11% decrease in mortality since 2008.

### Older Adult

The greatest impact of cancer is seen in the middle-aged and older adult populations since 77% of new cancer incidences occur in individuals 55 years and older (ACS, 2013; Terret, Zulian, Naiem, & Albrand, 2007). The relationship between increasing age and the development of cancer is attributed to cancer growth characteristics (age-related cellular mutations) and the biophysical environment (pro-oncogenic changes in the tissue milieu), allowing mutant cells to survive, proliferate, and express their neoplastic phenotype. First, cancer cells take time to proliferate; this growth may not be apparent until the later stages of life. This results in a lifetime risk. Relative risk compares the risk of developing cancer with certain exposure or disposition to persons who don't have the same exposure or disposition (ACS, 2014). Finally, a changing physical environment contributes to the programmed cell death of healthy cells and the propagation of cancer cells. As a result, older adults are at increased risk for cancer (Extermann & Hurria, 2007; Repetto et al., 2003; Terret et al., 2007).

## ■ PATHOGENESIS

The etiology of cancer is multifactorial, with genetic (nonmodifiable), environmental (modifiable), medical (modifiable), and lifestyle (modifiable) factors interacting to produce a given malignancy. Knowledge of cancer genetics is rapidly improving our understanding of the biologic aspects of cancer, helping to identify at-risk individuals, furthering the ability to characterize malignancies, establishing treatment tailored to the molecular fingerprint of the disease, and leading to the development of new therapeutic modalities, including early detection. As a consequence, this expanding knowledge base has implications for all aspects of cancer management, including prevention, screening, and treatment.

Malignant tumors are produced by a synergy between the accumulation of mutations and tissue changes that support the survival of mutant cells (Terret et al., 2007). Factors that cause or facilitate cancer development include chemical mutagens, radiation, free radicals, genomic instability, inherited cancer susceptibility, telomere shortening, and altered cellular environment. Factors such as smoking, diet, physical activity, and weight control are known modifiable risk factors that alter cellular environment and influence the proliferation of cancer cells. Carcinogenesis works in a stepwise progression in which a normal cell undergoes transformation to a malignancy. Steps include initiation, promotion, premalignant progression, and, finally, malignant conversion. The complete explanation of these steps is outside the scope of this chapter; however, this information provides a framework for further discovery and detailed understanding. Occasionally, family members will question the cause of cancer when a loved one is diagnosed; however, further investigation usually reveals an existential concern that a genetic explanation may not satisfy.

## ■ DISEASE TRAJECTORY

### Breast Cancer

Breast cancer is the most frequently occurring female malignancy in the United States and approximately 232,670 new cases of invasive breast cancer are estimated to be diagnosed in 2014, with roughly 2,360 new cases diagnosed in men. An additional 62,570 women will be diagnosed in 2014 with in situ breast cancer. Roughly 83% of those in situ cases will be ductal carcinoma. Estimated death occurrence is expected to reach over 40,430 women in the year 2014. Breast cancer is second to lung cancer as a cause of cancer death in women. However, incidence

and death rates have steadily decreased in the past 10 years due to reductions in the use of menopausal hormone therapy (MHT), early detection, and improved treatment (ACS, 2014).

Breast cancer is a complicated disease representing a highly heterogeneous patient population. Breast cancer originates in two separate cell types: ductal and lobular. Ductal cancers are the most common, with invasive ductal cancer representing 70% to 80% of all ductal cancer cases. Lobular breast cancer rarely occurs alone, is more hormonally influenced, and occurs predominately in premenopausal women. Breast cancer affecting the breast nipple is Paget's disease and is associated with intraductal or invasive ductal carcinoma. Breast cancer can be estrogen receptor (ER) positive or negative (ER+ or ER-) and progesterone receptor (PR) positive or negative (PR+ or PR-). Most breast cancers are hormone sensitive while nonhormone sensitive breast cancers are found to be the faster growing of the two. Generally speaking, the goal of treatment for women with early stage breast cancer is to prevent death and recurrence while minimizing side effects from treatment. The goal for women diagnosed with late-stage or metastatic breast cancer is to maintain quality of life (QOL), control the disease, and extend survival time (Hampton, 2008b; Holcomb, 2006).

Pathogenesis involves DNA mutation by genetic alterations or environmental agents, probably occurring early in life. Only 5% to 10% of all breast cancers are inherited and carry the breast cancer-specific gene. Growth factors then increase the growth rate of those mutated cells; finally, progressive alteration of specific oncogenes, or the loss of suppressor genes, leads to advanced metastatic disease (Robinson & Huether, 2009). The environment for breast cancer growth in older women is not as favorable as that of younger women because of the decrease of stimulating growth factor specifically for breast cancer and diminishing mononuclear cell reactions. Breast cancer in the older woman tends to be more differentiated and rich in hormone receptors than in young women. This renders nonmetastatic tumors more receptive to treatment. Thus, rather than treating cancer based on the patient's age, it is essential to treat each tumor individually, addressing the characteristics of the tumor and the desires of the patient (Extermann, 2005).

■ **Signs/Symptoms/Staging.** Most generally, breast cancer presents as a painless lump; other signs include palpable axillary nodes, dimpling, or bone pain due to metastasis. Breast cancer is evaluated with mammography, percutaneous needle aspiration, biopsy, and hormone receptor assays. Treatment is determined by cell type, stage, growth rate, and hormone



responsiveness. The tumor/node/metastasis (TNM) classification system evaluates primary tumor size (TX to T4), regional lymph nodes (NX to N3), and distant metastasis (MX to M1), while staging from 0 to IV is used in addition to the TNM determination. Staging levels increase with tumor size and node involvement; Stage IV is the only stage that represents metastasis. Rate of growth can be determined by S-phase or Ki-67 tests (Holcomb, 2006; Robinson & Huether, 2009).

■ **Disease Management.** Treatment options take into account tumor size, extent of spread, and patient preference regarding QOL. Those options include lumpectomy, simple mastectomy with sentinel node biopsy, radical mastectomy, radiation (external and brachytherapy), systemic therapy (chemotherapy and hormonal therapy), and adjuvant therapy (prior to surgery to reduce tumor size and burden). A bone scan and computed tomography of the abdomen and chest are performed to rule out metastasis.

■ **Surgery.** Surgical procedures for breast cancer include lumpectomy, quadrant excision, partial mastectomy, total or simple mastectomy, modified radical mastectomy, and radical mastectomy (Robinson & Huether, 2009). Options available for the surgical management of Stage I or II breast cancer are lumpectomy with removal of axillary lymph nodes, mastectomy with the removal of the axillary lymph nodes, radiation therapy, chemotherapy, or hormone therapy. Treatment is often multimodal and research has shown that in early breast cancer, long-term survival in breast-conserving surgery coupled with radiation is equal to that of mastectomy (ACS, 2014; Holcomb, 2006).

Axillary node involvement is the most important prognostic indicator for the breast cancer patient. Historically, many medical authorities suggest testing at least four nodes at the time of surgery; however, others recommend testing the sentinel node to accurately indicate lymph node involvement. Adequate nodal removal is not commonly offered to older adults, which may lead to inadequate adjuvant therapy (Holcomb, 2006; Robinson & Huether, 2009). Treatment for ductal carcinoma in situ (DCIS) includes excision of the tumor, radiation, and/or tamoxifen. High dose chemotherapy has been shown to increase survival rates up to 6 months; however, it is not considered a curative treatment option at this time for the older adult with multiple comorbidities (Coyne, Lyckholm, & Smith, 2006).

Treatment for Stage III (locally advanced tumors) does not usually involve curative surgery due to the poor prognosis associated with this stage. Conversely,

a combination of surgery, chemotherapy, and radiation would be an option for local control of the tumor since many locally advanced tumors carry the likelihood of metastasis (Thompson & Chochinov, 2009).

■ **Chemotherapy.** Factors to be evaluated when considering chemotherapy include physical well-being, staging, tumor type, comorbidity, patient preference, and drug efficacy in the older adult (Extermann, 2005). Tumors rich in hormone receptors are less sensitive to chemotherapy than tumors poor in hormone receptors. The international breast cancer study group concluded that overall survival benefits from chemotherapy decreased as age increased and was nonexistent in ages older than 65 years (Aebi & Pagani, 2007; Extermann, 2005). However, reports show that chemotherapy increases survival rates of older women significantly when compared to those who are not treated as long as frequent dose adjustments are made for toxicity. Low-dose taxanes, capecitabine, navelbine, and gemcitabine have low toxicity indices when dosed appropriately (Extermann, 2005). The controversy over chemotoxicity in older adults is a result of the heterogeneous population and the underrepresentation of older adults in clinical trial.

■ **Radiation Therapy.** External beam radiation and brachytherapy are current radiotherapies recommended for the treatment of breast cancer. External radiation is the typical radiation therapy given after lumpectomy and is given to the entire breast with an extra dose ("boost") to the site of the tumor from an external source. Treatment course could last up to 6 to 7 weeks with daily treatments. Brachytherapy is internal radiation or interstitial radiation. Radioactive materials, or "seeds," are placed in or near where the tumor was removed. They may be placed in the lumpectomy site to augment the radiation dose in addition to external beam radiation therapy (Holcomb, 2006). Older women assessed with adequate functional reserves tolerate radiation as well as their younger counterparts. However, radiotherapy can be problematic for the older patient with cognitive impairment since the procedure requires immobilization, which could create anxiety (Extermann, 2005).

■ **Hormonal Therapy.** ER+ breast cancer is responsive to tamoxifen (a nonsteroidal selective ER modulator) treatment, which significantly reduces the long-term risk of recurrence in the contralateral breast (Litsas, 2008), and was until recently the most prescribed adjuvant endocrine therapy (ACS,

2014). Recently, third-generation aromatase inhibitors (AIs) have shown superior results in comparison to tamoxifen efficacy, disease-free survival rates, occurrence of contralateral breast spread, delayed time to recurrence, and amount of metastases. The AIs provide women with a safer toxicity and side-effect profile than tamoxifen (ACS, 2014). The addition of tamoxifen provides optimistic results toward longevity, and is considered first-line treatment for endocrine therapy, regardless of node involvement (Aebi & Pagani, 2007; Mackay, 2000). When used in premenopausal women for 5 years or longer, the recurrence rate dropped 40% and the mortality rate dropped 32% (Aebi & Pagani, 2007). Systemic adjuvant treatment of breast cancer is most useful for women with a life expectancy of 2 or more years. Tamoxifen therapy extends over a 5-year period and therefore may not be considered an option for the frail older adult (Extermann, 2005; Litsas, 2008). Inhibition of the aromatase system using third-generation AIs and inactivators has shown statistically significant improvement in survival benefit for patients with advanced breast cancer as compared with standard hormonal treatment (tamoxifen or progestagens; Litsas, 2008; Mauri, Pavlidis, Polyzos, & Ioannidis, 2006).

■ **Palliative Care for Breast Cancer.** Treatment of women with advanced breast cancer is palliative in its intent. There are no data at this time from controlled trials comparing chemotherapy to best supportive or PC. No single regimen has been identified as the gold standard for disease control or symptom management. The literature shows that tumor shrinkage from chemotherapy can benefit some women suffering from tumor burden, yet side-effect profiles, including nausea, vomiting, and myelosuppression, have been reported with high symptom burden. A complete discussion regarding benefits versus burden should precede undergoing treatment (Thompson & Chochinov, 2009).

## Prostate Cancer

The ACS (2014) estimates 233,000 newly diagnosed cases in the year 2014; which is a decline from 2013. Prostate cancer is common in America, North America, and Northwestern Europe; conversely, it is rare in Asia, Africa, and South American populations. Incidence rates remain highest (70% higher than in Whites) in African American men and Jamaican men of African descent. Incidence rates decreased from 2006 to 2010 due to changes in screening and prostate-specific antigen (PSA) blood tests. Risk factors for prostate cancer include age, race, family history, and dietary factors. The only well-established risk factor remains increasing age. Approximately 60% of all prostate diagnoses

are in men 65 years and older, while 97% occur in men 50 years of age and older (ACS, 2014; National Cancer Institute, 2007).

Over 95% of prostate malignancies are adenocarcinomas, primarily occurring in the periphery of the prostate. Grading systems represent the glandular pattern, degree of differentiation, or a combination of the two (Robinson & Huether, 2009). The cancer cells metastasize via posterior local extension, lymphatic system, and blood vessels to distant lymph nodes, bone, liver, lungs, and adrenal glands. The most common sites of bone infiltration are pelvis, lumbar and thoracic spine, femur, and ribs. The 5-year survival rate for localized prostate cancer is nearly 100%, and has increased from 78% to 100% for all-stage prostate cancers. These figures do not factor coexisting conditions that may affect prognosis (Robinson & Huether, 2009).

■ **Signs/Symptoms/Staging.** Early and localized stages of prostate cancer generally do not present with symptoms. Hallmark symptoms that occur more frequently in advanced stage cancer are usually associated with urinary outlet obstruction: frequent urination, urinary hesitancy, inability to urinate, nocturia, and dysuria. Impotence, painful ejaculation, bloody urine or semen, frequent pain, and stiffness in lower back, hips, or upper thighs are additional symptoms signifying malignancy. Due to the fact that many of these symptoms can be caused by other factors, it is common for men to postpone medical consultation. Symptoms of malignant prostate disease usually do not subside, which distinguishes prostate cancer from benign disease. In advanced disease, upper urinary tract ureter and rectal obstructions are possible. If rectal obstruction occurs, bowel obstruction or difficult defecation will follow (Darmber & Aus, 2008; Ryan & Small, 2006).

Digital rectal examination, PSA blood test, and tissue biopsy are the three most effective diagnostic procedures; however, physicians and medical groups may not agree on when men should be routinely screened. Diagnosis of prostate cancer is confirmed by transrectal ultrasonography, intravenous (IV) pyelogram, and possibly cystoscopy. Biopsy is completed after the tumor has been visualized and when cancer is suspected.

■ **Disease Management.** Treatment depends on age, life expectancy, overall health status, PSA level, Gleason score, and tumor size and spread (as indicated by the TNM classification system). If factors appear favorable, the stage of neoplasm determines the treatment. After initial diagnosis, grading is determined to understand tumor growth rate. The Gleason grading is the most used grading scale using



numbers 1 to 5 with 1 signifying the least aggressive form with tissue cells looking normal. The numbers refer to the appearance and activity of the cancer cells and are useful in determining the most effective treatment options. The Gleason score adds the grades of the two most prevalent patterns of the cells. Scores may range from 2, representing nonaggressive cancer, to 10, signifying the most aggressive cancer with the greatest potential of spread. Historically, treatments have increased curative rates in many men with early and localized tumors, while treatments for more advanced disease are more beneficial to shrink tumors larger in size, palliate symptoms, and possibly increase survival time (Darmber & Aus, 2008).

Expectant management is referred to as “active surveillance” and involves watching for new signs and symptoms of disease progression between regular checkups and testing. At the onset of symptoms, hormonal treatment is initiated. Deferring treatment is only beneficial for Stages I and II cancers, since it postpones the undesirable side effects of hormonal therapy. In order to lengthen survival rates, hormonal treatment following a radical prostatectomy should be done immediately (Pignon et al., 1997).

■ **Surgery.** Surgery is most effective for individuals with poorly differentiated tumors. As a result of a stratified analysis, Merglen et al. (2007) recommend surgery for young patients with high Gleason scores. Hormonal therapy is normally indicated for pre- and postsurgical treatment. For the most part, the prostate cancer patient population represents a statistically diverse group and is considered highly heterogeneous due to the various grades, cellular responses, and sizes of tumors presenting in trials. Since surgical intervention can result in impotency and incontinence, it is important that treatment discussions involve the spouse or significant other in order to enhance emotional coping and physical healing (Merglen et al., 2007; Willert & Semans, 2000).

■ **Radiation.** Radiation therapy is offered as two different therapeutic approaches: (a) external beam—external application, and (b) brachytherapy—internal application of radioactive seed implants into the prostate. It is important to note that the effects of radiotherapy to the pelvis can result in gastrointestinal toxic effects, genitourinary toxic effects, urinary incontinence, erectile dysfunction, and mortality. Many men diagnosed with prostate cancer are older adults; in this case, the treatment burden may be overwhelming if the patient’s condition is compromised by comorbidity or the presence of a geriatric syndrome (Darmber & Aus, 2008). Patients with hypertension, diabetes mellitus, and pelvic inflammatory disease

are not considered candidates for radiation therapy (Pignon et al., 1997).

■ **Hormone Therapy and Palliative Care for Prostate Cancer.** For most men who are at high risk for systemic failure, hormonal therapy is recommended before metastatic disease is confirmed. Androgen-ablative therapy has been the mainstay for advanced prostate cancer since the 1940s. Approximately 70% to 80% of treated individuals will receive cancer-specific system relief including bone pain from metastatic disease. The side-effect profile associated with endocrine manipulation is mild compared to other anticancer therapies. Studies show that immediate hormonal therapy delays disease progression, yet not without cardiovascular toxic effects. Therefore, hormonal therapy is delayed until symptomatic progression is evident (Darmber & Aus, 2008). Until recently, cytotoxic chemotherapy was regarded as ineffective; however, recently, it is being considered second- and third-line treatment for hormone-refractory prostate cancer. Two large clinical trials have shown improved survival in men with hormone-refractory disease comparing docetaxel used alone or in combination with estramustine to mitoxantrone and corticosteroids. This treatment is still considered palliative in nature and the gastric/cardiotoxic side-effect profiles may not make the treatment option desirable to many men (Armstrong & Carducci, 2005; Darmber & Aus, 2008). Zoledronic acid, a bisphosphonate, was approved for use in men with hormone refractory metastatic disease to reduce bone pain. Long-term use of the bisphosphonate has recently been shown to cause osteonecrosis of the jaw (ONJ) causing alarm and caution in its use (Diel, 2011; Ryan & Small, 2006).

## Lung Cancer

Lung cancer remains the leading cause of cancer death in men and women in the United States and around the world with an estimated 224,210 new cases and 159,260 deaths projected in 2014 (ACS, 2014; Jemal et al., 2008). The incidence has reached a plateau in women and declined in men, reflecting the trends in smoking patterns over the past few decades (Dubey & Powell, 2008). Most individuals who are diagnosed with lung cancer are former, rather than current, tobacco smokers. Only 10% of lung cancers occur in individuals with no prior smoking history (Dubey & Powell, 2008). The overall 5-year survival rate is 15%, reflecting the poor prognosis associated with this disease (National Cancer Institute, 2007).

Lung cancer is divided into two main groups, non-small cell lung cancer (NSCLC) and small cell lung cancer (SCLC). NSCLC accounts for more

than 80% of all lung cancers and is further characterized by histology as squamous cell carcinoma, large cell carcinoma, and the most prevalent type, adenocarcinoma (NCI, 2007). SCLC (15% of lung cancers) has a very aggressive clinical course and poorer prognosis than NSCLC (84%). It is classified as limited stage or extensive stage and is usually detected at a more advanced stage, growing rapidly, and metastasizing early in the disease trajectory.

The disease trajectory for lung cancer is different, depending on the staging and, in NSCLC, depending on the sensitivity to newer treatments of targeted agents. If treated, locally advanced NSCLC (Stage IIIA or B) has a median survival of 16 to 17 months and Stage IV NSCLC has a median survival of 12.5 months (Sandler et al., 2005). Individuals with limited and extensive stage disease SCLC who are treated have a median survival of 18 to 24 months and 7 to 11 months, respectively.

About one third of surgically resected NSCLC recur in the ipsilateral and contralateral lung and can metastasize to various sites including bone, liver, adrenal glands, and brain. More than 80% of recurrences occur within 2 years and are complicated by distressing symptoms. Individuals with SCLC are at risk for brain metastases; however, prophylactic cranial irradiation significantly decreases the occurrence and improves 1-year survival in extensive stage disease (Slotman et al., 2007).

■ **Signs/Symptoms/Staging.** A tissue diagnosis and staging workup determines the type and extent of disease. Accurate staging is critical to determine if surgery is appropriate. Positron emission tomography/computer tomography (PET/CT) combined with cranial imaging is more accurate in identifying metastatic disease than conventional imaging (CT scan of chest, abdomen, and pelvis, bone scan, and cranial imaging) in NSCLC (Hampton, 2008a). In NSCLC staging, the TNM classification groups patients according to size and extent of the tumor (T), the lymph node involvement (N), and the presence or absence of metastatic disease (M). Seventy-five percent of patients with NSCLC have locally advanced or unresectable Stage IV disease at the time of diagnosis (Walker, 2003). SCLC is considered a systemic disease at diagnosis and has its own staging system. Two thirds of SCLC patients have metastatic disease at diagnosis (National Comprehensive Cancer Network [NCCN], 2008a). Once staging is completed, the treatment plan is individualized and based on staging classification; lung cancer genomics; biomarkers, which predict outcomes and treatment responses; the patient's ability to tolerate treatment; and the patient's performance status (Dubey & Powell, 2008).

■ **Disease Management.** Because SCLC is considered a systemic disease, surgery is not an option. Chemotherapy alone or with radiation is the usual treatment for SCLC with a high rate of early remission. Bevacizumab (Avastin), erlotinib (Tarceva), and crizotinib (Xalkori) are also offered to patients diagnosed with SCLC attempting to reduce disease burden (ACS, 2014). However, surgical resection remains the only potential curative treatment for patients with NSCLC presenting with surgically resectable disease. Surgery is recommended for all adults with a good performance status. There is no difference in overall survival between younger and older individuals (Yamamoto et al., 2003). Newer surgical techniques, such as the video-assisted thoracic surgery (VATS), have provided a minimally invasive approach with similar long-term survival rates as the thoracotomy (Molina, Yang, Cassivi, Schild, & Adjei, 2008). Current standard of care includes adjuvant chemotherapy for resected early stage disease, and studies of adjuvant, targeted therapies in this population are underway (NCCN, 2008a). For Stage IIIA NSCLC, a trimodality approach (chemotherapy with concurrent radiation followed by surgery) improves progression-free survival (Albain et al., 2005).

■ **Radiation Therapy.** Radiation therapy is an important treatment modality in inoperable regional NSCLC and in SCLC. It is also used as an alternative for older patients with NSCLC who are not considered surgical candidates due to comorbid disease states, or for those who decline surgery. Combined modality treatment with radiation therapy and chemotherapy in patients with nonresectable Stages IIIA and IIIB NSCLC and limited stage SCLC is the standard of care for physiologically fit individuals. In patients receiving radiotherapy alone, authors of a Cochrane review of 14 randomized trials of palliative radiotherapy to the chest concluded that the majority of patients with advanced NSCLC could be treated with short courses of palliative radiotherapy (one to two fractions; Lester, Macbeth, Toy, & Coles, 2006). This practice would greatly decrease the treatment burden for patients and families. Radiation has a major role in palliation of symptoms, in particular the pain associated with bone metastases, in managing dyspnea and hemoptysis from tumor invasion, and in controlling signs and symptoms associated with brain metastases (seizures, confusion, nausea and vomiting, and headache; Kvale, Selecky, & Prakash, 2007).

■ **Chemotherapy.** Chemotherapy has had some promising survival benefit as adjuvant therapy for high risk Stage I, Stage II, and select Stage III NSCLC (NCCN, 2008a). Chemotherapy and targeted therapies are the mainstay in advanced NSCLC. Standard



chemotherapy includes one of a number of chemotherapy doublet combinations given for four cycles. Doublet therapy, combining a platinum-based drug with vinorelbine, gemcitabine, or a taxane, has been shown to be more effective than single agents or best supportive care for first-line therapy (Obasuju et al., 2007). Concurrent chemoradiotherapy is superior to sequential treatment, but has an increased toxicity (Curran et al., 2003). Single agent chemotherapy is preferred for patients who have a poor performance status and multiple comorbidities. In individuals who have progressed on platinum-based therapy, second-line therapy includes docetaxel and pemetrexed. Predictive modeling, tailoring chemotherapy to individuals with overexpression of specific genes, is an exciting new area that holds promise for improving response and overall survival (Walker, 2003).

SCLC is a systemic disease; therefore, treatment options are usually limited to chemotherapy and/or radiation. Chemotherapeutic regimens for limited stage disease consist of concurrent combination chemotherapy and radiation, followed by prophylactic cranial irradiation, which can increase survival by about 5% (Jassem, 2007). This regimen is difficult to tolerate due to side effects associated with the toxic chemotherapeutic agents such as cisplatin and etoposide and the burden of concurrent chemoradiation. Targeted agents have not been shown to be effective.

Extensive stage SCLC is treated with etoposide/cisplatin, etoposide/carboplatin, and irinotecan/cisplatin (NCCN, 2008a). Slotman et al. (2007) demonstrated that prophylactic brain irradiation in patients with extensive SCLC who responded to chemotherapy reduces the incidence of symptomatic brain metastases and prolongs disease-free and overall survival. The debate continues as to whether highly toxic combination chemotherapy is appropriate for elders. Studies of elder patients to date suggest that they can derive benefit from treatment for SCLC; however, the limited data available support the need to include this age group in future large SCLC clinical trials. Targeted therapies are aimed at specific tumor pathways. The antiepidermal growth factor receptor (EGFR) inhibitor erlotinib reduces proliferation and survival of tumor cells by inhibiting tyrosine kinase. Bevacizumab, a recombinant vascular endothelial growth factor (VEGF) monoclonal antibody prohibits angiogenesis, the development of the tumor's vascular supply that provides needed oxygen and nutrients once the tumor reaches 2 to 3 mm in diameter.

Blocking angiogenesis limits local and systemic metastases. Targeted therapies are being used in combination with chemotherapies or as second-line treatment. As second-line therapy, erlotinib is especially

effective in a subpopulation of females, nonsmokers, individuals who are of East Asian descent, and those who have a histology of adenocarcinoma (Besse, Ropert, & Soria, 2007). Recently, bevacizumab has been shown to be effective in combination with platinum-based chemotherapy for nonsquamous cell advanced NSCLC (NCI, 2007). Additional targeted agents such as cetuximab, an EGFR inhibitor, and sunitinib and sorafenib, anti-VEGF receptor agents, have been investigated (Besse et al., 2007; Walker, 2003).

## Colorectal Cancer

The estimated new cases of colorectal cancer (CRC) in the United States in 2014 are 96,830 colon cancer cases and 40,000 rectal cancer cases (ACS, 2014). The projected combined death rate has declined 4.1% for those 50 years of age and older since 2005 due to improved screening procedures and significant advances in surgery, radiation, and chemotherapy (Wolpin, Meyerhardt, Mamon, & Mayer, 2007). Conversely, the incidence rate for adults under the age of 50 years has increased 1.8% per year (ACS, 2014). CRC ranks fourth as the most common noncutaneous malignancy in the United States and is the second leading cause of cancer death at an estimated rate of 50,830 in 2014. Mortality rates have decreased by 2.5% per year in men and 3.0% per year in women between 2006 and 2010 due to declining incidence rates and improvement in early detection and treatment (ACS, 2014). It is a disease of aging, as the median age of individuals with newly diagnosed CRC is 70 years (Rosati & Bilancia, 2008). In minorities, particularly African Americans, cancer-related mortality remains higher than in Whites (65% vs. 55%; Wolpin et al., 2007).

CRC is difficult to diagnose at an early stage without screening because patients are usually asymptomatic early in the disease process (ACS, 2014). Screening to detect polyps and cancer is important for all those deemed to be at risk and for those over the age of 50 years. Diagnosis of CRC in the older adult is especially challenging because many of the common changes of aging in the gastrointestinal tract can prevent early detection. For example, constipation, change in bowel patterns, and fatigue may be inaccurately attributed to the aging process.

Approximately 50% of patients present with hepatic metastases or develop them during the course of the disease (Pawlik, Schulick, & Choti, 2008). Because the portal vein drains the blood supply from the colon, the liver is the most common site of metastasis for advanced disease. Isolated lung or liver metastases may be resected in later stage disease (Engstrom et al., 2007a). As the disease progresses, patients may

experience bowel obstruction. Widespread metastases to the abdomen (carcinomatosis), lung, and/or liver are often the cause of death.

■ **Signs/Symptoms/Staging.** Most cancers of the bowel are moderately or well-differentiated adenocarcinomas. These cancers usually develop as a result of progressive colonic polyp mutations (Engstrom et al., 2007b). Screening for and removal of potentially malignant polyps can prevent development of metastatic disease. TNM staging has been modified to correspond with the Astler-Coller Dukes system. This staging process evaluates the depth of bowel wall penetration by the tumor, lymph node involvement, and presence of distant metastasis. The accuracy of the staging in high risk Stages II and III is associated with the number of nodes surgically removed (Engstrom et al., 2007b). Staging ranges from Stage I to Stage IV, with overall survival declining from greater than 90% to less than 10% for Stage IV disease (Meyerhardt & Mayer, 2005).

■ **Disease Management.** A complete staging workup includes a physical examination; pathologic tissue review; colonoscopy; baseline computed tomography of the chest, abdomen, and pelvis; complete blood count; chemistry profile; and carcinoembryonic antigen (CEA) determination.

■ **Surgery.** For resectable colon cancer, surgery remains the standard treatment. Tumor location, blood supply, and lymph node patterns in the area of cancer determine the extent of resection. Examination of a minimum of 12 lymph nodes is necessary for accurate staging (Engstrom et al., 2007a). Laparoscopic advances have allowed the use of minimally invasive surgical procedures to resect colon cancers without increasing recurrence rates (Clinical Outcomes of Surgical Therapy Study Group, 2004). Early mobility, return of pulmonary function, and decreased ileus and adhesion formation have made this procedure desirable for many patients, especially those with advancing age and comorbid illnesses (Baker, 2001).

Surgical management of rectal cancer involves resection with preservation of anorectal sphincter function and sexual and urinary function whenever possible (Engstrom et al., 2007a). Preoperative combined modality therapy (chemotherapy and radiation) has resulted in significant reductions in tumor size and decreased rates of local recurrence in rectal cancer. However, it is associated with increased toxicity when compared to surgery alone (Bosset et al., 2006).

■ **Radiation Therapy.** The role of radiation therapy is not well defined for colon cancer, but more studies are needed as those done are underpowered. Debate

over the value of pre- or postsurgical radiation therapy for rectal cancer continues. Although pre- and postoperative radiotherapy has been shown to reduce local recurrence when compared to surgery alone, neither intervention resulted in a statistically significant improvement in overall survival (Kapiteijn et al., 2001). Preoperative chemoradiotherapy doubled the rate of rectal sphincter sparing operations and lowered the rates of local recurrence, acute toxicity, and long-term toxicity (Sauer et al., 2004).

■ **Chemotherapy.** Current guidelines for adjuvant therapy do not recommend chemotherapy for individuals with Stage II disease. However, patients with advanced CRC do have a survival benefit from newer chemotherapeutic regimens and targeted agents. Current therapy includes bevacizumab, the VEGF blocker, plus FOLFOX infusional 5-fluorouracil (5-FU), leucovorin, oxaliplatin, FOLFIRI (infusional 5-FU, leucovorin, and irinotecan), capecitabine, or 5-FU/LV. The two EGFR monoclonal antibodies, cetuximab and panitumumab, have also been shown to be effective. Genotyping of tumors may help to predict which therapy is most beneficial to an individual. For example, patients with advanced CRC who do not have a mutated form of the gene *KRAS* may benefit from cetuximab and chemotherapy (McBride, 2008). Overall survival is improved with single agent cetuximab when other treatments fail (Jonker et al., 2007).

## ■ CANCER COMORBIDITIES

For many years, lung cancer risk has been associated with chronic obstructive pulmonary disease (COPD; Dubey & Powell, 2008) and tobacco smoke. Smokers are also known to be at risk for coronary artery disease, peripheral vascular disease, and stroke. These comorbidities may affect the performance status of individuals with lung cancer, limiting treatment options and increasing symptom burden.

Individuals at high risk for CRC are those with a first degree family history of CRC and women with a personal history of ovarian, endometrial, or breast cancer. Two major conditions that are known to have a genetic predisposition to CRC are familial adenomatous polyposis (FAP) and hereditary nonpolyposis CRC (HNPCC). Comorbidities often linked to CRC are the inflammatory bowel diseases, including ulcerative colitis and Crohn's disease. FAP, HNPCC, and inflammatory bowel diseases constitute about 10% to 15% of CRC cases. Comorbid conditions that have been identified as increasing the risk of CRC are obesity, sedentary lifestyle, diet high in fat, smoking, and alcohol consumption (greater than 4 drinks/week; ACS, 2014).



Frailty at any age adds a risk factor to cancer morbidity and anticancer therapies often decrease the patient's functional level, allowing for catabolic syndrome, muscle wasting, and infection secondary to immobility. Paraneoplastic syndromes are syndromes associated with tumor growth and anticancer therapies. To name a few, superior vena cava syndrome (SVCS) occurs within lymphoma, lung, and breast cancer. Deep vein thrombosis (DVT) and pulmonary embolism (PE) are blood clots commonly occurring in solid tumor cancers and increase in frequency with anticancer therapies. Spinal cord compression occurs in cancers with systemic tendencies. All require expert assessment and rapid management.

### ■ COMMON ASSOCIATED SYMPTOMS OF CANCER

PC is best initiated at the time of a cancer diagnosis, especially for patients with a life-limiting cancer. Many individuals experience symptoms that interfere with QOL at the time of diagnosis as well as other points in time along the disease trajectory. Hoffman, Given, von Eye, Gift, and Given (2007) have identified a symptom cluster of pain, fatigue, and insomnia in patients who are newly diagnosed and undergoing chemotherapy. Pain, dyspnea, fatigue, weight loss, and cough are commonly associated with lung cancer. Pain may occur as a result of tumor infiltration into lung parenchyma, the brachial plexus, spinal cord, bone metastasis, or brain metastasis-producing headache. Dyspnea occurs in as many as 55% of lung cancer patients, and in up to 80% of patients at the EOL (Becze, 2008). Interventions for dyspnea have been reviewed, critiqued, and summarized by the Oncology Nursing Society's Putting Evidence Into Practice (PEP) Dyspnea Intervention Project Team (DiSalvo, Joyce, Tyson, Culkin, & Mackay, 2008). Fatigue has been described as a very distressing symptom of the disease and treatment. Potentially treatable causes such as anemia should be identified and addressed.

More than 95% of individuals with lung cancer are symptomatic at the time of diagnosis (Kvale et al., 2007). Common symptoms such as cough, dyspnea, dysphagia, hoarseness, fatigue, and weight loss are frequently attributed to comorbid illnesses and are often ignored. Unfortunately with lung cancer, these common symptoms usually are the result of locally advanced or metastatic disease. Symptoms may be present as a result of primary cancer itself (dyspnea, wheezing, cough, hemoptysis, chest pain), from locoregional metastases within the chest (SVCS, pleural effusions, ribs, and pleura), or from distant

metastases (back pain, metastases to brain, spinal cord, or bone; Kvale et al., 2007).

Depending on the type of treatment received, there may be additional symptoms experienced. For example, persons receiving radiation therapy may have new or increased dysphagia because of the location of the treatment field. Individuals receiving chemotherapy or undergoing radiation may experience an increase in fatigue beyond initial presentation. Symptoms at the EOL are dependent on the type of cancer and the sites of metastases. NSCLC frequently goes to the bone, often causing excruciating pain. SCLC often progresses to the brain, causing headaches, nausea, and impaired mental status. These symptoms require aggressive PC intervention regardless of the point they occur in the disease trajectory (Kvale et al., 2007).

Chemotherapy and targeted agents used to treat lung cancer have the potential to cause side effects that negatively influence QOL. Body image, nausea and vomiting, and chemo-induced neuropathies require aggressive nursing management. However, it is important to note that for all individuals with NSCLC or SCLC, chemotherapy has been shown to relieve tumor-related symptoms such as pain, cough, and dyspnea, as well as offering survival benefit, and many patients choose to continue treatment in advanced disease for palliation (Stinnett, Williams, & Johnson, 2007).

Chemotherapy-related toxicities are common, undertreated, and most likely underreported. The deleterious effects of chemotherapy and other anticancer treatments can alter the patient's QOL and inhibit further treatments if symptoms limit the patient's physical ability to make it to the next treatment appointment. Some of the most debilitating side effects from chemotherapy require hospitalization for stabilization and the patient's decreased function level most likely will cause a delay in the treatment series. Common causes of hospitalization due to chemotherapy toxicity include infection and fever; neutropenia or thrombocytopenia; electrolyte disorders like dehydration related to nausea, vomiting, or diarrhea; fatigue and vertigo; DVT or PE; and malnutrition. Other chemotherapy-induced effects include anemia, constipation, oral mucositis, anxiety/depression, neurotoxicity, peripheral neuropathy, hand and foot syndrome, and cardiac toxicity (Moore, Johnson, Fortner, & Houts, 2008).

### ■ MANAGEMENT

Cancer care should be age appropriate and treatment should be easily accessed to ensure successful treatment of physical, emotional, and spiritual symptoms. The family (or family of choice for some

adults) should be considered within the unit of care throughout the life span for effective palliative management. From childhood to frail older adult, the responsibility of decision making shifts from parent (or support group) with possible patient input, patient with support group input, and back to support group with possible patient input (Scullion, 2005). An interprofessional, sometimes referred to as an integrated approach, is the gold standard for cancer care regardless of age, life expectancy, and treatment choices.

## Pediatric and Young Adult

■ **Children.** The life of a child who has been diagnosed with a life-threatening illness is drastically altered with wide-reaching and long-lasting effects on the family as a unit. PC health professionals working in the field of pediatrics have reported the parental need to provide every available therapy to their child in order to feel confident they have given their child the best chance for survival. Often, the attempt to defy death with anticancer treatment eliminated the chance of expert symptom management occurring simultaneously. Parental direction toward measures to defy death is now considered the reality of pediatric cancer care, and health care professionals, PC specialists included, can philosophically support parents when they maintain dual goals of hope for comfort and emotional support at the same time as hope for life extension. This is a healthier alternative not only for the patient and family but also for health care professionals since it is distressing for health care professionals when expert symptom management is delayed until all other options have been exhausted (De Graves & Aranda, 2005; Wolfe et al., 2002a). Pediatric oncology nurses report moral distress when “good nursing” is impeded as curative needs of the patient overshadow the patient’s physical and emotional needs. It is necessary that cure and palliation goals interface in cancer care, allowing an overlap so the palliative needs of the child are not sacrificed for the hope of a cure.

Symptom management, communication, and shared decision making resemble adult care with few exceptions, while spiritual care often presents slightly differently for children. Identification of meaningful activity will change from one development stage to another. Play and relational connection are two identified mainstays for children. School-age children may desire to maintain a school-day schedule to support their need to remain similar to and receive acceptance by their peers. Routine and normalcy are also recognized as important goals for care of children with life-altering illness, and religious ritual, as in routine visits to a church, synagogue, or mosque, maintains the family’s meaningful spiritual routine (De Graves

& Aranda, 2005; Wolfe et al., 2000b). Location of care and the pediatric patient’s preference continues to merit attention. Some suggest that family adjustment after the child’s death is better if the child dies at home, yet others have contended that family relationships are enriched if death occurs during hospitalization. Outpatient clinics resembling day care allow the pediatric cancer patient who is receiving chemotherapy to spend nights at home and receive treatment elsewhere. These day care clinics also encourage play that children need for emotional development. Parents frequently identify the decrease in their child’s activity level in play as a source of emotional distress. No matter what the location is for anticancer treatment and EOL care, it is worth noting that health care professionals specialized in symptom management and bereavement support make a difference in the family’s memory of the illness regardless of the outcome (De Graves & Aranda, 2005; Houlston, 2006; Wolfe et al., 2000).

High-quality care for children living with cancer includes expert pain and symptom management. Health care professionals have an opportunity to make a difference in the perceived and actual experience of the parents of dying children. Children dying of cancer experience many symptoms, and parents who witness the child suffering may experience additional suffering during grief work long after the child’s death (Pritchard et al., 2008). Wolfe et al. (2000b) discovered that discordance between parents and physicians regarding symptom recognition is similar to that of adults and their health care providers. Wolfe et al. also discovered that there was a direct correlation between a parent’s report of the child’s suffering and the level of involvement the physician displayed during the final phase of the child’s life. In other words, a parent was more likely to report the child suffering when the parent also reported feeling that the physician was not actively involved in care at the end of the child’s life. Wolfe also found that earlier discussions about hospice care were associated with a higher likelihood that the parent would report the child as calm and peaceful during the last month of life. These observations support the theory that active involvement by health care providers committed to palliation helps to alleviate the suffering of dying children (Pritchard et al., 2008).

■ **Young Adults.** Uncertainty while living with cancer has been identified as a significant aspect of pediatric cancer and a major concern of adolescent and young adult cancer survivors. Long-lasting disease control and long-term survival during and after childhood is now common due to major advances in surgery, chemotherapy, and radiotherapy. However,



treatment success can also have serious implications through each phase of the patient's life. Chemotherapy and radiation therapy can harm developing organs, and surgery can alter normal physical functioning or cause disfigurement (see Table 12.1). Previous studies have reported that as many as 69% of survivors of childhood cancer have physical, mental, or emotional limitations resulting from successful anticancer treatment (Decker, Haase, & Bell, 2007). A study of 226 adult survivors of childhood cancer showed that 12% of those interviewed reported some level of suicidal symptoms. Risk factors found for a higher significance of suicidal symptoms included younger age at diagnosis, a greater time lapse since diagnosis, and radiation treatments to the head. Add those risk factors to feelings of depression and hopelessness, chronic pain, physical dysfunction, and appearance alterations due to treatment, and the data suggest that health care professionals should perform a thorough psychosocial assessment upon long-term follow-up of survivors (Carroll, 2007). Decker et al. (2007) conducted a cross-sectional, secondary analysis study to examine uncertainty in three "time-since-diagnosis" groups of adolescents and young adults. The most recent diagnosed survivors had significantly higher uncertainty for recurring pain, an unpredictable illness course, and self-care concerns. Interestingly, survivors with 5 or more years from diagnosis had higher uncertainty related to knowing what to expect for disease recurrence. All survivor groups exhibited a significantly high uncertainty about multiple meanings of communication from doctors, leading the investigators to conclude that providers should have direct communication with adolescent and young adulthood patients. Uncertainty should be considered a concern throughout cancer survivorship and long-term support of the young cancer survivor is warranted.

## Adults and Older Adults

Critical assessment of the individual with cancer is important when determining life expectancy, treatment tolerance, and palliation. Physical reserve, psychosocial support, economic support, and comorbidity impact treatment outcomes (Repetto & Comandini, 2000).

The Karnofsky Performance Status (KPS; Table 12.2) is the most widely used assessment tool in the field of oncology (Repetto, Comandini, & Mammoliti, 2001). The KPS (Table 12.2) evaluates physical function and draws a close parallel with mortality (Repetto et al., 2001). The Eastern Cooperative Oncology Group (ECOG) assessment scale has also been used widely in oncology care to determine functional status and eligibility for treatment.

The Palliative Performance Scale (PPS) is correlated with the KPS and has been used by PC specialists, most generally hospice professionals, to determine and monitor a patient's eligibility for hospice services. The PPS is a reliable, valid tool that correlates well with actual and median survival time for cancer patients (Anderson, Downing, Hill, Casorso, & Lerch, 1996).

Age itself is not the most useful factor to determine prognosis and consider treatment options for older adults; however, a standardized nomenclature is required for a large and growing population. The concept of senescence by the passing of biological time is most useful in predicting survival, chemotherapy toxicity, postoperative morbidity, and mortality as opposed to chronological age (Audisio et al., 2004; Extermann & Hurria, 2007). Chronological age can be used as a functional status indicator for the older adults because it is assumed that adults living with cancer are more likely to need functional assistance than their same-age peers without cancer. For the sake of discussion and predicting functional needs of older adults, geriatric terminology categorizes elders as "young old" (70–74 years), "old-old" (75–84 years), and "oldest old" (85 years and older). These age-related categorizations should be considered with a complete functional assessment when developing a treatment plan since aging involves a progression of organ systems decline, coexisting physical conditions, cognitive impairment, social isolation, functional dependence, and economic limitations (Audisio et al., 2004; Extermann, 2005). Natural changes associated with age often lead to a greater susceptibility to chronic and acute disease, yet a comprehensive evaluation of the older adult's coexisting disease (comorbidities), cognition, functional status, nutritional status, social supports, psychological state, and personal resolve give a more accurate definition of age in relation to cancer treatment tolerance (Extermann & Hurria, 2007).

**TABLE 12.1 Potential Long-Term Effects of Childhood Cancer Treatment**

System	Causes
Cardiac	Anthracyclines, radiation to the chest
Reproductive	Alkylators, radiation to the ovaries
Respiratory	Busulfan, carmustine
Ocular	Busulfan
Auditory	Heavy metals

Source: From Lally (2007).

Another commonly used geriatric classification of the older adult is the “frail elder.” The use of the term “elder” is most generally reserved for patients older than 65 years and “frail” is a traditional term not well defined. The medical literature often refers to a frail individual as someone with poor physiological reserves and a high prevalence of repeated chronic illness requiring multiple hospital admissions. Additional characteristics of frailty include complex psychosocial problems and limited social support, which increases the risk of treatment-related complications and cancer-specific mortality (Audisio et al., 2004). In addition, the term is associated with more than one geriatric syndrome, a limited life expectancy not much beyond 2 years, the inability to maintain homeostasis in nonstressed conditions, and a greater risk of developing treatment-related toxicities with the loss of functional independence (Repetto & Comandini, 2000). Geriatric syndromes should also be included in a comprehensive assessment in order to determine accurately the elder’s stage of life and functional capabilities. Geriatric syndromes that have been defined and used in treatment planning within the last 10 years include dementia, depression, abuse/neglect, incontinence, osteoporosis, failure to thrive, and risk for falls (Extermann, 2005).

Since the evaluation of the older adult is obviously influenced by many factors, a geriatric assessment tool can equip health care providers to manage the complexity of geriatric oncology health care needs. The comprehensive geriatric assessment (CGA) is

recommended to determine the medical, psychological, and functional capabilities of elderly cancer patients. The CGA focuses on frail elderly people with complex conditions and a functional status relating to QOL, and incorporates an interprofessional team approach to assessment (Repetto et al., 2003). Activities of daily living (ADLs) and instrumental ADLs (IADLs) are useful tools for assessing functional ability and are incorporated into many comprehensive assessment tools (Table 12.2; Repetto et al., 2003). Dependence for ADLs and IADLs closely parallel limited life expectancy and dependence in IADL correlates with treatment intolerance, while comorbidity, a normal process of age, is known to complicate cancer diagnosis, prognosis, and treatment (Extermann, 2005; Lazzaro & Comandini, 2000). Comorbidity is associated with decreased survival rates and merits attention during a comprehensive assessment.

### Family Support

In addition to the physical care of a loved one with advanced cancer, comprehensive care requires family support. PC includes physical, emotional, and spiritual comfort of the patient and family. Spouses, adult children, extended relatives, and neighbors account for the 7 million Americans who consider themselves caregivers. Approximately 15% of those Americans care for individuals with serious illness and disability. Spouses represent roughly 62% of those caregivers,

**TABLE 12.2 Karnofsky Performance Scale (KPS)**

Definition	Rating %	Criteria
Able to carry on normal activity and to work; no special care needed	100	Normal; no complaints; no evidence of disease.
	90	Able to carry on normal activity; minor signs or symptoms of disease.
	80	Normal activity with effort; some signs or symptoms of disease.
Unable to work; able to live at home and care for most personal needs; varying amount of assistance	70	Cares for self; unable to carry on normal activity or to do active work.
	60	Requires occasional assistance, but is able to care for most of personal needs.
	50	Requires considerable assistance and frequent medical care.
Unable to care for self; requires equivalent of institutional or hospital care; disease may be progressing rapidly	40	Disabled; requires special care and assistance.
	30	Severely disabled; hospital admission is indicated although death is not imminent.
	20	Very sick; hospital admission necessary; active supportive treatment necessary.
	10	Moribund; fatal processes progressing rapidly.
	0	Dead.

Source: From McDonald (1993).



with women as 72% of those caregivers (Derby & O'Mahony, 2006). Often, primary caregivers are spouses with their own health care needs that may make them susceptible to depression, fatigue, and frequent acute illness. Other caregiving relationships involve adult children as dual role caregivers to parents and their own children, or the staff at the elder's nursing facility or assisted living environment. Researching the use of home medical/social services by elders in the last 6 months of life, Kobayashi (2000) found that the focus of care needed by the patient and family is that of medical and psychosocial treatment. Symptom management is more intense and requires regular evaluation. A large part of the advanced stage of illness may require more physical symptom monitoring; however, the psychosocial needs of the patient and family is just as important. Utilization of the PC team is vital at the EOL (Kobayashi, 2000).

EOL decisions place additional burdens on the family. Those decisions include where the final days will be spent, what impact there will be on loved ones, and whether the family can afford the care involved. Family members often take a leave of absence from their jobs to care for a dying loved one; those that do not have that option may experience feelings of remorse for taking a more peripheral role in the care of the older adult. Many Americans report they would prefer to die in the comforts of their home; however, a majority die in an acute-care or long-term facility. Nurses can support a dying patient by providing a home-like environment and a familiar surrounding with the patient's personal items, aroma, music, and support people (Beardsmore & Fitzmaurice, 2002; Higginson & Sen-Gupta, 2000; Hsieh, Huang, Lai, & Lin, 2007; Tang, 2003).

When patients reach the terminal phase of cancer, conflict may occur among the patient, family members, and health care workers. Conflict at the EOL transpires due to the disparity of patient/family expectations with the patient's function and symptom status, as well as the patient's attempt to maintain physical, emotional, and existential control. As the disease progresses, symptoms and physical function are in flux. Family members attempt to adjust to the changes; however, in advanced cancer, the changes can occur quickly, which provokes conflict.

Family concerns throughout the course of advanced illness are directed toward the physical comfort of the patient, the emotional impact on the family, and the desire for accurate information (Griffin et al., 2007; Kristjanson & White, 2002; Milberg, Olsson, Jakobsson, Olsson, & Friedrichsen, 2008; Tang, 2003; Valdimarsdóttir et al., 2007). It is commonly perceived by family members that

once the terminal prognosis is discussed, health care professionals do not feel the need to provide additional information. Due to the rapid change in physical and cognitive status, information updates are just as significant as before. Out of 22 terminally ill patients interviewed, Kutner, Steiner, Corbett, Jahnigen, and Barton, (1999) concluded that 98.2% requested information concerning changes in their disease status. It is interesting to note that even though most patients and families request the truth, they still want health care providers to be optimistic and maintain a sense of hope (Kutner et al., 1999). It is also worth noting that bereaved family members report higher satisfaction, fewer concerns, and fewer unmet needs pertaining to the care of a loved one when PC and hospice teams provide EOL care (Teno et al., 2004).

Initially, the family's focus of hope is often on cure. It is also the hope and goal of the family to provide comfort and support to their loved one as death becomes imminent. The PC team assists caregivers to develop the physical, emotional, and mental reserves that are required to maintain hope, coupling that with the provision of timely, accurate, and honest information of the impending death. Nurses should respond to patient and family concerns with patience and assurance of nonabandonment and an increase in attention to aggressive symptom management (Borneman, Stahl, Ferrell, & Smith, 2002; Valdimarsdóttir et al., 2007). Physicians often choose to limit or tailor prognostic information with the intention of maintaining a patient's hope.

Mack et al. (2007) conducted a cross-sectional, questionnaire-based study of parents and physicians of children with cancer. The study evaluated relationships between parental recall of prognostic disclosure from the physician and how that disclosure affected hope, trust, and emotional distress. In this multivariable model, parents frequently reported that "high quality" physician communication (defined by parents as trusting a familiar physician to give honest information) involving more elements of prognostic disclosure made them feel more hopeful. The study found that when the physician has established a compassionate, trusting relationship with the patient, family prognostic disclosure can support hope, even when the prognosis is poor. In fact, no data are available that show hope can be taken from patients and families despite the long-standing fear of clinicians (Harrington & Smith, 2008).

Parents of dying children often have an intellectual knowledge or emotional awareness of the child's impending death. Valdimarsdóttir and colleagues (2007) discovered that health care providers can influence the awareness of parents, encouraging a

“preparatory phase” of care that fosters an environment of talking about the child’s impending death and making a long-lasting beneficial effect on bereavement. Emotional awareness enables parents to see the patient’s weakening condition, obtain more information and assistance from health care providers, and discuss important issues on life and death. As the family’s focus of hope shifts due to the patient’s weakening physical condition, family members may strengthen the connection with their faith system, their relationship to the patient, and others. The connection made with health care providers prior to the death of the loved one is considered integral in the grieving process (Griffin et al., 2007; Kristjanson & White, 2002; Milberg et al., 2008; Tang, 2003; Valdimarsdóttir et al., 2007).

### Bereavement Support

Saying good-bye to a loved one is important to survivors. Those who lose a loved one unexpectedly often exhibit less resilience and more anger during the bereavement period. Anticipatory grief has not been shown to alter actual grief, but giving family members sufficient warning of an impending death will foster a shift of focus to meaningful discussions with the cancer patient. That meaningful time will have a lasting impact on the survivor, possibly alleviating any guilt the survivor may normally experience as a grieving caregiver. Since mourning is culture based, this is also a good time for the health care provider to inquire about and honor cultural and religious practices surrounding death. This display of respect for cultural and spiritual rituals surrounding the dying process and memorial can make the experience of death less traumatic. Data from two small studies (Cohen et al., 1997) of terminally ill cancer patients show that scores of existential well-being correlate with scores of physical well-being. Even in the presence of physical pain, depression and hopelessness are inversely related to spiritual well-being. After the death, a caring call from a familiar health care provider allows the survivor to reconnect with someone who shared the death experience and to discuss concerns regarding emotional and physical responses to grief. The bereaved often report the need to talk about the death experience many times. These phone calls can lend an additional listening ear for that purpose (Griffin et al., 2007). Milberg et al. (2008) learned from bereaved family members that half of them requested bereavement follow-up and many wanted to talk about the events occurring in the palliative phase of the decedent’s care, their own response to loneliness, and the future. Follow-up contacts were preferred in person and respondents expressed

appreciation to be recognized as a person with specific needs for contact.

## ■ PALLIATIVE CARE ISSUES

### Palliative Chemotherapy

#### ■ Goals and Use of Chemotherapy Near the EOL.

Since the 1970s, oncological trials have focused on chemotherapy response rates, disease-free intervals, and overall survival endpoints. At the same time, clinicians have observed and recorded the symptom improvement benefits during curative treatment efforts. As a result, the concept of “palliative chemotherapy” for the purpose of symptom improvement and slowing cancer growth became not only an acceptable practice but also a desirable choice for patients whose cancer was impossible to eradicate (Thompson & Chochinov, 2009). Chemotherapy is increasingly available and better tolerated; therefore, patients with incurable cancer are frequently offered the option of palliative chemotherapy even though there is no certainty that symptom burden will be relieved or survival will be extended. Patients and families will put their hope in treatments offered with limited scientific evidence of benefit; therefore, chemotherapy use for patients with advanced disease requires sophisticated oncologic assessment, clarity of the patient’s goals for care, and balanced shared decision making between patient and oncologist. Like other treatment decisions, it requires a complete burden versus benefit analysis. Since solid data are not available to support the palliative benefits of chemotherapy, smaller community hospice agencies are not willing to take on the cost of such treatment. Community resources offering interprofessional support not linked to the hospice benefit provide valuable support to individuals receiving palliative chemotherapy. Cancer clinics may be linked to national and local programs, and area hospices may have additional services for individuals ineligible to elect the hospice benefit.

Knowing what patients and families understand from diagnosis, treatment, and prognosis, discussions with their oncologists is paramount. Many studies have shown that patients and families report not knowing that late-stage chemotherapy was not intended to cure. Within those studies reported by Harrington and Smith (2008), many patients did not recall such a discussion regarding prognosis and the goal to treat with palliative chemotherapeutic agents. In an effort to support a patient’s hope for disease outcome, it has also been reported that many physicians will offer a wide range of outcomes to allow patients to assume for themselves the most favorable. Supporting a balanced exchange of information and



shared decision making between patients and their oncologists remains important. People living face-to-face with death will choose aggressive treatment with major adverse effects and a small chance of benefit. This is largely different from what their physicians and nurses who are not living with illness would choose. Individuals representing many socioeconomic levels and value systems are willing to place their hope in experimental drugs with a 10% mortality rate for one last chance of benefit (Harrington & Smith, 2008).

A discussion of patient preference for quality and quantity of life with or without chemotherapy is a good start to a palliative treatment discussion. Before chemotherapy is recommended, a definable benefit must be identified, and a straightforward discussion can be initiated by asking patients how much they want to know about their current condition and prognosis. Define the words “response” and “cure.” Many patients will use these terms interchangeably. Provide printed resources listing benefits of adverse reactions to chemotherapy, keeping in mind that there must be a definable benefit to chemotherapy before treatment can be medically justified. Ask patients about their goals for treatment, views on undesirable side effects, and plans for the future. Extending survival time for an upcoming special event may be the benefit that could justify treatment in the patient’s mind. Also, initiate discussion, with the intent of revisiting the plan when the cancer is resistant to chemotherapy.

Upon evaluation of the palliative treatment, the nurse can facilitate a meeting with the treating and PC team to clearly report on how the cancer is responding to chemotherapy. Working within an interprofessional framework, the physician, nurse specialist, clergy, patient, and family should be involved in this discussion. Continue a straightforward approach to communication by clearly defining the cancer’s response to treatment. Provide hope if there is reason to be hopeful; however, avoid offering false hope. Many people are able to be hopeful about something even if the cancer is growing, yet some physicians believe that disclosing a poor prognosis will reduce a patient’s hope. In a study of 194 parents of children living with cancer, Mack et al. (2007) discovered that clinician communication can foster hope even when the news is bad. In almost half of the parents receiving more prognostic, high-quality information from their child’s physician, a greater communication-related hope was reported (Mack et al., 2007). High-quality care was designated by clinician sensitivity and the clinician’s active listening skills. Supporting previous research findings, Mack and colleagues suggest that meaningful experiences and relationships can serve as a foundation for hope, as opposed to a hope based on unrealistic expectations for treatment outcome. In fact, there are no data that support the previous belief

that hope can be taken away from patients and that patients are harmed by sensitive, compassionate information exchange regarding prognosis (Harrington & Smith, 2008).

Body image changes associated with targeted agents, including facial and upper body rash and hair loss associated with many of the chemotherapeutic agents, can be devastating for patients and families. The pathophysiology of nausea and vomiting is quite complex and requires strong assessment skills to identify appropriate pharmacologic and nonpharmacologic interventions (Coyne et al, 2006; Thompson & Chochinov, 2009). Neuropathies associated with thoracic surgical resection and with chemotherapeutic agents, especially the platinum drugs and taxotere, can be very burdensome and require aggressive management. Medications for neuropathic pain, such as gabapentin, pregabalin, duloxetine, or the tricyclic antidepressants, may improve QOL (Coyne et al, 2006).

In addition to addressing physical symptoms associated with lung cancer, the nurse may be involved with PC to help the patient and family with complex decision making during the staging process, at the time of disease progression, and EOL. With the minimally toxic targeted agents now available, many are opting to choose treatment rather than supportive care alone. Hospice referral length of stay may decrease as more patients are continuing treatment late into the disease. The current hospice Medicare regulations require patients to choose either hospice care or continued therapy. Until there is a change in the hospice benefit, many will not have access to needed hospice care until the last days of life (Temel et al., 2008; Thompson & Chochinov, 2009). The role of the nurse as advocate is needed at this stage.

PC can also improve psychological, social, and spiritual concerns that confront patients and families with cancer. Guilt, associated with a history of smoking or current tobacco use, may increase distress in patients throughout the disease trajectory. Counseling may be of help to address emotions, fears, and concerns. Changes in roles and relationships as a result of disease progression also may require intervention from the counselors and social workers on the PC team. Involving spiritual care is important as individuals face the reality of the EOL and the importance of life closure.

Over half of all patients with CRCs are diagnosed in the advanced stages. Comfort measures to manage metastatic disease and side effects of treatment are essential for QOL. Trimodality therapy is difficult with patients battling fatigue, nausea and vomiting, diarrhea, and pain. In late-stage disease, bowel obstruction, pain, ascites, and nausea and vomiting require aggressive PC. For bowel obstruction, pharmacologic management (octreotide) and nonpharmacologic

interventions (percutaneous draining peg) may relieve pain and nausea/vomiting (Thompson & Chochinov, 2009).

Along with managing physical symptoms, the nurse must address the psychological, social, and spiritual issues that may be evident across the disease trajectory. Depression, frequently underdiagnosed and undertreated in patients with cancer, should be managed with medication and counseling. Financial

burdens associated with months of expensive treatment and inability to work requires help from social work. Spiritual care may alleviate the anxiety that comes from the uncertainty of disease progression in CRC and the challenges associated with treatment decisions. As hope and goals change from control of the disease to a comfortable death, the PC team in conjunction with the primary nurse can provide support to the patient and family.

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### CASE STUDY *Conclusion*

Mr. J. experienced the roller-coaster journey of advanced cancer. Throughout this journey, from diagnosis until death, he was supported by his primary treatment nurse and the cancer center's PC team. The best approach to patients with life-limiting illness is access to PC throughout the disease trajectory. Interventions from the advanced practice nurse, social worker, counselor, and spiritual care coordinator on the PC team were a support to Mr. J. and his family.

For some months, Mr. J.'s CT scans demonstrated response to treatment or stable disease. During other times of restaging, the CT scans and clinical symptoms were evidence of progression. Over the course of the first 20 months, he received a variety of combinations of chemotherapy and targeted agents. Pain, nausea and vomiting, anxiety, and depression were managed with pharmacologic and nonpharmacologic interventions. Mr. and Mrs. J. participated in counseling. The spiritual care counselor provided listening and presence during each of his treatment sessions.

In March of 2008, Mr. J. had progressive disease in the abdomen and liver and new pulmonary metastases; therefore, he chose to enroll in a phase I clinical trial. At that time, he was experiencing right upper quadrant pain associated with liver metastases, nausea and vomiting related to the treatment, cough, lower extremity peripheral neuropathy, and depression. Current medications included oxycodone SR 10 mg p.o. twice a day (b.i.d.), oxycodone 5 mg p.o. every 2 hours as needed for pain, and dexamethasone 8 mg daily for abdominal pain, ondansetron 8 mg p.o. every 6 hours as needed for nausea and vomiting, lorazepam 1 mg p.o. every 8 hours as needed for anxiety, benzonatate 100 mg p.o. every 4 hours for cough, gabapentin 300 mg p.o. b.i.d. for chemo-induced neuropathy, magnesium oxide 400 mg p.o. b.i.d., and setraline 150 mg p.o. daily for depression, which had been increased over time.

As his pulmonary metastases progressed, managing Mr. J.'s dyspnea became the major challenge. He was hoping to enroll in a second phase I clinical trial but required hospitalization for shortness of breath. Since current recommendations for progressive colon cancer suggest chemotherapy for symptom management and increased survival, and since Mr. J.'s goal was quantity and QOL, continuing chemotherapy was appropriate. However, during this admission, it became evident that he was dying from his pulmonary metastasis and would no longer be a candidate for more treatment.

The PC team worked with the nurses to manage his dyspnea with opioids and increase his IV lorazepam to alleviate his anxiety and restlessness. Mrs. J. met with the team in conjunction with the oncologists to review Mr. J.'s goals of care. Hospice was called in to help care for him at the end of his life. Mrs. J. was very worried about caring for him at home with the children experiencing another loss, and Mr. J. preferred to stay in the hospital with the staff he had come to know over the 2 years of care. The decision was made to keep him in the hospital with hospice care.

The children were brought to the hospital to see their dad and had time to work with the hospital child-life workers and receive counseling. All the children participated in decorating squares on a premade quilt on Mr. J.'s bed, expressing their love for him.



Time was set aside for Mr. J. and his wife to be alone in the room and their privacy was honored by the staff. Mr. J. died peacefully within 5 days of his sudden decline. The PC team, who had been with him throughout the cancer experience, supported him and his family at this difficult time and hospice continued to provide bereavement support and counseling to the family.

## Evidence-Based Practice

Hart, S. L., & Charles, S. T. (2013). Age-related pattern in negative affect and appraisals about colorectal cancer over time. *Health Psychology, 32*(23), 302–310.

### Research Problem

Application of a theoretical model of strength and vulnerability integration (SAVI) to understand age-related patterns in emotional responses of individuals diagnosed with CRC.

### Design

Diagnosed individuals completed surveys at four time points. Multilevel model.

### Sample and Setting

Sample size: 139 respondents in the age range of 28 to 89 years completed surveys prior to surgery (baseline), and 6, 12, and 18 months postsurgery.

### Methods

Multilevel modeling examined changes in measures of positive and negative affect, depressive symptoms, and appraisals of cancer over the determined period of time. Scales used: The Positive and Negative Affect Scale (PANAS) includes two 10-item scales rating the extent to which the respondent experiences various feelings on a scale of 1 to 5. The Center for Epidemiologic Studies–Depression Scale (CES-D) is a well-known, validated 20-item scale used to measure depressive symptoms. The Stress Appraisal Measure is a validated measure of a patient's understanding of the nature of his or her illness divided into three scales. Linear and nonlinear patterns of change were examined for a period of 18 months.

### Results

This examination discovered that emotional distress and age differences are less pronounced at the initial onset of illness and treatment of CRC. During the 18-month examination, age-related strengths came to light and older adults reported less negative affect than younger adults. In addition, it was found that older adults are more likely to use emotional regulation that allows them to adapt to their diagnosis and treatment plan. In other words, older adults are more likely to evaluate their illness as less threatening and a greater challenge than younger adults through the period of time during and after treatment.

### Commentary

This study is one of the first to examine colorectal patients immediately after diagnosis and is focused on the correlation between resiliency and age of patient. This study followed colorectal patients during the most critical and difficult parts of their cancer treatment. This study concluded that older adults present with a greater level of resiliency than their younger counterparts; yet more research is needed to examine the relationship to patient levels of education and geographic locations.

## Evidence-Based Practice

Given, C., Given, B., Rahbar, M., Jeon, S., McCorkle, R., Cimprich, B., . . . Bowie, E. (2004). Effect of a cognitive behavioral intervention on reducing symptom severity during chemotherapy. *Journal of Clinical Oncology*, 22(3), 507-516.

### Research Problem

To test the efficacy of a behavioral intervention for reducing the severity of multiple symptoms among patients diagnosed with different solid tumor sites undergoing a first choice of chemotherapy.

### Design

Randomized control trial.

### Sample and Setting

Patients ( $n = 237$ ) were accrued from comprehensive and community cancer centers, interviewed, and randomly assigned to the experimental intervention ( $n = 118$ ) or conventional care ( $n = 119$ ) groups. Patients were older than 21 years, diagnosed with a wide range of solid tumors, and undergoing a first course of chemotherapy.

### Methods

The control group received conventional care. The experimental group received a behavioral intervention based on the work of Bandura, using four approaches to develop self-efficacy: mastering skills through practice, observing others as they address problems, persuading oneself that the strategy will work, and convincing oneself that the strategy will reduce aversive symptoms. Fifteen symptoms (alopecia, constipation, cough, diarrhea, fatigue, fever, anorexia, coordination problems, nausea and vomiting, insomnia, dry mouth, pain, mouth sores, inability to concentrate, and shortness of breath), functional limitation, and emotional distress were evaluated at 10 to 20 weeks to assess the impact of intervention. Severity of symptoms was rated by patients on a 10-point scale ranging from 1 (*barely noticeable*) to 10 (*worst possible*). Nursing evaluation continued throughout the study to determine the appropriate intervention for the severity of symptoms. Those evaluations were guided by computerized protocols. Intervention themes included self-care management; information, decision making, and problem solving; communication with health care



problems and improving end support. Data analysis through two-sample *t*-tests for continuous variables and  $\chi^2$ -tests for categorical variables was used.

## Results

Two models were tested: (a) the additive effects of supportive medications; and (b) the possible interactions between group and number of supportive care medications on symptom severity at the 20-week observation. The behavioral intervention used a problem-solving approach designed to engage patients in specific intervention strategies to reduce total symptom burden. Baseline scores showed no statistically significant differences at entry. At 10- and 20-week evaluations, there was a significant interaction between the experimental group receiving cognitive-behavioral intervention and their baseline symptom severity. Patients in the experimental group who entered the trial with higher symptom burden reported significantly lower severity at 10 and 20 weeks. No evidence was found to indicate that supportive medicine confounded the effects of intervention.

## Conclusion

The relationship between the presence and severity of symptoms reported by cancer patients undergoing chemotherapy and their impact of QOL has been demonstrated in prior studies. This study tested the efficacy of a behavioral intervention for reducing the severity of modifiable symptoms among patients diagnosed with solid tumors undergoing a first course of chemotherapy.

This trial indicates that in the case of patients who entered the trial with higher symptom severity and were undergoing a first course of chemotherapy, a 20-week, nurse-administered cognitive-behavioral intervention resulted in significantly lower levels of symptom severity scores compared to patients receiving conventional care alone. The behavioral intervention was successful in engaging patients in specific intervention strategies designed to reduce total symptom burden. The intervention showed significant impact within 10 weeks with increasing impact evident at week 20. The intervention was integrated into the ongoing treatment plans equipping family caregivers and providing long-standing follow-up via telephone. This is one of the few trials contrasting the impact of behavioral intervention with supportive care medications to understand how these two approaches might work independently or complement one another. It is important to identify interventions that can be directed toward a patient's high symptom burden while equipping the patient and family caregivers with tools to integrate behaviors learned into day-to-day life.

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# End-Stage Heart Disease

## CHAPTER

### KEY POINTS

- Heart failure (HF) is a terminal disease.
- Ten million patients will have HF by 2037.
- Direct/indirect cost in 2008 was \$34.8 billion.
- Large-scale clinical trials give evidence-based guidelines as to the treatment.
- Predicting the illness trajectory is much harder in HF than in cancer.
- Communication of wishes and goals of care continues to be a problem.
- Nursing has a key role in the management and outcomes of patients with HF.
- Patients often turn to nurses for information on their disease especially in the end stages of the disease.
- A coordinated effort by nursing has been developed as to how to help patients with not only the physical symptoms of HF but also the psychosocial aspects.

### CASE STUDY

Mrs. L. is an 85-year-old woman who has been seen by the cardiologist on a weekly basis for the past 6 weeks in order to closely follow her progressive symptoms of heart failure (HF). At this point, she appears cachexic and now needs a walker, as she gets dyspneic and exhausted even at rest. She has been given maximal medical therapy including an angiotensin-converting enzyme inhibitor (ACEI) and beta-blocker (BB) for the last 5 years and she had a pacemaker and defibrillator implanted 2 years ago. She has been hospitalized three times in the last 6 months and wants to know her medical options.

Her son, who has been bringing her into the office, is confused about why his mom has deteriorated so quickly and does not understand why Mrs. L. would not want to go back to the hospital since it always helped her improve in the past. She has been living with him since her last discharge and is requiring more and more care.

Mrs. L. recognizes that the weekly visits and constant changes in her diuretic doses are making her feel weaker. Today on examination, she can barely speak in full sentences and her resting  $\text{SaO}_2$  is 88% on room air. She tells her health care provider that she is exhausted and does not know where to turn for help.

The nurse practitioner, who is her health care provider today, will need to address the following questions.

1. What concerns should be addressed?
2. What are the treatment options in this case?
3. What referrals would be appropriate and why?

HF is considered a terminal disease. In the final phase, patients and their families experience office visits, hospitalizations, and decreased quality of life (QOL) despite optimal therapy. Patients may suffer with intractable dyspnea, pain, profound fatigue, orthopnea, and psychological despair. The disease is difficult to prognosticate, making it challenging to know when end of life (EOL) discussions should occur. In addition, health care providers may find it difficult and feel they don't have the skills to discuss EOL issues. As professional nurses and nurse practitioners, how can we intervene with these patients who have very little "life" left and help their families cope with this reality? This chapter provides evidence-based strategies to address these questions.

## ■ END-STAGE HEART DISEASE OVERVIEW

The majority of end-stage heart disease patients have heart failure (HF) as it is the common endpoint for most cardiovascular diseases such as hypertension (HTN), atrial fibrillation, valvular disease, acute myocardial infarction (AMI), cardiomyopathies, and coronary artery disease (CAD; Jessup & Brozena, 2003). HF is not a disease, but rather a complex clinical syndrome evidenced by ventricular inability to fill or eject blood, generally as a result of structural or functional impairment (Yancy et al., 2013). The incidence of HF is projected to increase due to improved survival resulting from the success in recognition and treatment of other heart diseases, particularly AMI (Kirkpatrick & Kim, 2006). These same patients, however, eventually suffer the long-term effects of the heart damage incurred during the acute event such as decreased left ventricular (LV) function resulting from cardiac muscle damage. While many medications and interventional devices can prolong life, these patients eventually develop HF as they age and the medications or devices no longer aid them (Kirkpatrick & Kim, 2006). According to the most recent numbers from the American Heart Association (AHA; Go et al., 2013), one in five people in the United States is at risk for developing HF with one in nine death certificates listing HF as cause of death.

Despite considerable improvement in evidence-based therapies, HF continues to result in poor prognosis and poorer QOL than most cancers (Adler, Goldfinger, Kalman, Park, & Meier, 2009). In the last 6 months of life, 80% of HF patients will be hospitalized at least once and spend at least 4 days in intensive care. While hospice use increased from 19% to 40% between 2000 and 2007, 37% of these referrals occurred in the last week of life (Unroe et al., 2011). Because of the low rate of hospice utilization

and pattern of late referrals in end-stage heart disease, there is a need for the infusion of palliative care (PC) principles into general care (Fahlberg, Donoho, Paire, & Davidson, 2011). Patients with Stage D HF (Table 13.1), despite maximal support, are at high risk of sudden death (Hunt et al., 2009). In addition to the human cost of HF, there is a high societal cost as well. HF continues to pose heavy economic burden in the United States with a projected total cost increase from \$31 billion in 2012 to \$70 billion by 2030 (Heidenreich et al., 2013). Much of this cost is driven by frequent inpatient readmissions. PC, with its focus on symptom management and decisional support, has the potential to ameliorate some of the burden of HF.

## Heart Failure Is a Condition of Aging

Currently, more than 5 million people have HF and this is expected to increase to greater than 8 million by 2030 (Heidenreich et al., 2013). The projected increase in HF incidence and prevalence is strongly associated with the aging of the baby boomers. Almost 75% of those diagnosed with HF are older than 65 years (*Heart Disease and Stroke Statistics—2009 Update*, 2009). HF is the number one hospitalization diagnosis for older adults with the number of hospitalizations increasing 150% over the last 20 years (Yancy et al., 2013). Despite the prevalence of HF in older adults, cardiovascular clinical trials continue to exclude the typical older adult HF patient. In most of these trials, participants are younger than average (50–65 years of age vs. older than 75 years) and the samples are skewed toward males and those with fewer comorbidities. The trials target one specific therapy, whereas it is usual for there to be concurrent medications in the general HF population. Because of selection criteria, the participants are generally compliant with low risk of disability (Abete et al., 2012).



**TABLE 13.1** Stages in the Development of Heart Failure (HF)

Stage A	Stage B	Stage C	Stage D
<p>High risk for HF but no structural heart disease or symptoms of HF. For example, patients with:</p> <ul style="list-style-type: none"> <li>■ Hypertension</li> <li>■ Atherosclerotic disease</li> <li>■ Diabetes</li> <li>■ Obesity</li> <li>■ Metabolic syndrome</li> <li>■ Using cardiotoxins</li> <li>■ With family history of cardiomyopathy</li> </ul>	<p>Structural heart disease but no signs or symptoms of HF. For example, patients with:</p> <ul style="list-style-type: none"> <li>■ Previous MI</li> <li>■ LV remodeling including LVH and low EF</li> <li>■ Asymptomatic valvular disease</li> </ul>	<p>Structural heart disease with prior or current symptoms of HF. For example, patients with:</p> <ul style="list-style-type: none"> <li>■ Known structural heart disease</li> <li>■ Shortness of breath and fatigue, reduced exercise tolerance</li> </ul>	<p>Refractory HF requiring specialized interventions. For example, patients with:</p> <ul style="list-style-type: none"> <li>■ Marked symptoms at rest despite maximal medical therapy (e.g., those who are recurrently hospitalized or cannot be safely discharged without specialized interventions)</li> </ul>

EF, ejection fraction; LV, left ventricular; LVH, left ventricular hypertrophy; HF, heart failure; MI, myocardial infarction.

Source: Adapted from Jessup et al. (2009).

Real-world clinical practice is very different from the ideal world of the clinical trial, yet this type of research forms the basis of HF evidence-based practice. This disconnection between clinical trials and clinical practice makes it challenging to offer sound evidence on which to base practice. These limitations should be kept in mind when reviewing the literature in this chapter as well as on your own.

### Classifying and Determining Prognosis in Heart Failure

The AHA and the American College of Cardiology (ACC) collaboratively developed criteria that describe the stages in the development of HF, which is outlined in Table 13.1. HF is also classified using the New York Heart Association (NYHA) Functional Classification System (Exhibit 13.1). The patient with advanced heart disease is classified as NYHA Class III or IV, which is associated with radical clinical dysfunction resulting from symptoms and affecting the QOL of the individual. Symptoms considered are dyspnea, fatigue, or angina. The NYHA functional classification scale is very useful for clinicians who treat HF patients. It provides a benchmark to determine whether the condition is improving, staying the same, or getting worse and to easily communicate the severity of the patient's symptoms. It is also used in research studies to evaluate the effectiveness of new treatments.

This variability of symptoms is one of the difficulties in predicting EOL in HF. There are weeks or months when patients seem to favorably respond to the guideline-based therapies, and other times the same treatments are no longer tolerated and the patient requires

### Exhibit 13.1

#### The New York Heart Association Functional Classification

##### Early-Stage Heart Failure

- **NYHA Class I**  
No symptoms at any level of exertion and no limitation in ordinary physical activity.
- **NYHA Class II**  
Mild symptoms and slight limitation during regular activity. Comfortable at rest.

##### Advanced-Stage Heart Failure

- **NYHA Class III**  
Noticeable limitation due to symptoms, even during minimal activity. Comfortable only at rest.
- **NYHA Class IV**  
Severe limitations. Experience symptoms even while at rest (sitting in a recliner or watching TV).

Source: Compiled from the New York Heart Association classifications.

multiple hospitalizations. Often it's a balancing act, titrating medications to keep the patient stable and out of the hospital without exacerbating another problem, when you think the end may be near. Patients will often explain away an increase in symptoms such

as breathlessness as “just getting old” or a process of “deconditioning.” Patients and families often think of HF as episodic. If the patient is symptomatic, they will say that the patient has HF but when symptoms abate the patient and family often believe that the patient is no longer in HF. Rarely do they think of HF as a terminal diagnosis. Yet the same patient may be stable for many months or even a year or two and then die suddenly due to a new cardiac event or a concomitant or new medical problem.

Difficulty predicting prognosis presents barriers to appropriate treatments, such as when to deactivate devices or referral to hospice, for the last stage of HF. Hospice referral in the United States requires a predicted 6 month prognosis, yet many providers are hesitant in making this determination when the course of HF is often unpredictable. This also complicates decision making about what treatment options should be considered and how helpful treatments will be.

### The Role of Comorbidities in Heart Failure

Coexisting conditions such as diabetes mellitus (DM), renal disease, anemia, obesity, pulmonary disease, sleep-disordered breathing (SDB), and depression also factor into HF with 40% of HF patients having five or more comorbidities (Tevendale & Baxter, 2011). Comorbidity impacts both decision making related to treatment options and response to treatments. DM is considered a cardiac risk equivalent. This means that a diabetic patient is treated medically as if he or she has already had a cardiovascular event. Renal insufficiency is common in HF, often as a consequence of poor renal perfusion. This causes fluid retention and activation of the renin system, which vasoconstricts and increases myocardial demand. Pulmonary disease also leads to symptoms such as dyspnea or fatigue so it is important to ascertain whether the heart, the lungs, or both are the cause of the symptoms. SDB, common in HF, contributes to many cardiovascular symptoms such as pulmonary HTN and right-sided HF. When properly identified, SDB can be easily treated leading to improved symptoms and functional ability.

Depression and anxiety are important as they relate to the pathophysiology of HF. Depression may independently worsen HF and increase risk of death (Abete et al., 2012; Chung, Moser, Lennie, & Rayens, 2009). Cortisol levels are persistently high in patients with depression, which, over time, leads to HTN caused by increased afterload and an increase in heart rate resulting from decreased ventricular filling time. Proinflammatory cytokines, which are activated in the stress response, reduce the available serotonin, which leads to not only depression but also to increased platelet aggregation and ultimately coronary artery occlusion (Kubzansky & Kawachi, 2000).

### Prognostic Models to Predict End of Life in Heart Failure

Clinicians and researchers have attempted to address HF's prognostic uncertainty by developing prognostic models. Three of the better known models are a prognostic indicator model from the United Kingdom; a registry posthospital model developed by O'Connor et al. (2008); and the Seattle Heart Failure Model (SHFM). It is interesting to note that all three models use data that are easily available in the clinical setting and could be used by the nurse to assess his or her patients.

The National Health Service in the United Kingdom uses a prognostic model with three items ([www.gold-standardframework.org.uk](http://www.gold-standardframework.org.uk)).

- The clinician is first instructed to ask him- or herself, “Would I be surprised if this patient were to die in the next few months, weeks, or days?”
- The second item asks whether the patient shows signs of decline such as deterioration in physical or cognitive status or refusal of active care.
- The third item uses many of the same clinical indicators as the O'Connor and SHFM models such as NYHA class, symptoms at rest despite optimal treatment, renal impairment, low systolic blood pressure, cachexia, or recent IV inotropes.

This model has predictive power in other comparable EOL populations, such as renal (Moss et al., 2008) and cancer patients (Moss et al., 2010). It is currently being studied in HF populations (Boyd & Murray, 2010).

The second prognostic model was developed using the OPTIMIZE-HF registry data. O'Connor et al. (O'Connor et al., 2008) identified factors that predicted early posthospital mortality. Their analysis indicates that the following factors were predictive of both posthospital mortality and rehospitalization. The factors were as follows:

- Age
- Kidney, liver, or pulmonary (both reactive and obstructive) compromise
- Low systolic blood pressure, serum sodium, or admission weight
- Depression

The third model, the SHFM, was developed using data from the PRAISE clinical trial to predict survival of HF patients, not mortality like the previous two models. Its primary purpose is as an aid to decision making in transplantation and other advanced therapies. Demographic and clinical characteristics such as age, gender, NYHA class, ischemic etiology, ejection fraction (EF), systolic blood pressure, lab



values, and pharmaceutical use are entered into the online tool, which will then provide an estimate of survival, allowing for comparisons between different types of interventions and procedures. When populated with these data, the model gives survival and mortality rates at 1, 2, and 5 years as well as mean life expectancy (Levy et al., 2006). However, the SHFM has limited application in PC prognostication, as it can overestimate survival. Bakitas et al. (2013) conducted a retrospective chart audit of HF outpatients and found that the SHFM predicted median survival time at 2.8 years in their sample when the actual median survival time was 21 days. This suggests that the SHFM should be used with caution in PC populations.

## ■ PATHOPHYSIOLOGY OF HEART FAILURE

HF generally results from more than one factor. Cardiac overload, injury, genetics, and changes in the neurohormonal, inflammatory, and biochemical profile all interact to impact the heart (Braunwald, 2008). Development of HF results from both structural changes and neurohormonal compensatory mechanisms, which in turn lead to progression of HF in a downward spiral.

### Structural Changes in Heart Failure

Structural heart changes that contribute to HF result from cellular and mechanical cardiovascular abnormalities. HF can be classified according to two different types of pathophysiology that lead to similar symptoms. Systolic HF is caused by impaired ventricular contractility and is characterized by a low EF (less than 40%, normal 55%–60%). Contrasting with this, diastolic HF has a normal or near normal EF and impaired ventricular filling because the heart muscle cannot relax during diastole. Both types of HF are associated with poor cardiac output.

A variety of pathophysiologic mechanisms contribute to LV hypertrophy, which is the structural change responsible for diastolic HF. LV hypertrophy is a common consequence of prolonged HTN. Increased afterload in the aorta and high systemic vascular resistance compromise compliance of the ventricles, leading to problems with cardiac relaxation and filling, which is the underlying problem in diastolic HF. Changes in myocyte shape, size, and number, as well as the development of interstitial fibrosis, also contribute to hypertrophy (Yancy et al., 2013). These changes increase LV wall thickness causing septal hypertrophy and a reduction of diastolic compliance (Abete et al., 2012).

LV dilation and myocardial weakening are structural changes that commonly cause systolic HF. After cardiac injury, such as AMI, the damaged and weakened heart muscle dilates and fills with more blood in an attempt to compensate for its lower cardiac output. This leads to higher volumes and pressures in the heart. The end result of these pressure and volume changes in the LV is known as cardiac remodeling. In cardiac remodeling, the LV becomes more spherical, increasing the hemodynamic stresses on the chamber wall, decreasing mechanical performance and increasing the likelihood of mitral regurgitation (Yancy et al., 2013). The ventricle takes on a spherical instead of an elliptical shape as a dynamic of the Starling Law. This law maintains that if the myocardial fibers can be stretched by increased volume of blood within it, the force of contraction will be greater and the ventricle will more completely empty (Moser & Riegel, 2008). Over time, further remodeling occurs leading to increased disease progression.

Valvular malfunction can lead to both systolic and diastolic HF. This occurs because of either pressure overload associated with stenosis (valvular narrowing) or volume overload associated with regurgitation (valvular leakage). In stenosis, the heart valves become calcified, leading to narrowing of the valve diameter and increasing the pressure load on the heart chamber behind the valve. Stenosis is most often seen in the aortic valve and slowly progresses in severity. Volume overload, which is present in valvular insufficiency or regurgitation, most often occurs in the mitral and aortic valves. This condition also progresses insidiously, unless there is an associated acute cause, such as endocarditis, papillary muscle or chordae tendineae rupture, or interventricular rupture following a myocardial infarction (Moser & Riegel, 2008).

### Neurohormonal Changes in Heart Failure

Poor cardiac output, in both systolic and diastolic HF, triggers acute compensatory neurohormonal mechanisms (Dávila, Núñez, Odreman, & Mazzei de Dávila, 2005). These compensatory responses include the innervations of the sympathetic nervous system (increased heart rate), increased inotropy (increased contractile state in viable myocardium), arteriolar constriction to maintain vital organ perfusion, and activation of the renin–angiotensin–aldosterone system (RAAS) to maintain cardiac output. This occurs due to the vasoconstriction effects of angiotensin II and through volume expansion effects of aldosterone that promote retention of sodium and water. In the acute phase, these compensatory mechanisms attempt to maintain adequate cardiac output and vital organ perfusion, which would be appropriate in an acute state such as shock. However, when

poor cardiac output becomes chronic, each of these mechanisms leads to detrimental consequences for the patient. Chronic neurohormonal activation is another cause of HF symptoms and worsening heart function over time because ventricular remodeling develops in response to these chronic neurohormonal influences. When neurohormonal response and ventricular remodeling occur, the result is myopathy, which is a response to the increased afterload and fluid retention. Ventricular filling pressures (preload) increase further, the myocardial fibers overstretch, the mechanism of Starling's Law fails, cardiac output is compromised, and the increased pressure in the left ventricle backs up into the pulmonary vasculature. The heart can no longer meet the metabolic needs of the body for oxygen delivery to the tissues, and systolic hypoperfusion, severe vasoconstriction (increased afterload), and poor pump performance occur.

Inflammation, oxidative stress, and chronic neurohormonal activation are under current investigation as unique stressors to the myocardium potentially contributing to ongoing cardiac damage, even in the absence of new cardiac events (Braunwald, 2008). C-reactive protein, tumor necrosis factor- $\alpha$  (TNF- $\alpha$ ), and interleukins 1, 6, 18 are all inflammatory markers that appear to have direct adverse effects on the myocardium through myocyte apoptosis (programmed cell death) and necrosis (traumatic cell death). Oxidative stress, or the imbalance between reactive oxides and antioxidant defense mechanisms, damages cellular proteins, causing myocyte apoptosis and necrosis as well. This is characterized by elevated levels of norepinephrine, angiotensin II, aldosterone, endothelin-1, and arginine vasopressin arising from the activation of the sympathetic nervous and RAAS. Current drug therapies target many of these mechanisms to slow the progression of HF and decrease symptom burden. The study of biomarkers to identify anticipated patterns of HF progression and prognosis is another rapidly evolving field that may have important implications for PC. The expert clinician will keep up to date on the latest research and clinical practice guidelines.

## ■ CLINICAL SIGNS AND PRESENTING SYMPTOMS IN HEART FAILURE

### Clinical Signs of Heart Failure

HF can be due to either systolic or diastolic dysfunction but generally most patients will have varying forms of both dysfunctions (Yancy et al., 2013). Systolic dysfunction, also known as HF with reduced EF (HFrEF), is measured by the left ventricular ejection fraction (LVEF). Normal EF is approximately

60%, but in systolic HF, the EF is usually less than 40%. In end-stage systolic HF, the EF can be as low as 15% to 20% or less. Common causes of HFrEF are ischemic and valvular heart disease and cardiomyopathy. Diastolic HF, also known as HF with preserved EF (HFpEF), occurs when the EF is normal but ventricular relaxation and filling are compromised (Udelson, 2011). This leads to a lower stroke volume (amount of blood pumped to the body with each cardiac contraction), reducing cardiac output, especially with exertion. Because blood cannot move forward through the heart, it backs up into the pulmonary vasculature, which causes dyspnea and edema.

HFpEF accounts for approximately 20% to 50% of all cases of HF and is commonly seen in older women who are obese with HTN and DM (Yancy et al., 2013; Udelson, 2011). It is important to note that in the aging process, the relaxation of the heart in diastole is sometimes delayed, which causes a decrease in the filling time (Westenbrink, Damman, Rienstra, Maass, & van der Meer, 2012). While the treatment is often different for these two types of HF, you cannot determine on examination or history of symptoms whether a patient has preserved or reduced EF. The most accurate method of determining the type of HF is echocardiography; some diagnostic clues are identified in Table 13.2.

HF has been historically classified according to the side of the heart that is affected. It is important to understand that the right ventricle and the left ventricle are independent of each other, yet they are connected through the pulmonary vasculature. To function effectively, both ventricles must maintain equal outputs. Unless the patient has a history of chronic lung disease, the left ventricle is usually the first to become dysfunctional as the left ventricle must generate higher pressures to pump blood to the systemic circulation.

Right ventricular (RV) failure is generally the result of increased pulmonary pressure. This increased pressure can be due to chronic lung disease, pulmonary emboli, or left-sided HF. The clinical signs are those associated with increased systemic venous pressure with dependent peripheral edema or engorgement of the liver and mesenteric vasculature. Although HF may initially be either right- or left-sided, in end-stage HF it is generally biventricular.

It is important for clinicians to understand and be able to identify the symptoms of both right and left HF as treatment often differs. A patient may have typical right or left HF symptoms, but often in patients with end-stage heart disease combined symptoms occur. In Table 13.3, the symptoms of both RV and LV failure are outlined. The severity and progression of the symptoms are dependent on the extent of the failure and the type of dysfunction.



**TABLE 13.2 Characteristics of Patients With Diastolic (HFpEF) Versus Systolic HF (HFrEF)**

Characteristic	Diastolic HF (HFpEF)	Systolic HF (HFrEF)
Age	Elderly	All ages (50–70 years)
Sex	Frequently female	Often male
Ejection fraction	Normal or elevated	40% or less
Hypertension	Usually present	Often present
Diabetes mellitus	Usually present	Often present
Previous heart attack	Occasionally present	Usually present
Obesity	Usually present	Occasionally present
Chronic lung disease	Often present	Not present
Sleep apnea	Often present	Often present
Chronic renal disease	Often present	Not present
Atrial fibrillation	Occasionally present	Occasionally present

HF, heart failure; HFpEF, heart failure with preserved ejection fraction; HFrEF, heart failure with reduced ejection fraction.

Source: From Jessup and Brozena (2003).

## Presenting Symptoms in Heart Failure

According to the ACC/AHA guidelines (Yancy et al., 2013), patients with HF usually present in three ways:

- A recent syndrome of decreased exercise tolerance, usually due to dyspnea and/or fatigue. In this case, it is important for the provider to ascertain whether these symptoms represent HF or another condition such as pulmonary disease

- Fluid retention with complaints of leg edema or abdominal bloating
- With or without any symptoms of another cardiac or noncardiac disorder, such as DM, abnormal heart sounds, abnormal EKG, arrhythmia, HTN/hypotension, AMI, pulmonary emboli/other systemic thrombosis, or a chest x-ray that has evidence of cardiac enlargement

Dyspnea is the initial manifestation of HF in most patients. This occurs as hypoxemia as low cardiac output ensues. At first, this may be a subtle change, but as the condition progresses, this is the most common presenting symptom, especially in left-sided HF. As the LV fails, blood backs up to the left atrium and the pulmonary veins. As pressure rises in the pulmonary vasculature, blood moves into the alveoli and pulmonary edema occurs. Orthopnea and paroxysmal nocturnal dyspnea increase and often patients have to sleep in upright positions to rest. A dry or nonproductive cough is another common HF symptom, which can often be attributed to another cause (postnasal drip or cough from angiotensin-converting enzyme inhibitor [ACEI] medication). When fulminate pulmonary edema occurs, there is pink frothy expectorant and a feeling of “suffocating” or “drowning.”

Fatigue increases as HF progresses. Patients often report the inability to “do what they used to do.” Activity tolerance decreases and the smallest of tasks

**TABLE 13.3 Signs and Symptoms of Left and Right Heart Failure**

Left Heart Failure	Right Heart Failure
<ul style="list-style-type: none"> <li>■ Dyspnea, orthopnea, paroxysmal nocturnal dyspnea</li> <li>■ Pulmonary edema</li> <li>■ Dry cough</li> <li>■ S3, S4</li> <li>■ Fine crackles, wheezing</li> <li>■ Fatigue</li> <li>■ Hypoxemia</li> </ul>	<ul style="list-style-type: none"> <li>■ Abdominal pain/bloating</li> <li>■ Jugular vein distention</li> <li>■ Peripheral edema</li> <li>■ Hepatojugular reflex</li> <li>■ Liver engorgement (increased liver function tests)</li> <li>■ Splenomegaly</li> <li>■ Significant, recent weight gain of greater than 2 lbs/day</li> </ul>

can be overwhelming. Cachexia and malnutrition are also seen and muscle mass diminishes. Patients are often too tired to eat and say that it “takes too much energy” (which it does as eating increases myocardial oxygen demand). These men and women become frail and often have a low albumin level that only adds to their overall peripheral edema. The cardiac output becomes so low that the gut does not get adequate perfusion and becomes hypoxic. An oxygen-deprived gastrointestinal system does not function efficiently, which contributes to anorexia, early satiety, additional cachexia, and weight loss. In HF, blood flow to the kidneys decreases, reducing urinary output and compromising the effectiveness of diuretics. Renal insufficiency and eventually renal failure occurs in many cases as the creatinine rises and the patient and family are faced with the decision as to whether renal replacement therapy should be initiated. When oliguria and anuria occurs, fluid retention increases and peripheral edema and pulmonary edema become more pronounced. Eventually, cardiogenic shock occurs with marked hypoperfusion of poorly oxygenated blood to the tissues, which causes metabolic acidosis and death. HF should always be ruled out in patients who present with recurrent pulmonary infections, individuals with frequent exacerbations of COPD, and elders who experience acute confusion.

### ■ CLINICAL ASSESSMENT IN HEART FAILURE

According to the practice guidelines by the ACC/AHA (Yancy et al., 2013) the causal mechanism of the patient’s HF should be determined. Some conditions that lead to LV dysfunction are treatable and can be reversed. Measurement of brain natriuretic peptide (BNP) can be helpful in confirming the diagnosis of HF. BNP is a naturally occurring cardiac neurohormone secreted by the ventricular membrane in response to volume expansion and pressure overload. Its other functions are to regulate vascular tone and extracellular volume status as well as to counteract the effects of the RAAS. BNP is elevated in the failing heart when ventricular stretching occurs. BNP can be used to help differentiate between HF and chronic fibrotic lung changes, or an exacerbation of chronic obstructive pulmonary disease (COPD), which can present similarly. Therefore, BNP levels should be ordered when it is unclear as to the cause of presenting symptoms. A negative value of BNP is under 100 pg/mL and BNP trends are effective in showing changes in fluid status over time or in response to therapies. The finding of a BNP of less than 25 pg/mL is good evidence of the absence of HF. An alternative lab assay is NT-proBNP—inactive fragment of BNP,

negative value is under 300 pg/mL; less than 70 pg/mL is normal (Daniels & Maisel, 2007).

The clinical assessment of HF begins with a thorough history and physical, and with the assessment of the following conditions or comorbidities: HTN, DM, dyslipidemia, valvular heart disease, CAD, peripheral vascular disease (PVD), cardiomyopathy, rheumatic fever, sleep-disordered breathing, exposure to cardiotoxic medication (chemotherapy regimens; especially anthracyclines, herceptin, cyclophosphamide), current or past alcohol consumption, smoking, collagen vascular disease, thyroid disorder, obesity, pheochromocytoma, and exposure to sexually transmitted diseases. A family history should be taken with a focus on premature CAD in a first-degree relative, sudden cardiac death, conduction system problems, cardiomyopathy, and history of strokes or PVD. Recent recommendations involve assessing the family history for three generations.

The goal of the targeted HF assessment is to determine the type (right, left, and biventricular), severity, and progression of the HF. HF assessment includes cardiac, pulmonary, integumentary, and gastrointestinal systems as well as functional, symptom, self-care, and psychosocial/spiritual status assessments (Table 13.4).

### Cardiac Assessment

Assessment of the heart rate and rhythm are essential to determine whether there are any dysrhythmias that are compromising the function of the heart. Arrhythmias are common in advanced HF and may contribute to symptoms such as fatigue. The pulse is usually the initial response to decreased cardiac output. In HF, the pulse is often weak, or pulsus alternans may be present due to the altered function of the left ventricle. This is exhibited by strong beats, alternating with weak beats with a regular heart rhythm and low-voltage QRS complexes on the EKG.

On palpation of the chest wall, the point of maximum impulse (PMI), which normally is at the fifth intercostal space, midclavicular line, will be displaced laterally to the left toward the axilla. This displacement is due to the enlarged hypertrophied left ventricle. In HF patients, a third heart sound (S3) is often the first clinical sign of HF and is highly specific. This is caused by the overfilling of the ventricle and reduced cardiac output. A fourth heart sound (S4) may also be heard, which may indicate chronic ischemic disease and lack of ventricular compliance. While the S4 may be present in HF, it may also be a normal finding in some older adults. It is also important to be alert for murmurs, which indicate valvular malfunction or septal defects. A systolic murmur is common in systolic HF with LV dilation and fluid



TABLE 13.4 Heart Failure Assessment

Assessment Domain	Assessment Parameters	Indicators of HF
Cardiac assessment	<ul style="list-style-type: none"> <li>■ Palpate rate and rhythm</li> <li>■ Auscultate heart sounds</li> <li>■ Palpate the chest wall</li> <li>■ Inspect jugular pressure</li> </ul>	<ul style="list-style-type: none"> <li>■ Dysrhythmias</li> <li>■ S3, murmurs</li> <li>■ Displaced PMI</li> <li>■ Increased JVD</li> </ul>
Pulmonary assessment	<ul style="list-style-type: none"> <li>■ Auscultate lung sounds</li> </ul>	<ul style="list-style-type: none"> <li>■ Crackles, pleural effusions</li> </ul>
Integumentary assessment	<ul style="list-style-type: none"> <li>■ Palpate skin</li> </ul>	<ul style="list-style-type: none"> <li>■ Dependent edema</li> <li>■ Venous stasis</li> <li>■ Cool, clammy skin</li> </ul>
Gastrointestinal assessment	<ul style="list-style-type: none"> <li>■ Palpate abdomen</li> </ul>	<ul style="list-style-type: none"> <li>■ Liver, spleen enlargement</li> <li>■ Hepatojugular reflux</li> <li>■ Ascites</li> </ul>
Functional status assessment	<ul style="list-style-type: none"> <li>■ Interview for               <ul style="list-style-type: none"> <li>– Ambulation</li> <li>– Activity level</li> <li>– Self-care</li> <li>– Intake</li> <li>– Level of consciousness</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>■ Reduced to bedbound</li> <li>■ Normal with effort to reduced</li> <li>■ Assistance needed to total care</li> <li>■ Reduced to minimal</li> <li>■ Full to confused</li> </ul>
Symptom status assessment	<ul style="list-style-type: none"> <li>■ Interview for               <ul style="list-style-type: none"> <li>– Number of symptoms</li> <li>– Severity of symptoms</li> <li>– Distress caused by symptoms</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>■ Fatigue</li> <li>■ Dyspnea</li> <li>■ Decreased activity levels</li> </ul>
Self-care status assessment	<ul style="list-style-type: none"> <li>■ Interview for               <ul style="list-style-type: none"> <li>– Medication, dietary, daily weight patterns</li> <li>– Symptom response</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>■ Decreases in self-care</li> <li>■ Increasing symptoms and/or fluid imbalance despite adequate self-care</li> </ul>
Psychosocial/spiritual status assessment	<ul style="list-style-type: none"> <li>■ Interview for               <ul style="list-style-type: none"> <li>– Psychological distress/adjustment</li> <li>– Family resources/needs</li> <li>– Spiritual needs</li> <li>– Advanced care planning</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>■ Increasing distress as condition progresses</li> </ul>

JVD, jugular vein distention; PMI, point of maximum impulse.

overload, becoming more pronounced when fluid overload increases LV pressures, dilating the mitral valve (Leier & Chatterjee, 2007b).

Jugular venous pulses can estimate the central venous pressure and should be examined in the right internal jugular vein while the patient is positioned supine at a 30° to 45° angle. If the jugular vein is distended, it indicates RV failure and fluid overload. The hepatojugular reflex should also be elicited and is done by pressing on the right upper quadrant of the abdomen. With engorgement of the liver in right HF, the compression of the abdomen fills the jugular vein, causing increased jugular vein distention (JVD; Leier & Chatterjee, 2007a). Assessing daily weight patterns and changes from the “dry weight” will also provide information about fluid retention related to cardiac dysfunction. These are key findings of HF and usually indicate a need for additional diuretic therapy.

## Pulmonary Assessment

When pulmonary pressures are elevated, the hydrostatic pressure within the pulmonary capillaries surrounding the alveoli is elevated. This occurs as the left ventricle fails and causes backward flow. This increased pressure causes transudation of the fluid within the capillary into the alveoli. Dyspnea increases as fluid accumulates in the alveoli (pulmonary edema), oxygen saturation decreases, and the patient feels as if he or she is drowning.

The accumulated fluid can be heard when the patient inspires as “crackles.” These crackles do not clear with coughing and are initially heard in the dependent portions of the lung. As pulmonary pressures continue to rise with left HF, these breath sounds can be heard throughout both lung fields. It is important to note that some people with HF do

not exhibit pulmonary crackles when fluid volume is elevated, as their pulmonary lymphatic drainage has increased to compensate for this chronic condition (Leier & Chatterjee, 2007b). Pleural effusions may also be present.

### **Integumentary Assessment**

Dependent edema is a hallmark sign of right and biventricular HF. Edema is felt in dependent areas such as in the hips, legs, ankles and feet, or in the sacral area for those who are bedridden. It is important to accurately assess the extent of the edema by looking for pitting beginning at the ankle and continuing up the leg, thigh, and even hip if necessary until it is no longer seen. Extensive edema is often accompanied by weeping of the tissue and scrotal edema in men. Extensive edema is also accompanied by decreased mobility, as the weakened patient struggles to lift his or her fluid-filled legs. This edema may lead to stasis dermatitis, hyperpigmentation, and ulceration. The temperature of the skin is also very helpful in assessing cardiac output. Cool, clammy, or diaphoretic skin is an indicator of peripheral vasoconstriction, which is a sign of increased sympathetic nervous system response, a compensation for decreased cardiac output.

### **Gastrointestinal Assessment**

As mentioned in Table 13.3, liver enlargement occurs with right or biventricular HF due to venous congestion. The engorged liver can be felt below the right costal margin of the ribs. In advanced HF, the spleen can also be palpated below the left costal margin. End-stage HF may also result in ascites that can contribute to dyspnea, abdominal discomfort, and decreased mobility.

### **Functional Status**

In end-stage heart disease, symptoms of biventricular failure such as dyspnea, weakness, fatigue, and pain are present. It is important for health care providers to evaluate the impact of these symptoms on daily function by doing patient interviews or questionnaires at every visit. The Palliative Performance Scale (PPS; Anderson, Downing, Hill, Casorso, & Lerch, 1996) is an easy to use assessment of functional status. The clinician interviews the patient or caregiver, asking about the patient's ambulation, activity level, self-care practice, oral intake, and level of consciousness. Information from each of the items is recorded and the clinician then assigns a score that has been shown to be predictive of survival (Morita, Tsunoda, Inoue, & Chihara, 1999). The PPS identifies not only

changes in condition but also potential care needs. More information on the PPS is available at [www.eperc.mcw.edu/EPERC/FastFactsIndex/ff\\_125.htm](http://www.eperc.mcw.edu/EPERC/FastFactsIndex/ff_125.htm).

### **Symptom Status**

Patients' self-report is the gold standard for symptom assessment. The symptoms of HF are often associated with inflammatory and neurohormonal activation (Goodlin, 2009). HF symptoms commonly experienced are fatigue, dyspnea, and decreased activity levels. Older HF patients also commonly have symptoms associated with geriatric syndromes such as osteoarthritic pain. While NYHA status is often used to assess for and track patient's symptom status, clinician and patient reports do not correlate well. A better instrument is the widely used Edmonton Symptom Assessment Scale (ESAS; Chang, Hwang, & Feuerman, 2000). The ESAS assesses for pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being, and dyspnea using a 0 to 10 visual analog scale. The clinical interview can identify which factors precipitate, worsen, or improve each symptom.

### **Self-Care Status**

Self-care is a key in maintaining the HF patient's status at home and is critical to health promotion and rehabilitation. Self-care involves adhering to the plan of care, monitoring symptom status, and then responding in an appropriate way to symptoms when they occur (Riegel, Lee, & Dickson, 2011). However, many HF patients have difficulty with self-care due to cognitive changes, decreasing activity levels, lack of family support, and the complexity of the self-care regimen itself. The clinical interview should explore such issues as medication use, dietary intake, and daily weight patterns followed by questions assessing for correct responses to changes in weight or increasing shortness of breath. This is a good time to use motivational interviewing techniques to encourage adherence, provide education, and support successful practices.

### **Psychosocial/Spiritual Status**

A hallmark of quality PC is the assessment of the psychological, social, and spiritual/existential aspects of care (National Consensus Project for Quality Palliative Care, 2013). Particular areas for assessment involve taking a psychological history and assessing for reaction to the current condition, indicators of distress, family structure and function, strengths and vulnerabilities, caregiving needs, access to community services and resources, and advanced care planning. It



should also include a spiritual assessment, which has been mandated by The Joint Commission since 2001. One spiritual assessment tool is the FICA developed by Puchalski, Lunsford, Harris, and Miller (2006). Using the acronym *FICA*, the clinician assesses for faith or belief systems, important influences in the person's life, community support, and addressing the issues in the person's health care. Other instruments specific to the assessment of individuals with end-stage disease are available at TIME: Toolkit of Instruments to Measure EOL care, available at [www.chcr.brown.edu/pcoc/toolkit.htm](http://www.chcr.brown.edu/pcoc/toolkit.htm)

In addition to the complete physical examination needed for patients with HF, the following diagnostic studies may be indicated:

1. Complete blood count (CBC), urinalysis
2. Serum electrolytes, glycohemoglobin, lipid profile, blood urea nitrogen (BUN), creatinine, liver function tests, magnesium, calcium
3. Fasting transferrin saturation (to rule out hemochromatosis, or the cause of cardiomyopathy)
4. BNP or NT-proBNP
5. Chest x-ray and 12-lead EKG (should not be used as a primary determinant of cause of HF)
6. Thyroid studies (especially in those with atrial fibrillation and unexplained HF)
7. Transthoracic Doppler—two-dimensional echocardiography (most relevant diagnostic test)
8. Noninvasive stress testing (in patients with a previous history of myocardial infarction)
9. Cardiac catheterization in patients with angina or large areas of ischemic myocardium
10. MRI may need to be done to determine myocardial viability and scar tissue

## ■ HEART FAILURE MANAGEMENT

### Disease Management Guidelines in Heart Failure

The management of patients with cardiovascular disease is now widely based on the latest ACC/AHA guidelines (Exhibit 13.2). These guidelines were developed after reviewing multiple, large-scale studies. Most HF patients have other cardiovascular diseases so reviewing related guidelines may be helpful in HF management. While there are certainly principles to guide the management of patients with HFpEF, there are no specific guidelines or clear recommendations. So take note that most of the medication and device recommendations described in this chapter are specifically for patients with HFrEF.

## ■ GENERAL MEDICATION GUIDELINES FOR PATIENTS WITH HEART FAILURE WITH REDUCED EJECTION FRACTION

General medication guidelines for patients with HFrEF in Stages B through D and the landmark trials support the use of the following:

1. **Diuretics** with salt restriction are the mainstay for patients with fluid overload. Loop diuretics or thiazides are most often used.
2. **ACEIs**, based on the CONSENSUS, SOLVD, and ATLAS trials, are a key component in the treatment of HF antagonizing the RAAS. They have been shown to promote disease regression, symptom improvement, and decreased mortality.
3. **Angiotensin receptor blockers (ARBs)** are used when the patient is not able to take an ACEI. The ELITE and CHARM-Alternative trials showed that ARBs reduce endpoint mortality and morbidity and improve clinical signs and symptoms.
4. **Aldosterone antagonists**, such as Spironolactone or Eplerenone, were shown in the RALES, EPHESUS, EMPHASIS-HF trials to decrease mortality though they need to be used in conjunction with potassium monitoring due to the risk of hyperkalemia. This potassium-sparing effect is often beneficial when they are used in combination with potassium-wasting diuretics such as furosemide.
5. **Hydralazine and nitrates**, based on V-HEFT trial, are used when patients cannot be on an ACEI or ARB. The A-HEFT trial demonstrated improved mortality and reduced hospitalization rates when added on with other evidence-based therapies in African Americans.
6. **Beta-blockers (BBs)** are a standard of HF care based on the MDC, MERIT-HF, MOCHA, PRECISE, COPERNICUS, COMET, BEST, CIBIS, and CIBIS-II trials. BBs improve mortality and symptoms and prevent hospitalizations in patients with chronic HF. However, they may worsen symptoms initially, and their benefit is long term so they should be initiated and the dose up-titrated when a patient is stable, rather than during an episode of decompensation.
7. **Digoxin** is a positive inotropic medication that improves pump contractility. While it was widely used in the past, its substantial risk profile and limited benefit to long-term patient outcomes has reduced its use currently to those patients in whom other therapies, noted above, have not improved symptoms.

### Exhibit 13.2

#### ACC/AHA Joint Guidelines

Title	Year Published
Management of Patients With Atrial Fibrillation (Compilation of 2006 ACCF/AHA/ESC and 2011 ACCF/AHA/HRS Recommendations)	2013
2012 ACCF/AHA/ACP/AATS/PCNA/SCAI/STS Guideline for the Diagnosis and Management of Patients With Stable Ischemic Heart Disease	2012
2012 ACCF/AHA/HRS Focused Update of the 2008 Guidelines for Device-Based Therapy of Cardiac Rhythm Abnormalities	2012
2012 ACCF/AHA Focused Update of the Guideline for the Management of Patients With Unstable Angina/Non-ST–Elevation Myocardial Infarction (Updating the 2007 Guideline and Replacing the 2011 Focused Update)	2012
2011 ACCF/AHA Guideline for the Diagnosis and Treatment of Hypertrophic Cardiomyopathy	2011
2011 ACCF/AHA Focused Update of the Guideline for the Management of Patients With Peripheral Artery Disease (Updating the 2005 Guideline)	2011
ACCF/AHA 2011 Expert Consensus Document on Hypertension in the Elderly	2011
ACCF/AHA/ACP/HFSA/ISHLT 2010 Clinical Competence Statement on Management of Patients With Advanced Heart Failure and Cardiac Transplant	2010
Guidelines for the Diagnosis and Management of Patients With Thoracic Aortic Disease: Full Text	2010
2009 Focused Update: ACCF/AHA Guidelines for the Diagnosis and Management of Heart Failure in Adults	2009
2009 Focused Update Incorporated Into the ACCF/AHA 2013 Guideline for the Management of Heart Failure	2009
ACC/AHA 2008 Guidelines for the Management of Adults With Congenital Heart Disease: Full Text	2008
ACC/AHA 2008 Guideline Update on Valvular Heart Disease: Focused Update on Infective Endocarditis	2008
ACC/AHA/HRS 2008 Guidelines for Device-Based Therapy of Cardiac Rhythm Abnormalities: Full Text	2008
ACC/AHA/ESC 2006 Guidelines for Management of Patients With Ventricular Arrhythmias and the Prevention of Sudden Cardiac Death—Full Text	2006

### Discussion of Specific Categories of Medications Used in Heart Failure

■ **Diuretics.** Loop diuretics are the preferred class of diuretic, as these high ceiling diuretics promote sodium and water excretion even when renal function is compromised. Loop diuretics provide immediate relief of symptoms associated with fluid overload but should not be used as the only pharmacologic agent. When used on a chronic basis diuretics can increase renin,

magnifying the activation of the RAAS. Therefore, they should be combined with ACEIs (von Lueder, Atar, & Krum, 2013). Common loop diuretics used in HF are furosemide (Lasix), torsemide (Dema-dex), and bumetanide (Bumex). Because loop diuretics cause loss of essential electrolytes (hypokalemia, hypomagnesemia, hyponatremia), ongoing assessment of these lab values is recommended. The determination of the proper initial dose and readjustment of doses requires an ongoing evaluation of symptom



and careful titration based on daily weight and symptom patterns, especially in the older adult. Absorption of loop diuretics in the engorged, poorly perfused gastrointestinal tract is often compromised in the patient with worsening HF and increased diuretic dosages may be necessary (von Lueder, Atar, & Krum, 2013). In end-stage disease, periodic oral metolazone (Zaroxolyn) dosing may be necessary to promote diuresis, especially in patients with renal insufficiency. Metolazone should be used with extreme caution and careful assessment of the patient response, as it may cause overdiuresis, hypotension, and severe hypokalemia.

#### ■ Angiotensin-Converting Enzyme Inhibitors.

ACEIs have been studied extensively over the last 10 years in many large series studies. ACEIs were introduced initially as treatment for HTN. It was felt that since these agents vasodilated the peripheral blood vessels by inhibiting the RAAS, there might be an indication for use in HF. Extensive studies found that not only did these agents decrease afterload and preload as expected, but more importantly had a significant effect on ventricular remodeling. Through the mechanisms of decreasing aldosterone secretion and response of the sympathetic nervous system, symptoms dramatically improved almost immediately. There continues to be concern with hypotension and the use of ACEI, especially in the older adult, and further large-scale studies should be done with patients older than 65 years. Enalapril, one of the earliest ACEIs studied, has been shown to benefit older adults. ACEIs are better tolerated if patients are hydrated and electrolytes are within normal limits. ACEIs should not be used in patients with a history of angioedema or anuria. Also cautious use of ACEIs is warranted in those with high serum creatinine levels (greater than 3 mg/dL), bilateral renal stenosis, high serum potassium levels (greater than 5.5 mmol/L), and those with low systolic blood pressure who are symptomatic (Yancy et al., 2013, 2000). Many patients complain of an irritating dry cough, a common side effect, which is caused by ACEI's ability to increase bradykinin release and can be a major reason for treatment failure.

■ **Angiotensin Receptor Blockers.** These agents block angiotensin II and aldosterone at the receptor level. Hemodynamic effects are the same as with ACEI as far as reducing preload and afterload and increasing cardiac output, but these agents do not increase bradykinin levels, thus diminishing the side effect of cough (Moser & Riegel, 2008). The first of these agents, Losartan, was found to be well tolerated in older patients.

■ **Beta-Adrenergic Blocking Agents.** BB use in patients with chronic HF has been studied in 20

clinical trials with over 10,000 patients. These trials have shown that these agents reduce the risk of sudden death by 40% to 50% and the need for hospital admission, and improve the overall functional capacity (Hunt et al., 2009). The beneficial effects of BB in HF result from the blocking of adrenergic stimulation of the heart, specifically norepinephrine, which in HF is related to increased mortality (Bohm & Maack, 2001). BBs do have a negative inotropic effect, so for many years they were contraindicated in HF patients. In clinical trials, however, it was shown that this decrease in cardiac output was transient; in fact, BBs were shown to increase LVEF. These benefits were found in patients who were receiving therapeutic responses to diuretics and ACEI. Patients with NYHA Class II to IV HF were studied in multiple trials; one trial was able to show the decrease in mortality of 35% (Goldstein, 2001). The studies looking at BB in HF examined three agents: carvedilol, bisoprolol, and metoprolol CR/XL. The CIBIS-I trial found that there was a 34% reduction in hospital admission rates for patients who were on bisoprolol, and many showed improvements in overall QOL (CIBIS, 1994). In the second trial, CIBIS-II, in patients with NYHA Class III and IV HF, there was a 34% reduction in mortality and a 20% reduction in hospital admissions in those treated with Bisoprolol (CIBIS-II, 1999). BBs are contraindicated in patients with bronchospastic disease, advance heart block, or symptomatic bradycardia, and should be used with caution in those with low systolic blood pressure. BBs generally are added with or after ACEIs have been optimized, and the patient is clinically stable and euvoletic.

■ **Aldosterone Antagonists.** Low dose aldosterone antagonists, such as spironolactone (12.5–25 mg/day) or eplerenone, have been found to be helpful in patients with NYHA Class II to IV HF. These agents block aldosterone, which then causes diuresis and decreases preload. Patients, however, should have normal serum potassium levels (less than 5.0 mEq/L) and adequate renal function (creatinine less than 2.5 mg/dL) when taking these, and potassium should be monitored for hyperkalemia.

■ **Digitalis.** Digitalis glycosides, positive inotropic agents, have been a part of the medical regime for patients in HF for over 200 years. These agents are still indicated for use in patients with HFrEF and ongoing symptoms of HF despite already being on optimum doses of ACEIs or ARBs and BBs (Yancy et al., 2013). Patients with mild to moderate HF on digoxin experienced a decrease in the progression of HF and had decreased hospital admissions (28%), but had no overall decrease in mortality (Yancy et al., 2013). Digoxin is also indicated in patients with HF with atrial fibrillation and uncontrolled ventricular

response. However, this drug must be used carefully, monitoring for and preventing digoxin toxicity. Digoxin toxicity may cause arrhythmias, and it is potentiated by low potassium and magnesium levels,

common electrolyte abnormalities in patients with HF due to diuretic use.

The suggested dosing of these medications is as shown in Exhibit 13.3. The titration of each

### Exhibit 13.3

#### Evidence-Based Medications for Heart Failure With Reduced Ejection Fraction

Drug Name	Starting Dose	Target Dose
<b>Vasodilators (ACEI)</b>		
Captopril	6.25 mg 3×/day	50 mg 3×/day
Enalapril	2.5 mg 2×/day	10 mg 2×/day
Lisinopril	2.5–5 mg/day	20 mg/day
Ramipril	1.25–2.5 mg/day	5 mg/day
Fosinopril	2.5 mg 2×/day	20 mg 2×/day
Quinapril	5 mg 2×/day	20 mg 2×/day
Trandolapril	1 mg/day	4 mg/day
<b>Vasodilators (ARB)</b>		
Candesartan	4–8 mg/day	32 mg/day
Valsartan	20–40 mg 2×/day	80 mg 2×/day
Vasodilators (direct acting, a = arterial, v = venous)		
• Hydralazine (a)	25 mg 4×/day	–
• Isosorbide dinitrate (v)	10 mg 3×/day	–
• Isosorbide mononitrate (v)	30–60 mg/day	–
<b>Beta-Blockers</b>		
Carvedilol	3.125→6.25→12.5→25→50 mg	25 mg 2×/day (less than 85 kg) 50 mg 2×/day (greater than 85 kg)
Carvedilol CR	10→20→40→80 mg	80 mg once daily
Metoprolol succinate	25→50→100→150→200 mg	200 mg/day
Bisoprolol	1.25→2.5→5→10 mg	10 mg/day
Nebivolol	1.25→2.5→5→10 mg	10 mg/day
<b>Cardiac Glycoside Therapy</b>		
Digitalis	0.125–0.25 mg/day	0.5 mg/day <sup>a</sup>
<b>Aldosterone Antagonists</b>		
Spironolactone	12.5–25 mg/day (use low dose)	25 mg 2×/day



Drug Name	Starting Dose	Target Dose
Eplerenone	25 mg/day × 4 weeks → 50 mg/day	50 mg/day
Diuretics (Type)	Relative Potency	Note
Furosemide (loop)	40 mg/day	
Bumetanide (loop)	1 mg/day	
Ethacrynic acid (loop)	50 mg/day	Take with/before loop diuretic Used to treat hypertension
Torsemide (loop)	20–40 mg/day	
HCTZ (thiazide)	–	
Chlorthalidone (thiazide)	25–100 mg/day	
Metolazone (thiazide-like)	2.5–5 mg/day	Take with/before loop diuretic Does not inhibit aldosterone Does not inhibit aldosterone
Triamterene	–	
Amiloride	–	

<sup>a</sup>Refer to facility formularies for target dosing of digitalis.

Source: Albert et al. (2013).

medication dose is based on careful evaluation of the patient's tolerance and response.

### Drugs to Avoid in Heart Failure

Three classes of drugs that should be avoided in most HF patients are the following:

1. Antiarrhythmic agents that may lead to cardiodepression and proarrhythmic effects. Only amiodarone and dofetilide have been shown to be safe in patients with HF.
2. Calcium channel blockers should be used with caution because they may lead to increased risk of cardiovascular events and decreased survival.
3. Nonsteroidal anti-inflammatory drugs cause sodium retention and peripheral vasoconstriction, as well as decrease efficacy and increase toxicity of diuretics and ACEI. In addition, they increase the risk of bleeding when used with anticoagulants such as warfarin, a drug widely used in this population. Because this important class of analgesics cannot be safely used in HF, pain management can be challenging in this population.

### Complementary and Alternative Medicine in Heart Failure

People are becoming increasingly interested in holistic modalities in prevention and treatment of disease. Natural treatments, vitamins, herbs, antioxidants, and

other nontraditional (at least to Western or allopathic medicine) therapies are used by many patients to complement or even replace drugs and other interventions. Adjuvant healing modalities can be a benefit to allopathic medicine. There are specific complementary and alternative medicine (CAM) therapies that have shown some efficacy in HF. According to the NHIS 2007, 38.3% of all U.S. adults used some form of CAM in the prior 12 months. A study of older HF patients from eight medical centers found that 93% used over-the-counter (OTC) drugs, while 11.5% used herbal therapies (Albert et al., 2009). While the literature yields no specific information on number of HF patients using all CAM modalities, a breakdown by age of CAM use shows that there is a substantive usage in populations known to be at high risk for HF (Barnes, Bloom, & Nahin, 2008), with the highest use being of biologically based (natural product) therapies.

■ **Evidence-Based Complementary and Alternative Medicine.** According to the National Center for Complementary and Alternative Medicine (NCCAM; one of the institutes of the National Institutes of Health [NIH]) classification of therapies, there is sufficient evidence to warrant considering recommending certain mind–body therapies in HF (Table 13.5).

Spirituality is another mind–body modality used by patients to cope with the uncertainty of HF. Spirituality influences the manner in which a patient adjusts to a chronic illness. Patients with end-stage heart disease often reflect on their past and attempt

TABLE 13.5 Mind–Body Therapies

CAM Modality	Evidence
Exercise and relaxation	<ul style="list-style-type: none"> <li>■ Two randomized, controlled quantitative/qualitative studies (RCT; <math>n = 95</math>, <math>n = 57</math>) of U.S. veterans with moderately severe HF showed significant improvement in QOL measures/ reported emotional improvement after participating in relaxation response interventions (Chang et al., 2004, 2005).</li> <li>■ Two RCTs of older Chinese HF patients (<math>n = 121</math>, <math>n = 59</math>) examined effects of relaxation therapy and found significant improvement in psychological well-being compared to the control group (Yu, Lee, Woo, &amp; Hui, 2007; Yu, Lee, &amp; Woo, 2010).</li> </ul>
Meditation	<ul style="list-style-type: none"> <li>■ RCT (<math>n = 19</math>) of older patients with HF showed significant improvement in the QOL and improved measurements on cardiopulmonary exercise testing (Curiati et al., 2005).</li> <li>■ Clinical trial (<math>n = 23</math>) of older African American patients with HF found improved QOL and measurements on cardiopulmonary exercise testing (Jayadevappa et al., 2007).</li> </ul>
Acupuncture	<ul style="list-style-type: none"> <li>■ RCT (<math>n = 17</math>) of stable HF Class II–III patients found no improvement in cardiac ejection fraction or peak oxygen uptake, but significant improvement in the 6-min walk test and postexercise recovery (Kristen et al., 2010).</li> </ul>
Yoga	<ul style="list-style-type: none"> <li>■ RCT (<math>n = 40</math>) of predominantly African American HF patients showed significant improvement in flexibility, treadmill time, <math>VO_2</math> peak and inflammatory biomarkers compared to controls, and in posttest versus pretest scores (Pullen et al., 2010).</li> <li>■ RCT (<math>n = 19</math>) of Class I to II HF patients showed significantly improved exercise tolerance and inflammatory biomarkers, with a trend toward improvement in QOL (Pullen et al., 2008).</li> </ul>
Tai chi/qi gong	<ul style="list-style-type: none"> <li>■ Systematic review of tai chi (TC) exercise effectiveness for individuals with heart disease summarized evidence of effectiveness in heart disease from three studies (Ng et al., 2012). <ul style="list-style-type: none"> <li>– Evidence suggests TC exercise may improve perceived symptoms, mood, and QOL</li> <li>– Evidence suggests improvement in EF and BNP</li> <li>– Mixed results found an effect on exercise capacity and inflammatory biomarker levels</li> <li>– One study demonstrated improvement in sleep stability (Yeh, Wayne, &amp; Phillips, 2008)</li> </ul> </li> <li>■ RCT (<math>n = 100</math>) of NYHA I–II HF outpatients found TC patients showed significant improvement in QOL, exercise self-efficacy, and mood. However, there were no differences in 6-min walk distance or peak <math>O_2</math> uptake (Yeh et al., 2011).</li> <li>■ Clinical trial (<math>n = 28</math>) found TC reduced somatic subscore on a depression scale but did not significantly reduce fatigue (Redwine et al., 2012).</li> </ul>

CAM, complementary and alternative medicine; HF, heart failure; NYHA, New York Heart Association; QOL, quality of life; RCT, randomized controlled trial.

to nurture hopes for the future. Symptomatic HF patients have been found to have higher depression scores and lower spiritual well-being than patients with advanced cancer, suggesting the need for support in this important area particularly because of links between spirituality and hope (Bekelman et al., 2009; Davidson, Dracup, Phillips, Daly, & Padilla, 2007). Westlake and Dracup (2001) looked at how spirituality affected adjustment in end-stage HF. Eighty-seven patients were interviewed using a semistructured questionnaire, and a three-step process was identified in which they adjusted or came to terms with their illness. The three steps were development of regret regarding past behaviors and lifestyles, the search for meaning within the present experience of HF, and the search for hope and optimism.

Dietary supplements, herbs, and botanicals, as well as traditional medicine formulations, make up the category known as natural products (formerly classified as biologically based). There are varying levels of evidence

to support the efficacy of these products in HF (Table 13.6). In addition to studies into these products, there have been numerous recent calls for additional research on the role of micronutrients in HF and for careful nutritional assessment (Agarwal, Phan, Willix, Barber, & Schwarz, 2011; Alsafwah et al., 2007; Azizi-Namini, Ahmed, Yan, & Keith, 2012; Kamalov, Bhattacharya, & Weber, 2010; Lee et al., 2011; McKeag, McKinley, Woodside, Harbinson, & McKeown, 2012).

## Experimental Treatments

■ **Cardiovascular Regeneration and Cell-Based Therapies.** Regeneration of myocardial cells and activation of myocardial stem cells to replace infarcted myocardial cells has the potential for a positive effect on HF patients but is in the experimental stages (Choi & Poss, 2012). Major advancements over the past decade have occurred in investigating



TABLE 13.6 Natural Products

CAM Modality	Evidence
Dietary supplements	<ul style="list-style-type: none"> <li>■ Systematic review of evidence on studies of micronutrients and HF (McKeag et al., 2012):               <ul style="list-style-type: none"> <li>– <i>Selenium, zinc, and copper</i>—Evidence that patients with HF have lower levels of circulating selenium and zinc and higher levels of copper. Higher selenium levels were associated with O<sub>2</sub> uptake in bicycle stress test</li> <li>– <i>Vitamins A, C, or E</i>—No conclusive evidence they are related to improved outcomes in HF</li> <li>– <i>B vitamins: Thiamine, riboflavin, pyridoxine, B12, and folate</i>—Inconclusive evidence on the role of these in HF</li> <li>– <i>Vitamin D</i> <ul style="list-style-type: none"> <li>■ Evidence that HF patients have lower circulating levels of vitamin D than those without</li> <li>■ Observational study evidence of a relationship between vitamin D status and prevalence and incidence of HF; possible relationship between vitamin D and physical function in HF; possible relationship between vitamin D and prognosis in HF</li> <li>■ Intervention study evidence that higher level of vitamin D supplementation associated with significant increase in levels of IL-10</li> <li>■ Caution that vitamin D supplementation up to 10k units daily is not associated with toxicity, while hypercalcemia and other toxic effects are commonly associated with doses of 50k units or more daily</li> </ul> </li> </ul> </li> </ul>
Herbs and botanicals	<p><i>Crataegus</i> spp. (common name, Hawthorn)</p> <ul style="list-style-type: none"> <li>■ Cochrane systematic review of 10 double-blind RCTs (<math>n = 855</math>) using extract of Hawthorn flower or leaf as an adjuvant therapy to treat patients with NYHA I–III HF (Pittler, Guo, &amp; Ernst, 2008) found that compared to controls               <ul style="list-style-type: none"> <li>– Exercise tolerance significantly increased</li> <li>– Maximal workload improved</li> <li>– Decreased cardiac oxygen consumption observed</li> <li>– Symptoms of shortness of breath and fatigue significantly improved</li> <li>– Adverse events were infrequent, mild, and transient and included dizziness, nausea, cardiac, and GI complaints</li> </ul> </li> <li>■ Systematic review of 24 studies (<math>n = 5,577</math>) with dosage ranging from 160 to 1,800 mg taken over 3 to 24 weeks found a total of 166 AEs reported. Most were mild to moderate including dizziness, nausea, headache, migraine, palpitation, and GI complaints. Eight involving use of the extract LI132 were severe: GI hemorrhage (2), circulation failure (2), erythematous rash (2), and fall (2) (Daniele, Mazzanti, Pittler, &amp; Ernst, 2006)</li> <li>■ Clinical implications of potential interactions: Since clinical trials have shown Hawthorn causes a slight reduction in BP in patients with heart conditions, monitor use in conjunction with antihypertensives. Contains OPCs, which could theoretically reduce absorption of alkaloids and alkaline drugs—take 2 hours away from medication (Mills &amp; Bone, 2005)</li> </ul>
Traditional medicine formulations	<ul style="list-style-type: none"> <li>■ Cochrane systematic review updated in 2012 included nine RCTs (<math>n = 600</math>; Chen, Yao, Chen, Kwong, &amp; Chen, 2012)               <ul style="list-style-type: none"> <li>– Seven of the studies compared Shengmai, a traditional Chinese herbal medication, with standard treatment to standard treatment alone; three studies compared Shengmai to placebo (one did both)</li> <li>– The seven trials reported significant improvement in patients taking Shengmai as opposed to those with standard treatment alone using various outcome measures.</li> <li>– Three RCTs likewise reported significant improvement in patients taking Shengmai as opposed to controls using various outcome measures.</li> <li>– Evidence lacks strength due to poor study quality, small sample sizes, and lack of comparability of outcome measures.</li> <li>– Mild AEs were reported in six patients from three of the studies, generally in the higher dosage cohorts (60 mL/day). They included dry mouth and fidgety (2), mild sleep disorder (2), stomach discomfort, and hypoglycemia (2).</li> </ul> </li> </ul>

AEs, adverse effects; GI, gastrointestinal; HF, heart failure; IL-10, interleukin 10; OPCs, oligomeric procyanidins; RCT, randomized controlled trial.

the mechanisms of action and the clinical application of cell-based therapy for ischemic heart disease. This field is evolving rapidly and large numbers of studies are testing a variety of cell sources, delivery methods, and patient characteristics. These therapies show incredible promise as a treatment to prevent or reverse myocardial remodeling and to promote cell regeneration in the future (Suncion, Schulman, & Hare, 2012).

■ **Xenotransplantation.** In the future, this may become a therapeutic option for those people dying each year of heart, kidney, lung, and liver failure. Xenotransplantation involves the transplantation of nonhuman tissues or organs into human recipients. Xenotransplantation between closely related species, such as baboons or pigs and humans, offers an alternative to allotransplantation as a source of human organ replacement, but problems with rejection remain a major concern (Ekser & Cooper, 2008).

■ **Device Therapies in Heart Failure.** Because pharmacologic agents alone rarely improved QOL and prognosis, especially in those with chronic ventricular dysfunction, recent consideration has been given to device therapies in HF. These therapies include biventricular pacing, implantable cardioverter defibrillators (ICDs), and LV assist devices (LVAD).

■ **Biventricular Pacing or Cardiac Resynchronization Therapy.** Since the early 1990s, there have been numerous approaches to improve LV function in patients with HF by means of cardiac pacing. In the last 10 years, the most promising of these approaches has been biventricular pacing, or cardiac resynchronization therapy (CRT).

Normally, electrical impulses arise in the sinoatrial node of the heart, travel down through the atrioventricular node, to the bundle of His, through the left and the right bundle branches to the Purkinje fibers, where simultaneous depolarization of the atrium and the ventricles occurs. This coordinated conduction enables stroke volume to be maximized. If one or more of these conduction pathways (left bundle or right bundle) is damaged or blocked, the impulse will reach one ventricle before the other, causing asynchrony of the ventricular contraction. When this occurs, it is called intraventricular conduction defect (IVCD). This can be seen in the QRS (measurement of time for ventricular depolarization) of the EKG, which becomes prolonged: more than 120 ms. This IVCD has been found in 30% to 50% of patients with HF (Saxon et al., 1999). These conduction delays cause inefficient ventricular contraction, with segments of the ventricle contracting at different times. Short diastole occurs with overlapping of systole and diastole and cardiac output decreases. If the patient already has a failing left ventricle, this

dysynchrony with decrease in cardiac output leads to further dysfunction and increased symptoms.

The biventricular pacemaker looks like other pacemakers, but it has three leads instead of two. Electrical leads are threaded both to the left and right ventricle, as well as the right atrium. This device provides electrical stimulation that is programmed precisely to synchronize and coordinate the right and left ventricular contraction.

Evidence of the use of biventricular pacing with HF patients in large series clinical trials has been done in the COMPANION, MUSTIC trials, REVERSE (Daubert et al., 2009) and efficacy of this treatment has been well documented (Cleland et al., 2005). Most patients in these trials had NYHA Class II to IV HF, prolonged QRS duration (greater than 150 ms), and were on optimum medical therapy (Saxon et al., 1999). Primary endpoints for these trials were 6-minute walk tests, QOL, and O<sub>2</sub> consumption at peak exercise (Cazeau et al., 2002). Consistently, it was found that there was an almost immediate increase in cardiac output, a positive effect on LV remodeling, and an improvement of diastolic function.

■ **Implantable Cardiac Defibrillators and Cardiac Resynchronization Therapy in Combination.** Sudden death occurs in 30% to 59% of patients in NYHA Class IV (Cazeau et al., 2002). Because of these alarming statistics, the role of combining implantable cardiac defibrillators (ICDs) and CRT devices in chronic HF patients has been investigated. ICD implantation is a lifesaving option for the patient who has a substrate for sudden cardiac death due to lethal ventricular arrhythmia. In the VENTAK CHF, Insync ICD, and COMPANION MADIT-CRT and MIRACLE ICD trials, both of these devices were investigated (Barsheshet et al., 2011; Dresing & Natale, 2001; Young et al., 2003). The results of these studies in primary reports have indicated an improvement of symptoms, increased QOL, and decreased incidence of sudden death. The efficacy of biventricular pacing and ICDs in patients with HF and IVCDs in the general HF population is now a proven therapy and a lifesaving device in those patients who meet criteria for placement. However, ICDs and/or CRT are considered of uncertain benefit to patients with advanced frailty, multiple comorbid conditions, and high risk for nonsudden death as are usually seen in PC settings (Yancy et al., 2013).

■ **Left Ventricular Assist Devices.** These mechanical devices are percutaneous or implanted into the abdomen or chest of the recipient. Left ventricular assist devices (LVADs) are attached to a weakened heart to assist with pumping. LVADs were first used as a bridge therapy to help keep heart transplant candidates alive while they waited for a donor heart. LVADs are now considered as destination therapy or an alternative to



transplantation. Implanted heart pumps can significantly extend and improve the lives of some people with end-stage HF who are not eligible for or able to undergo heart transplantation. There is now evidence that mechanical circulatory support, such as LVADs, is considered reasonable in carefully vetted end-stage HF patients to improve survival, functional capacity, and QOL (Yancy et al., 2013). The Randomized Evaluation of Mechanical Assistance for the Treatment of Congestive Heart Failure (REMATCH) trial evaluated the survival benefit of this implanted left heart pumping device after 2 years and found that there was significantly more improvement in QOL than in those patients who were receiving optimal medical therapy (52% vs. 25%; Stevenson et al., 2004). However, there are serious side effects of this device, which include infection, bleeding, and stroke. LVAD implantation is generally not recommended for use in PC but it is required by CMS that all LVAD recipients be referred to PC for symptom management and decision-making support (Swetz et al., 2011).

### Evidence for Heart Failure Management

The evidence in the literature is robust regarding the management of HF patients. In particular, there are multiple, relatively recent meta-analyses, considered the strongest evidence, describing effective HF systems of care, treatment recommendations, and communication principles. Included in Table 13.7 is a selection of these recent HF meta-analyses.

In addition to the meta-analyses, there are many evidence-based clinical trials as to the appropriate treatment

of end-stage HF. Recently completed or ongoing clinical trials are COACH, I-PERSERVE, CUPID, PAIN-HF, UPSTEP, PEP-HF, CHARM, SENIORS, TOPCAT, PARADIGM-HF, ALDO-HF, PREVENT-HF, DOT-HF, OptiLink, EMPHASIS-HF, DOSE, CARRESS-HF, RELAX-HF trials, and OPTIMIZE-HF and ADHERE registries. Information on these clinical trials can be accessed from the Internet by searching for the name of the particular trial. The most recent clinical trials can be accessed on [www.clinicaltrials.gov](http://www.clinicaltrials.gov). When reviewing the evidence from these clinical trials, remember to assess the patient sample. Ask whether the clinical trial sample is reflective of the HF population in your practice. While it is important to keep up with the current state of the HF science, there are also structured guidelines that have been developed from the most recent and strongest clinical trials. HF care, unlike some other conditions, is guideline driven.

### Acute Decompensated Heart Failure Management

Guidelines are lacking for the management of acute decompensated HF (ADHF), so therapy is based on the best available clinical research and expert consensus. When patients develop signs and symptoms of HF, they often need to be hospitalized. Hospitalization is typical when a patient is first diagnosed with HF. However, readmission of patients who already have been diagnosed with HF is extremely common, usually due to fluid overload. Many of these rehospitalizations are preventable through close outpatient follow-up and self-care. Recent changes in hospital reimbursement guidelines have made this a

**TABLE 13.7 Recent Heart Failure Meta-Analyses**

Meta-Analysis Topic	Citation	Findings
Preventing HF hospital readmission	Benbassat and Taragin (2013)	<i>n</i> = 99 systematic reviews of RCTs, disease management programs significantly reduce hospital readmissions
Effectiveness of disease management in HF	Takeda et al. (2012)	<i>n</i> = 25 RCTs, case management nurses reduce mortality and readmission rates
Telemonitoring interventions	Inglis, Clark, McAlister, Stewart, & Cleland (2011)	<i>n</i> = 25 papers/five published abstracts, telemonitoring reduces risk of mortality and rehospitalization, improves quality of life, reduces costs
Efficacy of BNP-guided therapy	Li, Luo, & Chen (2013)	<i>n</i> = 11 RCTs, BNP-guided therapy reduces mortality and rehospitalization, particularly in younger or higher BNP patients
Efficacy of different beta-blockers in reduced ejection fraction HF	Chatterjee et al. (2013)	<i>n</i> = 21 RCTs, beta-blockers provide mortality benefits as a class effect, no superiority of a single agent over another
EOL discussions in HF	Barclay et al. (2011)	<i>n</i> = 23 papers, EOL conversations rarely take place because of prognostic uncertainty

BNP, brain natriuretic peptide; EOL, end of life; HF, heart failure; RCT, randomized controlled trial.

critical issue. Earlier referral to PC is one solution to the burgeoning problem of repeat HF admissions.

The primary goal for HF-related hospitalization is to relieve symptoms, particularly congestion. Determining the etiology of the HF and EF will help determine what therapies are initiated. Another key goal while in the hospital is to identify and address precipitating factors for the decompensation such as poor adherence to medications or diet and fluid recommendations, poor social support or financial resources, lack of self-care education, or inadequate medical regimen prior to admission, as well as medical conditions such as atrial fibrillation, worsening renal function, HTN, or ischemia (Lindenfeld et al., 2010).

The majority of patients are admitted due to fluid overload resulting in symptoms such as dyspnea, orthopnea, weight gain, or edema. Initially, these are treated with IV loop diuretics with the goal of getting the patient back to his or her “dry weight.” Most patients respond to standard IV diuretics and transition to oral diuretics, but for those patients with chronic HF and cardiorenal syndrome other therapies may be needed such as ultrafiltration. Ultrafiltration is a mechanical strategy developed to affect diuresis in patients unresponsive to pharmacologic diuresis. It involves the movement of water and solutes across a semipermeable membrane from higher to lower concentration. Ultrafiltration in refractory HF is considered a reasonable alternative; however, a nephrologist should be consulted prior to implementation (Yancy et al., 2013). A recent study, CARRESS-HF (Bart et al., 2012), raised some interesting questions about the efficacy of ultrafiltration in HF with renal impairment, a common comorbidity with HF. The investigators, while reporting a similar amount of weight loss in a medication arm and ultrafiltration arm, reported significant deterioration in renal function and more adverse events in the ultrafiltration arm. Continuing study is needed.

Many episodes of ADHF are precipitated by new cardiac events or other medical conditions. Identification and treatment of these events is paramount such as rate and/or rhythm control in atrial fibrillation, controlling HTN, and determining if a patient is ischemic. The number one cause for developing HF is CAD, so if this is the first presentation of HF ruling out CAD is essential. If the patient has evidence of ischemia, revascularization with percutaneous coronary intervention may improve symptoms, prevent further hospitalizations, and have a survival benefit (Lindenfeld et al., 2010).

If the patient exhibits low perfusion HF, this is a more complicated picture and will require more advanced therapies such as inotropes or mechanical support. However, most patients admitted with HF are perfusing well and may even be hypertensive. Once the newly diagnosed HF patient is euvolemic

and decongested, oral evidence-based medications can be started and doses optimized. While in the hospital, the patient should also be evaluated for further advanced therapies such as device therapy—if this is consistent with his or her goals of care.

The discharge process starts early in the hospitalization. To prepare patients and families for HF self-care, the following acronym, DAMES, highlights areas of needed education:

Diet and fluid recommendations  
Activity/work recommendations  
Medications education  
Everyday weights  
Symptoms to monitor and how to manage if they occur

Instilling the importance of adherence to the treatment plan and to follow-up with a practitioner within 7 to 10 days of discharge is the standard of care. Patients admitted to the hospital with HF are at high risk for readmission. Consider, where possible, a referral to a formal HF disease management program where much time and effort is spent on preventing readmissions.

### Disease Management Programs

Disease management is increasing the use of evidence-based therapies to improve patient education and decrease readmissions. Postdischarge interventions have been identified by multiple studies as being imperative for HF patients. These interventions include clinic follow-up with a nurse practitioner with cardiology or primary care physician supervision, home nursing follow-up, or a telephone follow-up with a nurse practitioner or specialized registered nurses (Takeda et al., 2012). It is suggested that algorithms, tables, development of “pocket cards,” HF preprinted discharge sheets, and systematic use of guideline summaries be developed to help nurses to manage HF patients so that the practice is more uniform and effective. The American Association of Heart Failure Nurses (AAHFN) website ([www.aahfn.org](http://www.aahfn.org)) is a good resource for this information and tools.

■ **Team-Based Care in Heart Failure.** Nurses are active in the planning and management of care of HF patients. Care that is collaborative, often nurse directed, and in many areas multidisciplinary is available in HF clinics. The optimal treatment for patients with HF involves considerably more than prescribing the right medicine. It requires the full support of the patient and family, working with the health care team, to manage his or her HF. It has been well established that the main reason for rehospitalization is the discontinuation of prescribed medications, dietary indiscretions, and the failure to identify early signs of worsening HF.



Care provided by specialists or board-certified HF nurses in outpatient clinics has been shown to improve outcomes for patients, significantly reducing the number of unplanned readmissions (Takeda et al., 2012). As part of the interprofessional integrated team, nurses, dietitians, social workers, pastoral care, physical therapists, occupational therapists, case managers, pharmacists, and physicians must take part in a coordinated approach in counseling and educating patients and families with end-stage heart disease. A consistent plan of care should be maintained across all settings of care.

## Palliative Care Guidelines

There is a common misperception that disease management and PC are synonymous types of care (Buck & Zambroski, 2012). But current disease management, while evidence based, does not include all of the domains identified in quality care for people with life-limiting conditions such as HF. For example, the psychological and psychiatric, social, spiritual, religious, and existential, cultural aspects of care and care of the patient at the EOL are not addressed in the scientific statement from the AHA disease management taxonomy writing group (Krumholz et al., 2006). Disease management is currently defined as a system of care that coordinates medical interventions, including communication, for populations with chronic disease. The focus of disease management is on supporting clinician/patient dyads, practicing evidence-based medicine, empowering patients, and evaluating outcomes (Krumholz et al., 2006). PC is not just a system of care, it is a philosophy of care, which focuses on alleviating suffering and improving QOL for patients and families (National Consensus Project for Quality Palliative Care, 2013).

Even disease management and palliative care are not synonymous; neither are PC and hospice care. Hospice care is one type of PC, under a special Medicare benefit, which is delivered at the EOL. When it is time for hospice care, criterion from the National Hospice and Palliative Care Organization can help in determining when a patient is appropriate for hospice. In addition to the general hospice referral criteria, there are criteria specific to heart disease patients; these include the following:

- Intractable or recurrent symptoms of HF
- Optimal medical treatment for HF should be in place
- Presence of symptomatic arrhythmias
- History of cardiac arrest and resuscitation or syncope
- Cardiogenic brain embolism
- Co-occurring HIV disease

For those patients covered by the hospice Medicare benefit, an advanced practice clinician must manage their care and certify that they are expected to survive 6 months or less. It is hard to predict who is at the EOL in HF because the trajectory of HF is so uncertain. Therefore, to practice at the highest level the nurse needs to blend aspects from both PC and disease management with all HF patients. Patients should receive evidence-based treatments in a holistic framework that engages every part of their life—not just their HF (Fahlberg et al., 2011).

The evidence-based management of HF has improved considerably over the last 10 years, but those who will eventually die from this condition are first and foremost in need of respectful and comprehensive PC. The ACC/AHA 2009 and 2013 guidelines certainly helped to develop benchmarks for PC of the HF patient. ACC/AHA's EOL considerations are as follows:

1. Ongoing patient and family education regarding prognosis and impact on their functional capacity
2. Patient and family education options for formulating and implementing advanced directives and the role of palliative and hospice care
3. Discussion regarding the option of deactivating implantable assist devices
4. Continuity of medical care between inpatient and outpatient settings should be ensured
5. Components of hospice care should include opiate use, inotropes, and IV diuretics
6. All professionals should examine current EOL processes and work toward improvement of approaches to PC
7. Aggressive procedures performed in the final days of life are not appropriate

The committee also recommended that all involved with HF care make it a priority to improve the recognition of end-stage disease and provide appropriate care (Yancy et al., 2013). Although the ACC/AHA recommends hospice care as an option, the number of patients who are referred to hospice is relatively small. In a retrospective review of approximately 300,000 Medicare beneficiaries with HF, while overall hospice use increased between 2000 and 2007, the percentage of HF patients with short stays (less than 3 days) remained steady at 19%. Approximately 37% of HF patients had stays of less than 7 days, demonstrating the need for more timely hospice referrals in this population (Unroe et al., 2011).

■ **Communication.** Discussions about prognosis and care preferences should begin early in the disease process. It is too late to discuss PC and EOL wishes when the patient is near death. As with all patients in

this stage of life, ongoing communication is the key in achieving the goal of dying well. Communication skills needed for the discussions necessary are often lacking in health care education. Providers who work with HF patients may feel poorly prepared or uncomfortable having these conversations. Care philosophies of providers often impact the decisions they make, determining options offered to patients and families, and whether palliative approaches to care are utilized (Low, Pattenden, Candy, Beattie, & Jones, 2011). Most patients are aware they are dying and appreciate the discussion of their death. Many patients are not aware of the choices they have and can make. When patients reach the place where they want and need to discuss their wishes for their EOL, they often depend on their health care provider to initiate the conversation. These discussions need to happen before the patients become too ill to participate because these decisions impact not only their own lives but also the lives of their loved ones. Health care providers rarely raise these issues for fear of “decreasing hope.” Selman et al. (2007), in a qualitative study conducted in the United Kingdom, reported a wide range of preferences for EOL care by patients and their caretakers. Some were ready for death and preferred to die at home; those with poorer mobility said that they did not want their lives prolonged; family members were hesitant to make decisions regarding PC; and none of the respondents had discussed their preferences with their health care provider.

■ **Shared Decision Making.** The AHA released a recent scientific statement on shared decision making (Allen et al., 2012). In this important document, high-quality decisions involve medically reasonable care options, which align with the values, goals, and preferences of an informed patient. Decision making is seen as an iterative process that allows for change over time. Over the course of a person’s illness, advanced therapies such as a pacemaker, ICD, LVAD, heart transplantation, or transcatheter aortic-valve implantation may be discussed. Surgical or interventional revascularization options may be appropriate when patients experience new cardiac events, if these are in keeping with the patient’s goals of care. Shared decision making involving a trusted clinician will help ensure that the patient’s goals and wishes match proposed therapies. It is recommended that HF patients and their clinicians have yearly “HF review” conversations to discuss concerns and preferences about therapies, potential adverse events, current symptom burden, changes in functional status, QOL, and caregiver burden.

■ **Symptom Management.** Aggressive symptom management is a hallmark of quality PC. The four most

prevalent symptoms in HF are dyspnea, pain, depression, and fatigue (Adler et al., 2009). The strongest evidence for managing dyspnea supports the use of loop diuretics with or without thiazides and opioids. Pain management involves assessing the source of pain and treating according to source. The strongest evidence is for the use of opioids for general pain and bisphosphonates for bone pain as nonsteroidal anti-inflammatory drugs (NSAIDs) are contraindicated due to their potential to worsen HF and renal failure. Nitrates, BBs, vasoselective calcium channel blockers such as amlodipine, ranolazine, and coronary revascularization should be used for anginal pain. Selective serotonin reuptake inhibitors have the most evidence to support their safety and efficacy in advanced HF. Other alternative agents that have been identified as safe in HF are bupropion, mirtazapine, venlafaxine, and duloxetine (Harris & Heil, 2013). At this time, there isn’t strong evidence for the treatment of fatigue. Optimizing the management for other causes of fatigue such as anemia, infection, sleep disorders, and deconditioning is recommended. There is a divergence of opinion on the usefulness of treating fatigue with stimulants especially if the etiology is ischemia or CAD (Adler et al., 2009).

■ **Deactivation of Devices in Heart Failure.** Cardiologists who implant devices rarely discuss EOL issues or device deactivation at the time of implantation (Barclay, Momen, Case-Upton, Kuhn, & Smith, 2011). The American Academy of Hospice and Palliative Medicine recommends that the status of the device (whether activated or deactivated) should be consistent with patient and family goals of care. The ACC has issued guidelines related to deactivation of device-based therapies (Epstein et al., 2008). These deactivation guidelines state that

- Patients or surrogate decision makers should be fully informed of the consequences to deactivation and offered alternatives.
- An order for a do not resuscitate (DNR) should accompany the deactivation.
- Psychiatric and ethics consultations should be arranged in the setting of impaired decision making or disagreement.
- If the clinician has personal beliefs that prohibit deactivation, the patient should be referred to another clinician.
- Deactivation can occur at the implanting center or a local site at the patient’s request.
- Implanting clinicians should encourage, at the time of the implantation, the completion of advanced directives, which include device management and deactivation at EOL.

A more recent joint consensus statement from six national and international EOL or cardiology



societies discussed the ethical, legal, religious, and procedural issues surrounding the deactivation of cardiac devices in patients nearing EOL or who were requesting withdrawal of therapy and made recommendations for processes to implement the patient and family wishes (Lampert et al., 2010).

### Concurrent Care With Disease Management

Concurrent care is a care delivery model where the patient receives standard HF care while also being followed closely by a PC clinician (Maloney et al., 2013). This model is borrowed from oncology where patients are routinely referred to PC while still in active treatment, particularly if there is need for symptom management and decision-making support. A recent HF chart review assessing the reasons for PC consultations was conducted at a large health care system with almost 4,000 PC consultations (inpatient and outpatient) per year. This review of the electronic medical record showed that 80% of palliative consultations were for goals of care conversations, followed by decision making and hospice referral/discussion (Bakitas et al., 2013). These numbers support the idea that there is a need for a concurrent model of care. In a state-of-the-art paper published in the *Journal of the American College of Cardiology* (Goodlin, 2009), a table that makes recommendations for HF care by NYHA class provides guidance for delivering care that blends both standard HF care with PC (Table 13.8). This is a valuable resource for delivering concurrent care.

In this concurrent care model HF medications, discussed in this chapter, continue as they are palliative in scope. Medications that can potentially be discontinued as EOL approaches are statins, digoxin (digtoxicity increases as renal function decreases), and anticoagulation and antiplatelet therapy. Furthermore, if the patient has symptomatic hypotension, ACEI, ARBs, and other antihypertensives may need to be stopped. If the patient is in fluid overload, the BB should be tapered. Diuretics are often a key to symptom management in HF requiring careful titration based on daily weights and symptoms/signs of fluid overload, while avoiding dehydration and orthostatic hypotension. Many patients and families find additional “as needed” dosing of furosemide to be useful, allowing the patient more dietary choices during this time when appetite is often limited. Depression is common and normal during this time and should be treated. Selective serotonin receptor inhibitors are usually well tolerated and improve QOL. The defibrillator function of an ICD may be turned off during this period, but this option should be addressed early in the disease process and agreed upon by patient, family, and health care provider. This needs to be included in advanced directives.

PC has now been widely studied in the HF population. Therefore, we as nurses need to take advantage of the findings of these studies and discuss them with our patients. Oncology nurses are a great role model for those of us who care for HF patients. Their familiarity with discussing the palliative treatment modality should be emulated. Our efforts should begin with educating ourselves about PC; then examining our own feelings toward death and dying. There is a wealth of information available in resources such as the End-of-Life Nursing Education Consortium (ELNEC). We need to keep abreast of all the nursing interventions that are evidence-based so that our practice reflects these standards of care.

### OLDER ADULTS AND HEART FAILURE

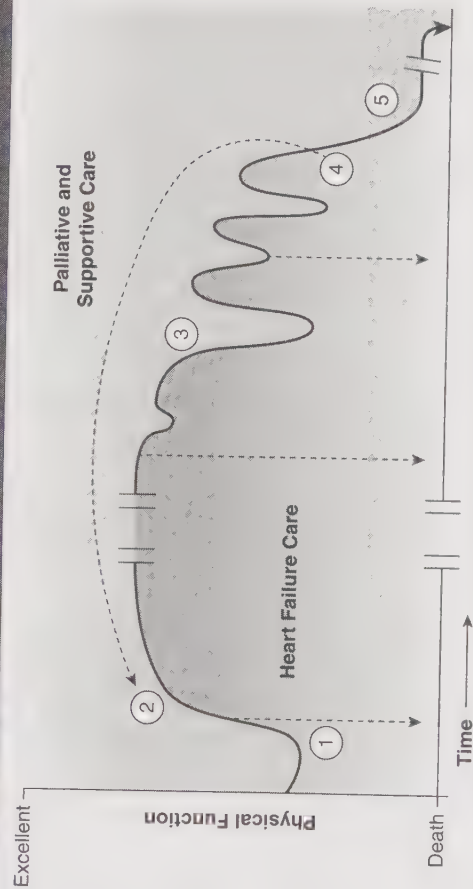
There can be many adverse reactions to cardiovascular therapies when used in the older adult population. Physiologically, changes in the metabolism and excretion of drugs occur with age. It is well known that there is a decrease in the glomerular filtration and tubular secretion with age. Cardiac medications that are dependent upon the kidney for excretion should be titrated appropriately; digoxin and ACEI are those that fit into this category. The hepatic metabolism of drugs also decreases with age. The commonly used medications for relief of symptoms in HF can therefore have a delayed absorption that can be variable in the older patient. Careful dosing and titration of these drugs on an individual basis is imperative.

#### General Pharmacological Recommendations for Older Adults

The following recommendations should be considered when prescribing cardiac medications for older adults:

1. Start low and go slow. Always begin with the smallest effective dose; titrate up in small increments, keeping in mind the patient's comorbid conditions that could influence the pharmacokinetics of the drug(s).
2. As dose adjustment is made, clinical evaluation should occur.
3. Review each medication the patient is currently taking, even over-the-counter medications and herbal remedies, and be aware of contraindications or adjustments needed.
4. Avoid empiric treatment of symptoms. Have a diagnosis before initiating drug therapy.
5. Keep it simple! Adherence decreases as the number of medications and frequency of dosing increases.

TABLE 13.8 Comprehensive Heart Failure Care



	Phase 1	Phase 2	Phase 3	Phase 4	Phase 5
	Initial symptoms of HF develop and HF treatment is initiated	Plateau of variable length reached with initial medical management, or following mechanical support or heart transplant	Functional status declines with variable slope; intermittent exacerbations of HF that respond to rescue efforts	Stage D HF, with refractory symptoms and limited function	End of life
NYHA functional classification	II–III	II–IV	III	IV	IV
HF care and interventions	<ul style="list-style-type: none"> <li>Identify etiology of HF</li> <li>Eliminate precipitating factors and causative conditions</li> <li>Diuretics → euvoolemia</li> <li>ACE inhibitor</li> <li>Beta-blocker</li> <li>Evaluate for coexistent conditions<sup>a</sup></li> </ul>	<ul style="list-style-type: none"> <li>Spironolactone if NYHA functional Class III–IV</li> <li>Digoxin if NYHA functional Class III–IV and LVEF less than 35%</li> <li>Hydralazine/nitrites?</li> <li>Evaluate and treat for sleep-disordered breathing</li> <li>ICD if EF less than 35% and defibrillation desired for SCD</li> <li>CRT or CRT/D</li> </ul>	<ul style="list-style-type: none"> <li>Reevaluate medication and compliance</li> <li>Reevaluate for precipitating factors and coexistent conditions</li> <li>Diuretics → euvoolemia</li> </ul>	<ul style="list-style-type: none"> <li>Evaluate for heart transplant</li> <li>Evaluate for destination LVAD</li> <li>Metabolic fluid management</li> <li>Inotrope trial if hypotensive and volume-overloaded (LVSD)</li> <li>Intravenous nitrates/hydralazine</li> </ul>	<ul style="list-style-type: none"> <li>Discontinue medications not impacting symptoms</li> <li>Continue ACE inhibitor or ARB, titrate beta-blocker dose, or stop if hypotensive</li> <li>Diuretics → euvoolemia</li> <li>Inotrope trial if hypotensive and volume-overloaded</li> </ul>



Decision making	<ul style="list-style-type: none"> <li>■ Preference for CPR/defibrillator</li> <li>■ Durable power of attorney for health care or proxy</li> </ul>	<ul style="list-style-type: none"> <li>■ Defibrillator for primary prevention of SCD</li> <li>■ Durable power of attorney for health care or proxy decision maker</li> <li>■ General goals for care, preferences for unacceptable health states</li> </ul>	<ul style="list-style-type: none"> <li>■ Urgent care decisions using clinician's best judgment or clear patient preferences</li> <li>■ Are advanced or invasive therapies indicated?</li> <li>■ Are advanced therapies consistent with patient preferences?</li> </ul>	<ul style="list-style-type: none"> <li>■ Possible candidate for transplant or destination VAD?</li> <li>■ Is palliative care appropriate?</li> <li>■ Does patient benefit from inotrope infusion?</li> <li>■ Review preferences for CPR/defibrillator</li> </ul>	<ul style="list-style-type: none"> <li>■ Clarify goals of care</li> <li>■ Site of care (hospital, home, other)</li> <li>■ Health care delivery (hospice, other provider)</li> <li>■ How to manage death (review CPR decision, review ICD and other devices; if appropriate, plan deactivation)</li> </ul>
Supportive care A. Communication	<ul style="list-style-type: none"> <li>■ Understand patient concerns and fears</li> <li>■ Identify life-limiting nature of HF</li> <li>■ Elicit preferences for care in emergencies or sudden death and for information and role in decision making</li> <li>■ Elicit symptoms and assess QOL</li> </ul>	<ul style="list-style-type: none"> <li>■ Elicit symptoms and assess QOL</li> <li>■ Reevaluate resuscitation preferences for care in emergencies</li> <li>■ Set goals for care</li> <li>■ Identify coping strategies</li> <li>■ Reeducate about sodium, weight, and volume status</li> </ul>	<ul style="list-style-type: none"> <li>■ Elicit symptoms and QOL</li> <li>■ Elicit values and reevaluate preferences</li> <li>■ Identify present status and likely course(s)</li> <li>■ Reevaluate goals of care</li> <li>■ Reeducate about sodium, weight, and volume status, medication compliance</li> </ul>	<ul style="list-style-type: none"> <li>■ Elicit symptoms</li> <li>■ Acknowledge present status</li> <li>■ Elicit preferences and reset goals of care</li> <li>■ Identify worries</li> <li>■ Review appropriate care options and likely course with each</li> <li>■ Explore suitability and preferences about surgery or devices</li> </ul>	<ul style="list-style-type: none"> <li>■ Elicit desired symptom relief and identify medication for symptom goals</li> <li>■ Assistance with delivery of care</li> <li>■ Preferences for EOL care, site of care, family needs, and capabilities</li> <li>■ Plan after death (care of the body, notifications, memorials, burial)</li> </ul>
B. Education	<ul style="list-style-type: none"> <li>■ Patient and family self-management (sodium, weight and volume)</li> <li>■ Diet, exercise</li> <li>■ HF course including sudden death and options for management</li> </ul>	<ul style="list-style-type: none"> <li>■ What to do in an emergency</li> <li>■ Review self-management</li> </ul>	<ul style="list-style-type: none"> <li>■ Review self-management</li> <li>■ Review what to do in an emergency</li> <li>■ Symptom management</li> <li>■ Eliminate NSAIDs</li> </ul>	<ul style="list-style-type: none"> <li>■ Optimal management for given care approach</li> <li>■ Interventions for deterioration in status</li> <li>■ What to do in an emergency</li> </ul>	<ul style="list-style-type: none"> <li>■ Likely course and plans for management of events</li> <li>■ Symptom management</li> <li>■ What to do for worsened or change in status</li> <li>■ What to do when death is near and at the time of death</li> </ul>

(continued)

TABLE 13.5 Comprehensive Heart Failure Care (continued)

	Phase 1	Phase 2	Phase 3	Phase 4	Phase 5
C. Psychosocial and spiritual issues	<ul style="list-style-type: none"> <li>● Coping with illness</li> <li>● Insurance and financial resources</li> <li>■ Insurance and financial resources regarding medications and loss of income</li> <li>■ Emotional and spiritual support</li> </ul>	<ul style="list-style-type: none"> <li>■ Roles and coping for patient and family</li> <li>■ Emotional support</li> <li>■ Spiritual support</li> <li>■ Social interaction</li> <li>■ Evaluate both patient and family anxiety, distress, depression, impaired cognition</li> </ul>	<ul style="list-style-type: none"> <li>● Family stress and resources</li> <li>■ Reevaluate patient and family needs</li> <li>■ Caregiver education and assistance with care</li> <li>■ Evaluate cognition</li> </ul>	<ul style="list-style-type: none"> <li>■ Insurance coverage</li> <li>● Reevaluate stresses, needs, and support patient and family</li> <li>■ Address spiritual and existential needs</li> <li>■ Support coping with dying</li> </ul>	<p>For both patient and family:</p> <ul style="list-style-type: none"> <li>● Address anxiety, distress, depression</li> <li>■ Address spiritual and existential needs, concerns regarding dying</li> <li>■ Anticipatory grief support</li> <li>■ Assist in care provision</li> <li>● Postdeath bereavement</li> </ul>
D. Symptom management	<ul style="list-style-type: none"> <li>■ HF medications for dyspnea</li> <li>■ Exercise/endurance training for fatigue</li> <li>● Antidepressant (check Na<sup>+</sup> with SSRIs)</li> <li>■ Local treatment and/or opioids for pain</li> </ul>	<ul style="list-style-type: none"> <li>● Identify new or worsened symptoms</li> <li>■ CPAP/O<sub>2</sub> for sleep-disordered breathing</li> <li>● Exercise program (lower extremity strengthening)</li> <li>■ Local treatment and/or opioids for pain</li> <li>■ SSRI or tricyclic or stimulant for depression</li> </ul>	<ul style="list-style-type: none"> <li>● Oxygen for dyspnea; consider opioids for acute relief of dyspnea</li> <li>■ Lower extremity strengthening for dyspnea/fatigue</li> <li>■ CPAP/O<sub>2</sub> for sleep-disordered breathing</li> <li>■ Local treatment and/or opioids for pain</li> <li>■ Benzodiazepines/ counseling for anxiety</li> <li>■ Stimulant for depression</li> </ul>	<ul style="list-style-type: none"> <li>● Oxygen for dyspnea</li> <li>■ Opioids for dyspnea</li> <li>■ Lower extremity and inspiratory strengthening</li> <li>■ CPAP/O<sub>2</sub> for sleep-disordered breathing</li> <li>■ Local treatment and/or opioids for pain</li> <li>■ Benzodiazepines/ counseling for anxiety</li> <li>■ Stimulant for depression</li> </ul>	<ul style="list-style-type: none"> <li>● Opioids for dyspnea and pain</li> <li>■ Oxygen for dyspnea</li> <li>■ Stimulants for fatigue</li> <li>■ Benzodiazepines/ counseling for anxiety</li> <li>■ Lower extremity strengthening for fatigue and dyspnea</li> <li>■ CPAP/O<sub>2</sub> for sleep-disordered breathing</li> <li>■ Stimulant for depression</li> </ul>

ACC, American College of Cardiology; ACE, angiotensin-converting enzyme; AHA, American Heart Association; ARB, angiotensin receptor blocker; CPAP, continuous positive airway pressure; CPR, cardiopulmonary resuscitation; CRT, cardiac resynchronization therapy; CRT/D, cardiac resynchronization therapy defibrillator; EF, ejection fraction; HF, heart failure; ICD, implantable cardioverter-defibrillator; LVAD, left ventricular assist device; LVEF, left ventricular ejection fraction; LVSD, left ventricular systolic dysfunction; NSAID, nonsteroidal anti-inflammatory drug; NYHA, New York Heart Association; QOL, quality of life; SCD, sudden cardiac death; SSRI, selective serotonin reuptake inhibitor; VAD, ventricular assist device.

\*Coexistent conditions: atrial fibrillation with uncontrolled rate, sleep-disordered breathing, anemia, physical frailty, coexistent pulmonary disease.

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6. Make sure that the patient can read the labels; if not, a family member or home care nurse should set up a weekly pill dispenser. Patients can also have large print labels on their prescription bottles.
7. Patient education is key. Make sure that each patient understands the adverse reactions to watch for and knows when to call for assistance.

### Specific Pharmacological Recommendations for Older Adults

In addition, health practitioners should be familiar with the cardiovascular recommendations for older adults by the American Geriatrics Society (American Geriatrics Society, 2012; Beers Criteria Update Expert Panel, 2012). The following recommendations should be considered when prescribing cardiac medications for older adults:

1. Alpha-blockers, such as doxazosin, prazosin, and terazosin, should be avoided as antihypertensives. They create a high risk for orthostatic hypotension.
2. Central alpha agonists, such as clonidine, reserpine (greater than 0.1 mg/day), and methyldopa, should be avoided as antihypertensives. They create a high risk for adverse central nervous system (CNS) effects, bradyarrhythmias, and orthostatic hypotension.
3. Class Ia, Ic, III antiarrhythmic drugs, such as amiodarone, procainamide, and quinidine, should be avoided. They have been associated with multiple toxicities. Rate control is recommended over rhythm control for older adults.
4. Disopyramide is a potent negative inotrope in older adults and should be used with caution as it may induce HF.
5. Dronedarone is to be avoided in patients with HF.
6. Avoid Digoxin (greater than 0.125 mg/day). Higher doses increase risk of toxicity in the presence of slow renal clearance common in older adults.
7. Avoid Nifedipine (immediate release). Increases the risk of hypotension or myocardial ischemia.
8. Avoid Spironolactone greater than 25 mg/day. Risk of hyperkalemia. Avoid in CrCl less than 30 mL/min.

### Nonpharmacological Recommendations

For older adults (as well as those younger than 65), aggressive use of the nonpharmacologic measures is imperative. Drug therapy can often cause unpleasant side effects, which often lead to nonadherence, and are costly now that Medicare D plans are in place. General measures are recommended as follows:

1. Decreasing more or new cardiac injury by risk factor reduction

2. Limiting alcohol use to two glasses/day
3. Maintaining fluid balance by restricted salt intake (2 g/day)
4. Improving physical conditioning
5. Careful management of comorbid conditions
6. Patient education regarding self-care
7. Smoking cessation when appropriate
8. Influenza vaccination every fall
9. Pneumococcal immunizations after diagnosis and revaccination every 5 years
10. Care of patients with HF across settings and by interprofessional teams
11. Careful monitoring of fluid status

### CONCLUSION

In caring for the patient with advanced HF, there are clinical, evidence-based therapies that should drive our clinical decision making. Hopefully, this chapter has helped the reader to understand the disease of HF; how important disease management is, how nurse-based HF interventions can lead to positive outcomes, and most importantly, how to communicate with patients and families regarding their treatment options and what is important to them in the final phase of their life.

### HELPFUL RESOURCES AND WEBSITES REGARDING HEART FAILURE

1. AHA
  - Very helpful in assessing data regarding statistics, patient information, risk factor identification, publications/brochures for patient education
2. AAHFN ([www.aahfn.org](http://www.aahfn.org))
  - Provides latest, guideline-directed professional education materials, caregiver resources, and patient education materials
3. National Guideline Clearinghouse
  - Latest evidence-based guidelines on the care of patients with heart disease
4. National Heart, Lung and Blood Institute ([www.nhlbi.nih.gov](http://www.nhlbi.nih.gov))
  - Health information on cardiac risk factors with guidelines for management
5. Center to Advance Palliative Care ([www.capc.org](http://www.capc.org))
  - Publications, resources, conferences on PC
6. Heart Failure Society of America ([www.hfsa.org](http://www.hfsa.org))

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## CASE STUDY *Conclusion*

Now back to Mrs. L., the 85-year-old patient presented at the beginning of this chapter. She is in her final phase of life and is very ill with Class IV symptoms, associated with Stage D, and is interested in knowing what to do next. Her son is also struggling with the fact that his mom is getting worse and yet she doesn't want the treatment that helped her in the past. In his own mind he thinks that maximal medical care and hospitalization should be planned for his mom, but this may be contradictory to what Mrs. L. wishes at this point. The priority concerns to be addressed today are as follows: address their hopes and worries, determine her goals of care, symptom management, and discussion of care options consistent with her goals.

These conversations take time and thoughtful planning. Research has shown that health care practitioners do not feel prepared or confident to have these difficult EOL discussions. Why are we hesitant to talk about the full spectrum of HF? Why can't we share the prognosis of heart disease with our patients? Why can't we make their fears and misunderstandings about how they feel a priority in their care? Is it because we have trouble with the idea of death ourselves? Is it because we are afraid that it would be somehow a failure on our part? There are patient and family barriers to these conversations as well such as a lack of understanding of what the disease entails and what to expect, their own fears around death, fear of not wanting to disappoint or question their physician, or not knowing how to bring up such topics. We know from multiple studies that patients want to talk about these issues and that many patients feel that a frank discussion about their diagnosis and prognosis would be helpful and even welcome.

In the ideal world, Mrs. L. and her son would have been more prepared for what was happening at this point in her HF trajectory. By incorporating shared decision making at each interaction throughout the course of her illness, her health care practitioners would have prepared her and her son for the future and what to expect. By having advance care planning discussions at each clinical encounter, it normalizes these often hard conversations. The first of these conversations may be suggesting an advance directive and choosing a surrogate decision maker and later bringing up decompensation events and EOL issues. While you cannot plan for every situation, helping the patient and family have these conversations can help develop a preparedness plan. The plan could include explanation that the HF course and prognosis is uncertain at first, the possibility of hospitalizations, suggestions of advanced therapies, decreasing functional status, and even sudden death. As HF progresses, patient's goals may change. Health practitioners have an obligation to review the goals of care regularly in order to make the appropriate treatment recommendations.

To begin a goals of care conversation, practitioners need to have a sense of Mrs. L.'s prognosis. Given her recent hospitalizations, declining functional status, and progression of symptoms, it is evident that she is nearing the end of her life. Next, it is important to determine her and her son's understanding of her illness and their prognostic awareness so they are able to make the right treatment choices. Building this foundation fosters and guides the rest of the conversation, allows the correction of misconceptions, clarifies concerns/worries, and gently helps patients and families to understand the illness trajectory. Upon determination of what is most important to the patient and what she is hoping for in the context of her illness, clinicians can help to match the patient's goals of care with the appropriate treatment plan. Mrs. L. verbalized that she wanted to be home and spend as much time with her family and to feel as good as possible for whatever time she had left. Being in the hospital or continuing some of her HF therapies would not help meet these goals. Since her goals valued QOL over life-prolonging therapies, the deactivation of her ICD was also discussed. While this therapy was appropriate for her earlier in her disease process, it was no longer recommended treatment.



The second priority to address is Mrs L.'s symptoms, their burden on her and her family, and how best to manage them. Again, an understanding of her goals and where she is on her disease trajectory will inform how the symptoms should be managed, given their impact on her quality of life. It may actually be time to discontinue some of her medications like ACEI and BBs to allow her blood pressure to increase. This may improve her fatigue and shortness of breath. By increasing her diuretics the swelling and dyspnea may improve. Reinforcing the low sodium diet and fluid recommendations may also be appropriate. At some point, the burden of the diuretics will also have to be balanced with QOL issues. Home oxygen therapy may improve her energy and can help even when oxygen saturation levels are within normal range. General measures to alleviate breathlessness can be suggested, such as use of a fan, pursed lip breathing, and proper body positioning. Oral morphine prior to exertional activities and with episodes of dyspnea can also be beneficial. Depression and anxiety can make patients more dyspneic, so screening for these symptoms is essential and appropriate medication may be prescribed. Exploring the role of spirituality is important in our treatment of Mrs. L. because it often brings inner peace and comfort in these end stages.

Since Mrs. L. desires to be at home, discussions about future hospitalizations need to be clarified, as well as EOL care planning, including where she would want to be when she dies. Her symptoms and prognosis qualify her for hospice and both she and her family would benefit from the support hospice provides. Consideration of other referrals, such as support groups, a social worker, or psychologist, may also meet the patient's and family's needs. It may even be appropriate at this time for referral for physical therapy to help with energy conservation. Mrs. L. and her son agreed that a hospice plan of care would best meet their needs and welcomed the referral. Although this conversation is often difficult and emotional, it is often valuable and appreciated to know the resources available. Mrs. L.'s primary care practitioner was notified of the discussion, and with the collaboration of the cardiologist and other members of the health care team, including nurses, a coordinated and comprehensive plan of care was provided to promote Mrs. L.'s QOL until its end.

## Evidence-Based Practice

Bekelman, D. B., Nowels, C. T., Retrum, J. H., Allen, L. A., Shakar, S., Hutt, E.,...Kutner, J. S. (2011). Giving voice to patients' and family caregivers' needs in chronic heart failure: Implications for palliative care programs. *Journal of Palliative Medicine*, 14(12), 1317-1324.

### Background

There is a lack of evidence to guide practice in HF related to palliative care needs. The purpose of this study was to describe HF patient and family caregivers' major concerns and needs and explore the usefulness of palliative care.

### Methods

Purposive sampling in semistructured one-on-one interviews. Digital recordings, transcribed and entered in ATLAS.ti, were coded and analyzed using constant comparison and thematic analysis techniques.

## Results

Seventy-two hours of interviews with 33 HF patients and 20 family caregivers resulted in the identification of the need for (a) early support in the HF trajectory; (b) symptom relief; and (c) involvement of the family in the team. Patients and family caregivers supported early integration of palliative care into their concurrent disease-specific care, retaining known clinicians.

## Conclusions

Palliative care should be integrated into routine HF disease management early in the disease trajectory.

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# Chronic Lung Disease

## CHAPTER

### KEY POINTS

To provide palliative care (PC) for patients at every stage of chronic obstructive pulmonary disease (COPD), from diagnosis to end-of-life (EOL), the nurse needs to consider the following questions and acquire the knowledge and skills for expert nursing care.

- What are the pathophysiological changes associated with COPD?
- What are the etiologies involved in the development of COPD?
- How is COPD diagnosed and what are the current medical treatment modalities?
- How are the extrapulmonary manifestations of COPD treated?
- What interventions are effective for smoking cessation?
- Are there alternative/complementary therapies that can assist the older adult with COPD?
- What can nurses do to assist the client at the end stage of COPD?
- What are the goals for patients with COPD and how do they differ according to the severity of the disease?

### CASE STUDIES

#### Mr. H.

Mr. H. is a 65-year-old male with a 40 pack-year smoking history. Over the past year, he has complained of progressive shortness of breath and a cough. Pulmonary function tests (PFTs) have revealed Stage II, COPD with moderate airflow limitation. Mr. H. is currently using an albuterol inhaler as necessary when short of breath.

Psychosocial history reveals he has been married for 30 years and recently retired as a police officer. His physical examination reveals that he is a pale, middle-aged, obese male, with slight shortness of breath with exertion. Lung sounds are diminished.

Mr. H. and his family have admitted to a knowledge deficit related to COPD and have asked his physician and nurse to educate them about the disease. When asked if he was interested in quitting smoking, he replied that he had been thinking about quitting recently and wanted to learn more about the nicotine patch.

**Mrs. S.**

Mrs. S. is a 75-year-old female with a 50 pack-year smoking history. She was diagnosed with COPD 5 years ago. Last year, home oxygen was initiated for an oxygen saturation level of 87% on room air. She has been hospitalized four times in the last year with acute exacerbations of her COPD. Recent PFTs revealed Stage IV COPD/severe airflow limitation.

Her psychosocial history indicates that she is widowed and lives with her daughter and her family in the suburbs. She has expressed feelings of sadness over the last several weeks and has lost interest in socializing with family and friends. Physical examination reveals an elderly, cachectic woman who looks older than her stated 75 years of age. She wears a nasal cannula that delivers oxygen at 2 L/min and is visibly short of breath. She has a poor appetite, and recently lost 10 lbs. Her examination is also notable for an increased anteroposterior (AP) diameter of her chest. Lung sounds are diminished bilaterally, with extensive wheezing. Intercostal muscle retractions are noted. Mrs. S.'s medication regimen includes an albuterol nebulizer, Tiotropium via nebulizer, and Prednisone.

Chronic lung disease, specifically COPD, is the third leading cause of death and is the most common cause of death from respiratory disease in the United States (American Lung Association, 2013). Clients with COPD experience pulmonary complications as well as a spectrum of extrapulmonary complications arising from the disease including malnutrition, pain, anxiety, and depression (Global Initiative for Chronic Obstructive Lung Disease Guidelines [GOLD], 2013). As COPD progresses, it is the 7th leading cause of disability and the 12th most common cause of morbidity (American Lung Association, 2013). About 80% to 90% of COPD cases are the result of smoking (American Lung Association, 2013). Ninety percent of patients with COPD die from causes attributable to smoking (Centers for Disease Control and Prevention [CDC], 2013). COPD is progressive, yet variable, and the course of the disease is characterized as a slow decline with intermittent episodes of exacerbations (Curtis, 2008). Due to the progressive nature of COPD, as well as the increased complications and disability, palliative care (PC) should be implemented at the point of diagnosis. According to the National Consensus Project for Quality Palliative Care (2013), the objective of PC is "to prevent and relieve suffering and to support the best possible quality of life (QOL) for patients and families, regardless of the stage of the disease or the need for other therapies" (p. 6). However, due to the variable and often unpredictable course of the disease, fewer patients with COPD receive PC than patients with other chronic diseases (Curtis, 2008; Yohannes, 2007). As part of an interprofessional, team-based approach, integrated PC needs to be initiated at the time of diagnosis and tailored to the stage of COPD to promote QOL for clients throughout the continuum of the disease. Although their goals of care may

be different, both Mr. H. and Mrs. S. require PC, which is specific to the stage of their disease.

### ■ CHRONIC OBSTRUCTIVE PULMONARY DISEASE DEFINITION

COPD is defined as follows:

a common preventable and treatable disease, [it] is characterized by persistent airflow limitation that is progressive and associated with an enhanced chronic inflammatory response in the airways and the lungs to noxious particles or gases. Exacerbations and comorbidities contribute to the overall severity of the disease in individual patients. (GOLD, 2013, p. 2)

The pulmonary aspect of COPD reflects airflow limitation and includes alterations in the different structures of the lung, including inflammation of the small airways, destruction of the pulmonary alveoli with diminished elastic recoil, and loss of parenchymal tissue (GOLD, 2013). Emphysema, the destruction of alveoli with subsequent dysfunction of gas exchange, one of the changes that may occur with COPD (GOLD, 2013). Bronchitis, associated with excessive sputum production, may or may not occur with COPD but does not reflect the major airflow obstruction that is characteristic of COPD (GOLD, 2013). The constellation of symptoms including dyspnea on exertion, chronic cough, and chronic sputum production suggests a possible clinical diagnosis of COPD; however, spirometry is required for a definitive diagnosis of COPD.

### Causes

Smoking is a major precursor to the development of COPD. Individuals who have been smoking for



10 years begin to develop pulmonary changes associated with COPD (American Lung Association, 2013). However, only 15% of smokers go on to develop COPD (Mosenifar, 2013). Urban living and air pollution have also been implicated in the development and the exacerbation of COPD (Mosenifar, 2013). Alpha-antitrypsin is a glycoprotein that appears to protect the alveolar walls from destruction; congenital deficiency of alpha-antitrypsin has been implicated in the diagnosis of COPD in persons who are nonsmokers (Mosenifar, 2013). In the 15% of nonsmokers who will develop COPD, a deficiency of alpha-antitrypsin may be suspected (Barnes, 2001).

## Pathophysiology

Clients with COPD have a number of pathological changes in the bronchioles, lower airways, lung parenchyma, and pulmonary vessels. Exposure to cigarette smoke, toxic gases, air pollution, and noxious substances induce widespread tissue damage and inflammation. Smokers are thought to have increased levels of inflammatory cells including neutrophils, macrophages, and T-lymphocytes (GOLD, 2013). These cells damage the airways and stimulate proteases, which destroy connective tissue and overwhelm the number of protective antiproteases. As the pulmonary cells undergo repeated episodes of damage and cell repair, structural changes occur in the normal epithelium of the airways. Fibrosis and inflammation replace normal epithelium, contributing to weakness and narrowing of the airways. The resultant narrowing of the airways causes an obstruction to airflow, particularly expiratory flow. As airways weaken and collapse, air in the airways is unable to be expired and becomes trapped. The residual air causes a breakdown of the alveoli and further damages the structure of the lungs.

Airflow limitation and obstruction of airflow are the hallmark consequences of COPD.

Airflow limitation can be accentuated by three main processes:

1. Loss of elastic recoil of the alveoli
2. Inflammation causing narrowing of the airways
3. Hypertrophy of the mucus-producing goblet cells causing obstruction of the lumen of the airways with thickened mucus. As COPD progresses, there is a decline in lung function that is three to five times more dramatic than in age-related matched groups without COPD (Hardin, Meyers, & Louie, 2008).

## Diagnosis

The diagnosis of COPD is often considered when a client reports a chronic cough, sputum production, or progressive dyspnea (GOLD, 2013). A

comprehensive history should be obtained including the duration and type of cough, whether dyspnea occurs at rest or with exercise, and the amount of sputum production. The baseline functional status of the client should be established and monitored over the course of the disease. Information regarding smoking history, recent exposure to toxic substances, or exposure to occupational fumes is necessary in establishing a diagnosis.

Once the diagnosis of COPD is considered, pulmonary function tests (PFTs) are needed to objectively confirm the diagnosis. PFTs measure the degree of airway obstruction. The stages of COPD are classified according to the degree of airway obstruction and are primarily measured with three spirometric parameters. The first is the forced expiratory volume in 1 second (FEV1). In healthy individuals, 80% of air is forcibly expired in 1 second. In patients with COPD, expiration of the normal volume of air is diminished due to airway limitation with FEV1 measurements less than 80%. The forced vital capacity (FVC) measures the maximum amount of air expired after a maximal inhalation. The FEV1/FVC is the ratio of the forced expiratory volume relative to the FVC and should be greater than 70%. Both the FEV1 and the FEV1/FVC are used to classify the severity of the airflow limitation and, accordingly, the severity of the disease (see severity of airflow limitation in patients with COPD; GOLD, 2013, Exhibit 14.1). For example, if a patient's spirometry reveals FEV1/FVC equal to or less than 70% and if the FEV1 is 60%, the patient is classified as having a moderate degree of airflow obstruction. The different stages of COPD are described as follows: (a) Stage I COPD indicates mild airway obstruction; (b) Stage II COPD indicates moderate airway obstruction; (c) Stage III COPD indicates severe airway obstruction; and (d)

### Exhibit 14.1

#### Severity of Airflow Classification in COPD

Patients With FEV1/FVC $\leq$ 70%	
Classification	Criteria
Mild	FEV1 $>$ 80% predicted
Moderate	50% $\geq$ FEV1 $\leq$ 80% predicted
Severe	30% $\geq$ FEV1 $\leq$ 50% predicted
Very severe	30% $<$ FEV1 predicted

Source: Adapted from Global Initiative for Chronic Obstructive Lung Disease [GOLD]. (2013).

Stage IV COPD reveals very severe airway obstruction. Pharmacotherapy and treatments are individualized according to the degree of airway obstruction and symptoms (GOLD, 2013).

Additional diagnostic tests may be necessary for further investigation including a chest x-ray, arterial blood gases, and bronchodilator reversibility testing. If a client is diagnosed with COPD before the age of 45, and has a family history, alpha-1 antitrypsin testing may be performed. The chest x-ray examination may demonstrate hyperinflation, flattened diaphragms, and an increased anteroposterior (AP) diameter (Barnes, 2001). The arterial blood gases (ABGs) will remain fairly normal until the later stages of the disease. Use of the modified Borg scale (see Exhibit 14.2) and noninvasive technology, such as pulse oximetry, may also help to quantify the changes in respiratory status of the older adult (Duthie, Katz, & Malone, 2007).

## ■ REVIEW OF SYMPTOMS AND PHYSICAL EXAMINATION FINDINGS

The client may complain of dyspnea upon exertion as well as at rest. A decrease in appetite, or a loss of appetite, can occur as dyspnic symptoms worsen. As a result of the increased effort of breathing and decreased food intake, the older adult may

report weight loss. Additionally, due to decreased oxygenation, mental status changes may be reported by family members or significant others.

Upon physical examination, auscultation of the lungs may reveal wheezing, rhonchi, or diminished lung sounds. With disease exacerbation, accessory muscle use will become visible—typically involving the sternocleidomastoid and trapezius muscle groups with intercostal muscle retractions as examples. Due to an increased AP diameter, the heart sounds may be distant.

## Complications of Chronic Obstructive Pulmonary Disease

The systemic and extrapulmonary complications of COPD may include cardiac, pulmonary, and gastrointestinal dysfunction. Some of the complications associated with COPD include pulmonary vascular vasoconstriction, cor pulmonale, atrial arrhythmias, pneumothorax, recurrent respiratory infections (such as pneumonia), respiratory failure, and malnutrition. Pulmonary vascular hypertension develops as the result of hypoxia, which causes vasoconstriction of the pulmonary arterioles. As the vasoconstriction worsens, increased pressure is reflected to the right side of the heart. Cor pulmonale, or enlargement of the right ventricle, occurs in response to increased pulmonary pressures and is a common feature of severe COPD (Sommers & Johnson, 2002). Cor pulmonale accounts for 25% of all types of heart failure and is more common in middle-aged and older males (Sommers & Johnson, 2002). Cor pulmonale is a late sign of COPD and there is a poor response to therapeutic interventions (GOLD, 2013).

A pneumothorax, an accumulation of air within the pleural space, may occur due to rupture of emphysematous bullae. Bullae develop as the result of cell and alveolar damage associated with COPD. Recurrent respiratory infections, commonly viral and bacterial in origin, can cause a transient worsening of COPD symptoms and are the most common cause of acute exacerbations (Sethi & Murphy, 2008). COPD patients are likely to experience one to two acute exacerbations per year (Sethi & Murphy, 2008). *Haemophilus* and *Streptococcus* pneumonia infections are the most common bacterial infections (Sethi & Murphy, 2008). The rhinovirus is responsible for approximately 25% of acute exacerbations (Sethi & Murphy, 2008). Frequent infections are likely to worsen pulmonary function.

The development of malnutrition is multifactorial in the older adult and occurs in up to 25% to 50% of COPD patients (Dine, Williams, & DeLisser, 2009). There is a 20% to 50% increase in metabolic

### Exhibit 14.2

#### Modified BORG Scale for Perceived Dyspnea

0 = Nothing at all
0.5 = Very, very slight (just noticeable)
1 = Very slight
2 = Slight (light)
3 = Moderate
4 = Somewhat severe
5 = Severe
6-----
7 = Very severe
8-----
9 = Very, very severe (almost maximal)
10 = Worst imaginable

Source: From Spector and Klein (2001).



demands associated with COPD as the normal work of breathing becomes more difficult and requires more effort (Dine et al., 2009). Calorie expenditure may increase tenfold to more than 700 calories/day (Dine et al., 2009). Patients with COPD find it difficult to satisfy the excessive caloric requirements associated with breathing. Nutrition is compromised as a result of decreased food intake due to dyspnea and the increased energy expenditure due to the disease process. Early satiety may develop due to the diaphragmatic changes associated with COPD, with the lowering and flattening of the diaphragm resulting in gastric compression. Fatigue and dyspnea can result in decreased oral intake. Depression due to the chronic illness, progressive changes in lifestyle, and personal losses may decrease the client's interest in eating.

Changes that occur with normal aging may predispose the patient to COPD or may worsen COPD. There are changes in lung function that are associated with the aging process. As individuals age, elastic recoil decreases and the chest wall stiffens. As a result of these changes, there is a decrease in compliance, resulting in decreased lung pressures and volumes (Sheahan & Musialowski, 2001). The residual volume, or air remaining in the lungs after a maximal expiration, increases (Duthie et al., 2007). This increase in residual volume contributes to the breakdown in lung elasticity. Airway compression occurs earlier in the expiratory phase of ventilation resulting in air trapping and altered gas exchange (Sheahan & Musialowski, 2001). Mucociliary clearance in both upper and lower airways may be diminished (Duthie et al., 2007). Coupled with the earlier airway compression, the older client is predisposed to lung infection.

The partial pressure of arterial oxygen ( $\text{PaO}_2$ ) also decreases with age due to the premature airway closure. According to Hall (1998) and Sheahan and Musialowski (2001), exercise capacity can be diminished as a result of decreased muscle mass, decreased cardiac function, and decreased level of conditioning that may occur in some older adults. A decrease in the function of lymphocytes and a decreased humoral response also predispose the older client to viral and bacterial infections (Duthie et al., 2007).

Respiratory failure is a serious complication of COPD and could necessitate hospitalization, intubation, and mechanical ventilation. Patients with COPD are at an increased risk of developing respiratory failure since the inflammation and damage of the alveoli-capillary membrane are progressive. Respiratory failure is characterized as a failure of either oxygen exchange or carbon dioxide elimination. The clinical criteria of respiratory failure include a  $\text{PaO}_2$  of less than 60 mmHg,  $\text{PCO}_2$  of greater than 50 mmHg,

or respiratory rate of greater than 30 breaths/min (Sharma, 2006). The complication of respiratory failure can be due to an acute insult (such as an infection), or progressive worsening of COPD.

In addition to the physical changes, many patients with COPD experience psychological manifestations, including depression and anxiety. The prevalence of depression increases with the severity of the disease, approaching 80% in individuals with Stage IV obstruction or severe disease (Schneider, Jick, Bothner, & Meier, 2010). Some studies suggest that the development of depression in COPD is related to an increase in inflammatory markers, specifically the levels of interleukin-6 (IL-6; Lu et al., 2013). Although the incidence of depression is greater for patients with COPD than for other chronic illnesses, many clients are not screened for depression and therefore are not treated. Depression is thought to contribute to an increased risk of both hospitalizations and mortality (Yohannes, Willgoss, Baldwin, & Connolly, 2010).

## ■ TREATMENT

The goal of PC for patients with COPD is to promote quality of life (QOL; Hardin et al., 2008). The principles that underlie the provision of PC include effective communication among providers, clients, and their families, as well as maintaining independence and promoting psychosocial, spiritual, and emotional health (Hardin et al., 2008). Patient education is an important component of communication and may help clients adjust to their illness. Effective communication may assist clients with smoking cessation. Providers should educate clients about the causes of COPD as well as the progressive nature of the disease. Discussions about advanced directives and EOL care should be carried out throughout the early and late stages of the disease. Education about the nature of COPD, the course of the illness, and advance directives has been shown to allay patients' anxiety (Knauff, Nielsen, Engelberg, Patrick, & Curtis, 2005).

### Management of Stable Chronic Obstructive Pulmonary Disease

PC for patients with COPD involves comprehensive care including disease-directed treatment, such as promoting independence and reducing symptoms. The treatment of patients often depends upon the stage of their diagnosis and their symptoms. In mild COPD, therapy is targeted toward prolonging life. In contrast, treatment of patients with very severe

disease is aimed toward promoting comfort and helping patients and families cope with EOL decisions and issues.

Current treatment modalities for all patients with COPD include smoking cessation, prevention of infection, maximizing pulmonary function, and education (Barnes, 2001; Hanania, Sharma, & Sharafkhaneh, 2010). After the age of 65, smoking continues to be a major risk factor for death as well as a decreased QOL (Duthie et al., 2007). Cessation of smoking is the most effective intervention to reduce the progression of COPD (GOLD, 2009). Smoking cessation in older adults can improve their QOL, prevent the progression of COPD, and therefore, reduce the development of complications due to COPD (Duthie et al., 2007). The risk for the development of influenza and pneumonia decreases as the result of smoking cessation in the older adult.

Counseling has been shown to be a very effective intervention to reduce smoking. The GOLD Guidelines (2013) recommend that clients should receive counseling at every health care visit. Counseling can range from a brief, informal episode to longer, more structured interventions; however, both are effective (Fiore et al., 2008a, 2008b). A recommended strategy for health care providers is to utilize the five As approach at every visit (Fiore et al., 2008a, 2008b; GOLD, 2009, 2013).

1. *Ask*: Identify all smokers.
2. *Advise*: Advise smokers to quit smoking at every visit.
3. *Assess*: Assess a client's willingness to quit smoking.
4. *Assist*: Assist client to quit by encouraging use of counseling and pharmacotherapies.
5. *Arrange*: Arrange for the client to receive follow-up care.

A growing evidence base reveals that several therapies are effective in achieving and sustaining smoking cessation (Fiore et al., 2008a, 2008b; Stead et al., 2012). Guidelines advocate the use of nicotine replacement therapies (NRTs) in the form of nicotine inhalers, lozenges, gum, nasal spray, and patches (Fiore et al., 2008a, 2008b; Stead et al., 2012). The goals of NRT are to reduce the desire to smoke and to decrease the physical, psychological, and physiological signs and symptoms of nicotine withdrawal. In a systematic review (Stead et al., 2012), all of the different NRTs increased the success of smoking cessation by 50% to 70%. The most effective medical therapy to date is Varenicline, a partial agonist of nicotine receptors. Varenicline is thought to increase

levels of dopamine in the brain and decrease satisfaction associated with smoking (Cahill, Stead, & Lancaster, 2009). A systematic review found the use of Varenicline was two to three times more effective in achieving smoking cessation when compared with placebo and was superior to Bupropion in achieving abstinence from smoking at 24 and 52 weeks (Cahill et al., 2009). Side effects associated with the use of Varenicline include nausea, insomnia, and bad dreams. Concerns regarding depression and suicide have prompted the FDA to issue a black box warning regarding the development of neuropsychiatric syndromes. An assessment of the patient's risk of depression must be conducted prior to prescribing this medication. Bupropion, an antidepressant thought to antagonize nicotinic receptors in the brain, has been found to be effective in increasing smoking cessation; a few studies have shown it to be superior to NRTs (Hughes, Stead, & Lancaster, 2007; Stead, Perrara, Bullen, Mant, & Lancaster, 2008). The addition of NRT to Bupropion is more effective than nicotine replacement alone (Stead et al., 2008). Side effects associated with Bupropion include dry mouth, insomnia, and nausea. Seizures occur in 1 of 1,000 patients treated with this medication and the risk of seizure increases with higher doses. While each of the aforementioned therapies has been successful in achieving outcomes, the combination of counseling and medications greatly increases the rate of cessation (Fiore et al., 2008a, 2008b).

The prevention of infection is an important consideration in the older adult with COPD. Simple interventions, such as handwashing and avoidance of exposure to illness, can reduce the development of respiratory infections. Immunizations, such as the influenza vaccine and the pneumococcal vaccines, are important vaccinations to prevent disease exacerbations (Barnes, 2001). Maximizing pulmonary function includes pharmacologic therapy, pulmonary rehabilitation, breathing retraining, and the prevention of malnutrition. Standard pharmacologic therapies include bronchodilators, steroids, and supplemental oxygen (Exhibit 14.3). If the older client has developed cor pulmonale or atrial arrhythmias, pharmacologic therapy is directed toward reducing the adverse cardiovascular effects that occur.

The importance of good nutrition in patients with COPD cannot be underestimated. A diet high in protein and calories is indicated to counter the possible protein breakdown that may occur with inadequate nutritional intake, particularly as the disease progresses. Small frequent meals with soft, nutrient-dense foods are recommended, such as yogurts, puddings, and omelets (Dine et al., 2009).



**Exhibit 14.3****Pharmacologic Interventions for Chronic Lung Disease**

<b>Bronchodilators<sup>a</sup></b>	<b>Routes</b>
<b><i>Sympathomimetics</i></b>	
Epinephrine	Inhaled, oral, parenteral
Isoproterenol	
<b><i>Beta-2 Agonists</i></b>	
<i>Short-acting</i> Albuterol	Inhalation—drug of choice in acute exacerbations; oral—duration of action is 4 to 6 hours
<i>Long-acting</i> Salmeterol	Duration of action is 12 hours
<b><i>Xanthines</i></b>	
Theophylline	Oral
Aminophylline	Parenteral
<b><i>Anticholinergics</i></b>	
Ipratropium	Inhaled
<b><i>Supplemental O<sub>2</sub></i></b>	
Nasal cannula	Compressed gas, liquid, or concentrate
<b><i>Steroids<sup>a</sup></i></b>	
<b><i>Corticosteroids</i></b>	
Prednisone	Oral
Methylprednisolone	Parenteral
Beclomethasone	Inhaled

<sup>a</sup>Not an all-inclusive list of medications.

Oxygen provided with meals may help to treat the shortness of breath while eating. Nutritional supplements in the form of thick shakes may help patients receive their daily amount of vitamins and minerals. Multivitamins should be prescribed for all patients.

■ **Respiratory Pharmacologic Therapy of Stable Chronic Obstructive Pulmonary Disease.** Pharmacotherapeutic agents are recommended for the treatment of symptoms and prevention of acute exacerbations for clients with COPD. Bronchodilators constitute the foundation of pharmacotherapy for all patients with COPD (GOLD, 2013). Treatment with bronchodilators are associated with a reduction of dyspnea and an improvement in exercise capacity (GOLD); however, their use is not associated with an improvement in survival. Bronchodilators can be administered via metered-dose inhalers, by nebulizer, or by oral administration. The bronchodilators most often prescribed for patients with COPD include beta-2 agonists and anticholinergic agents. Beta-2 agonists stimulate the beta-receptors in the lung and promote bronchodilation of the proximal airways and vasoconstriction of the pulmonary vessels. In mild cases of COPD, the prototypical, short-acting beta-2 agonist (SABAs), albuterol, is prescribed on an as-needed basis to reduce symptoms such as wheezing, shortness of breath, and chest tightness. As COPD increases in severity to moderate and severe forms of the disease, long-acting beta-2 agonists (LABAs) are recommended. LABAs, such as salmeterol, provide sustained bronchodilation with daily or twice daily dosing. Research suggests that LABAs may be associated with improved QOL, reduced symptoms, and a decrease in the frequency of acute exacerbations (GOLD, 2013).

Anticholinergic agents promote bronchodilation in patients with COPD and work by activating muscarinic receptors in the airways. Tiotropium, a long-acting anticholinergic agent, is recommended for daily use. A recent systematic review (Barr, Bourbeau, & Camargo, 2008) compared Ipratropium, administered twice daily as a less selective agent, with Tiotropium, an agent with greater selectivity. Tiotropium was shown to reduce exacerbations of COPD and decrease the number of hospitalizations (Barr et al., 2008). Patients with moderate to severe COPD, who were managed with Tiotropium, had significant improvements in QOL and reduction in symptom scores when compared with LABAs (Barr et al., 2008). Additionally, when compared with LABAs, treatment with Tiotropium resulted in fewer exacerbations of COPD and a decrease in disease-related hospitalizations (Chong, Karner, & Poole, 2012). Additionally, the use of Tiotropium in conjunction with a LABA has been shown to improve QOL; however, there are limited data on the efficacy and the safety of this combination (Karner & Cates, 2012).

As the severity of COPD increases, and patients are diagnosed with moderate to severe forms of the disease, the GOLD Guidelines recommend the addition of an inhaled corticosteroid to long-acting

bronchodilator therapy for all patients diagnosed with moderate stage COPD, having a FEV1 of less than 50%, with frequent exacerbations of COPD (2013). Inhaled corticosteroids, such as Fluticasone, have been shown to decrease the number and severity of exacerbations (Cayley, 2008; Yang, Fong, Sim, Black, & Lasserson, 2007). Additionally, treatment with inhaled corticosteroids is associated with an improvement in QOL despite the fact that the therapy does not slow the decline of lung function (Yang et al., 2007). Adverse effects associated with inhaled corticosteroids include hoarseness and vocal cord myopathy caused by the topical placement of the steroids on the vocal cords with resultant muscle breakdown. Rinsing after administration of the inhaled steroids helps to reduce the oropharyngeal complications. Some studies suggest an increased risk of pneumonia in patients who use inhaled corticosteroids. At this point, there is insufficient evidence to know whether there is an associated increase in pneumonia as a result of long-term therapy.

Theophylline, a methylxanthine, is a bronchodilator with a narrow therapeutic index, requiring frequent monitoring of drug levels and adjustments of the dose. Side effects including palpitations and tremors are associated with their use and can be troublesome, often relegating theophylline to second- or third-line therapy. Changes in cardiac or liver function associated with aging can decrease the clearance of theophylline, contributing to side effects and necessitating dosage adjustments (Barnes, 2001). Cigarette smoking can also negatively influence the metabolism of theophylline. Some evidence suggests that low-dose theophylline may be associated with an increase in FEV1 and fewer exacerbations.

### Acute Exacerbations

Acute exacerbations may be triggered by both bacterial and viral infections. Infections may exacerbate inflammation and contribute to impairment of cilia and hypersecretion of mucous goblet cells. Oral and intravenous (IV) steroids are administered to patients to treat acute exacerbations of chronic obstructive lung disease. The main advantage to glucocorticoid steroids is their anti-inflammatory effect. Oral and parenteral glucocorticoids are effective in reducing COPD exacerbations (Walters, Gibson, Wood-Baker, Hannay, & Walters, 2009). Glucocorticoids suppress a number of inflammatory mediators and, thus, decrease the inflammation associated with the exacerbation. Evidence revealed that the use of systemic glucocorticoids for acute exacerbations significantly decreased dyspnea, the risk of treatment failure, and appearance of recurrent exacerbations

within 30 days (Wood-Baker, Gibson, Hannay, Walters, & Walters, 2008). There was a significant increase in the volume of expired air and an improvement in arterial blood gases within the first 72 hours (Wood-Baker et al., 2008). However, even short-term use is associated with an increased incidence of adverse side effects including increased risk of infection, hyperglycemia, weight gain, and insomnia (Walters et al., 2009). Nonsignificant increases in depression and anxiety have also been noted. Long-term complications include muscle breakdown, suppression of the hypothalamus–pituitary axis, and osteoporosis. Treatment for acute exacerbations is usually short term to avoid complications associated with their use.

Oxygen therapy can decrease the potentially harmful effects of hypoxemia-induced vasoconstriction on the pulmonary vasculature. Oxygen is utilized during acute exacerbations (Brashers, 2002) to reduce the dyspnea associated with hypoxemia and the long-term consequences of hypoxemia such as pulmonary hypertension and cor pulmonale (Barnes, 2001). Oxygen therapy is titrated to a PaO<sub>2</sub> of 55 to 60 mmHg in order to avoid “turning off” the hypoxic drive in clients with COPD (Barnes, 2001).

Small breaths and a decreased respiratory rate is a COPD client’s response to exercise (Collins, Langbein, Fehr, & Maloney, 2001). As stated previously, the older adult will reduce his or her activity in order to reduce the occurrence of dyspnea. Pulmonary rehabilitation is focused on exercise and muscle reconditioning. Rehabilitation can take place in a community setting as well as in the client’s home. By increasing physical activity, muscle atrophy may be reduced and the efficiency of oxygen uptake will be improved (Collins et al., 2001).

Breathing retraining for clients with COPD includes the techniques of pursed-lip breathing and diaphragmatic/abdominal breathing (see Exhibit 14.4). Due to the pathophysiology of COPD, air becomes trapped in the terminal airways and adequate ventilation decreases. Lung changes associated with aging can result in air trapping without the presence of COPD (Sheahan & Musialowski, 2001). Pursed-lip breathing facilitates the expulsion of air from the lungs by the client controlling and lengthening the expiratory phase of respiration (Collins et al., 2001; Dunn, 2001).

Diaphragmatic/abdominal breathing serves a similar purpose as pursed-lip breathing. The client utilizes the diaphragmatic and abdominal muscles to control both inspiration and expiration (Dunn, 2001). Both techniques assist the client to reduce panic and anxiety associated with dyspneic episodes (Dunn, 2001). The older client can perform both of these exercises while seated comfortably in a chair.



### Exhibit 14.4

#### Breathing Exercises

##### Pursed-lip:

- Breathe slowly through nose.
- Hold your breath to a count of 3 seconds.
- Purse lips like you are whistling; breathe out to a inspiration; should drop with expiration; exhale through mouth.
- By exhaling through pursed lips, air is expelled from the lungs and breathing is slowed.

##### Abdominal/diaphragmatic:

- Sit comfortably with feet on floor.
- Press one hand to abdomen, rest the other hand on chest.
- Inhale through nose slowly; use abdominal muscles.
- Abdominal hand should rise with a count of 3 seconds.
- Hand on chest should stay still.

Source: From Sheahan and Musialowski (2001).

Malnutrition negatively affects the pulmonary system as well as the immune system in the older adult. Due to the physiologic changes associated with aging, immunity and pulmonary function can already be compromised (Sheahan & Musialowski, 2001). If an older adult is concurrently on diuretic therapy, losses of phosphorus and potassium can contribute to further muscle weakness (Hanania et al., 2010). Recommendations to improve nutrition include eating smaller, more frequent meals (Sommers & Johnson, 2002), increasing protein and calories (Berry & Baum, 2001; Collins et al., 2001; Sommers & Johnson, 2002), and limiting carbohydrates to 50% of the total caloric intake (Marini & Wheeler, 2010). In a Cochrane Systematic Review, when nutritional supplementation, defined as oral, enteral, or parenteral caloric substances administered over at least a 2-week period, were compared with usual diet, there were significant improvements in weight gain and the 6-minute walk test (Ferreira, Brooks, White, & Goldstein, 2012). Additional anthropometric parameters revealed a significant increase in fat mass index, lean body mass index, and skinfold thickness (Ferreira et al., 2012).

Administering bronchodilators prior to meals can also facilitate intake by decreasing dyspneic episodes. Oral care prior to meals can improve the eating experience for clients who mouth-breathe or have sputum production. Improving nutritional intake can increase the patient's response to hypoxemia, decrease

hypercarbia, and maintain immune function, which is often diminished as a result of the physiologic changes associated with aging as well as the pathophysiologic process of COPD (Barnes, 2001).

Education is incorporated in the care of the older client during each contact. Explanations should be given regarding smoking cessation, medication administration, and potential side effects of these medications. Instructions should be given regarding exercise, retraining, and pulmonary rehabilitation and, if necessary, home oxygen therapy. Because significant others often function as caregivers in the home, they should be included in the education sessions.

### Determining Prognosis in Pulmonary Disease

Determining prognosis in end-stage lung disease is extremely difficult. There is marked variability in survival. Physician estimates of prognosis vary in accuracy, even in patients who appear end stage. Even at the time of intubation and mechanical ventilation for respiratory failure from acute exacerbation of COPD, 6-month survival cannot be predicted with certainty from simple data easily available to the clinician. Far less information than this is available to most hospice programs at the time of referral.

Although the end stages of various forms of lung disease differ in some respects, most follow a final common pathway leading to progressive hypoxemia, cor pulmonale, and recurrent infections. Thus, these guidelines refer to patients with many forms of advanced pulmonary disease. Once the older adult is diagnosed with COPD, the individual and his or her significant others should be made aware of the predictors of a poor prognosis (see Exhibit 14.5). Death generally occurs within 5 years of diagnosis of advanced disease (Barnes, 2001).

At the present time, it is uncertain what number or combination of these factors might predict 6-month mortality; clinical judgment is required. Patients who fit the following parameters can be expected to have the lowest survival rates:

- I. Severity of chronic lung disease documented by
  - A. Disabling dyspnea at rest, poor oxygenation, or unresponsiveness to bronchodilators, resulting in decreased functional activity, for example, bed-to-chair existence, often exacerbated by other debilitating symptoms such as fatigue and cough. FEV<sub>1</sub>, after bronchodilator, less than 30% of predicted, is helpful supplemental objective evidence, but should not be required if not already available

- B. Progressive pulmonary disease
  - 1. Increasing visits to emergency department or hospitalizations for pulmonary infections and/or respiratory failure
  - 2. Decrease in FEV1 on serial testing of greater than 40 mL per year is helpful supplemental objective evidence, but should not be required if not already available
- II. Presence of cor pulmonale or right-heart failure (RHF)
  - A. These should be due to advanced pulmonary disease, not primary or secondary to left-heart disease or valvulopathy
  - B. Cor pulmonale may be documented by
    - 1. Echocardiography
    - 2. Electrocardiogram (EKG)
    - 3. Chest x-ray
    - 4. Physical signs of RHF
- III. Hypoxemia at rest on supplemental oxygen
  - A. PO<sub>2</sub> less than or equal to 55 mmHg on supplemental oxygen
  - B. Oxygen saturation less than or equal to 88% on supplemental oxygen
- IV. Hypercapnia
  - A. PCO<sub>2</sub> equal to or greater than 50 mmHg
- V. Unintentional progressive weight loss of greater than 10% of body weight over the preceding 6 months
- VI. Resting tachycardia greater than 100/min in a patient with known severe COPD (National Hospice Organization, 1996)

The endpoint of the disease is pulmonary hypertension and the development of cor pulmonale (Marini & Wheeler, 2010). All information regarding the diagnosis and prognosis should be delivered honestly to the elder client and significant others at their level of understanding (Meier, Morrison, & Ahronheim, 1998).

Once the diagnosis has been made, it is appropriate to begin discussions about advance directives. Discussion regarding advance directives should begin prior to the development of a life-threatening event (Meier et al., 1998). If a patient has two or more of the clinical predictors identified in Exhibit 14.5, discussions regarding EOL care are necessary. Even though predicting the exact time of death is difficult, the client and significant others should be offered options in treatment. Information regarding PC can also be included in the treatment plan for clients with COPD (Meier et al., 1998).

### Symptom Identification and Treatment

Symptom management is important in the PC of clients with COPD but does not alter the trajectory of

### Exhibit 14.5

#### Predictors of Poor Prognosis in Patients With COPD

1. FEV1 less than 30% of predicted
2. Declining performance status, with increasing dependence on others for activities of daily living
3. Uninterrupted walk distance limited to a few steps
4. More than one urgent hospitalization within the past year
5. Left-heart and/or other chronic comorbid disease
6. Depression/anxiety
7. BMI less than 21 kg/m<sup>2</sup>
8. Poor QOL per patient
9. Long-term oxygen therapy
10. Intolerable dyspnea
11. BODE Index score greater than 7

Source: From Hardin et al. (2008).

the disease or the survival odds. Dyspnea and the resultant development of anxiety are commonly associated with end-stage COPD (Meier et al., 1998). Dyspnea may also be associated with cor pulmonale, which is a late sign and poor outcome indicator of COPD (Marini & Wheeler, 2010). However, in the older adult with COPD, dyspnea and complaints of breathlessness may be difficult to ascertain (Duthie et al., 2007). Dyspnea is a subjective symptom of breathlessness, but the older adult may compensate for its development by decreasing his or her level of activity (Duthie et al., 2007).

Once dyspnea has been diagnosed, the underlying cause needs to be identified. In the older adult with COPD, dyspnea can be the result of the disease process itself, the development of cor pulmonale, or a respiratory infection, such as pneumonia. Nonpharmacologic interventions for symptom relief of dyspnea include repositioning the client with his or her head up or to a position of comfort in a chair (Kazanowski, 2001; LaDuke, 2001). A cool environment can decrease the perception of dyspnea (Kazanowski, 2001; Meier et al., 1998). Balancing rest and exercise as tolerated can also assist the client to breathe easier (Kazanowski, 2001; LaDuke, 2001). Frequent reassurance and providing a physical presence can assist in decreasing anxiety and therefore decrease dyspnea (Meier et al., 1998).

The pharmacologic interventions chosen to treat dyspnea depend upon the underlying etiology. Oxygen can be an initial adjunctive therapy



for dyspnea (Kazanowski, 2001; LaDuke, 2001; Meier et al., 1998) and can be delivered via nasal cannula, face mask with cool mist, bi-level positive airway pressure (Bi-PAP), or mechanical ventilation. Oxygen is the only therapy associated with increased survival (GOLD, 2009). The administration of oxygen has a number of salient effects including improvements in pulmonary hemodynamics, functional status, and well-being (GOLD, 2008). Although Bi-PAP is used in the acute care setting to reverse respiratory failure, it may provide some relief from dyspnea (McGowan, 1998). Bi-PAP may also be desirable because it may be chosen as a less invasive alternative to mechanical ventilation (McGowan, 1998).

Opioids, such as morphine sulfate, can be administered to decrease the perception of dyspnea as well as decrease the sensation of dyspnea (Kazanowski, 2001; LaDuke, 2001; Meier et al., 1998). Morphine can be administered sublingually, orally, parenterally, and via nebulizer (see Exhibit 14.6). Anxiety is also reduced because of the mood-altering effects of morphine (LaDuke, 2001; Meier et al., 1998). Somnolence is the main side effect of morphine; however, no severe respiratory compromise is noted (Kazanowski, 2001). Steroids can be administered to the client with COPD to alleviate the inflammatory effects within the lungs (Kazanowski, 2001; LaDuke, 2001). Bronchodilators can also relieve the dyspnea associated with end-stage COPD (Kazanowski, 2001; LaDuke, 2001).

Dyspnea related to cor pulmonale may respond to the administration of diuretics. If the client has tenacious secretions associated with COPD or a respiratory infection, mucolytics may be administered (Kazanowski, 2001). A recent systematic review reveals a reduction in the number of acute exacerbations and a decrease in the number of days of associated disability (Poole & Black, 2010). If a respiratory infection, such as pneumonia, has been identified as the source of dyspnea (fever, congested cough), antibiotic therapy is appropriate (Kazanowski, 2001; LaDuke, 2001). Anxiolytics, such as benzodiazepines, barbiturates, and phenothiazines, may be prescribed to relieve the anxiety and fear associated with the feelings of breathlessness (Kazanowski, 2001; LaDuke, 2001; Meier et al., 1998).

Depression and anxiety are common in patients with COPD and are related to increased morbidity and mortality, declining functional status, decreased QOL, and difficult breathing. The prevalence of anxiety ranges from 10% to 96% of individuals (Putman-Casdorph & McCrone, 2009). Increased anxiety may be associated with difficulty breathing (Putman-Casdorph et al., 2009).

The incidence of depression is higher in clients with COPD than in the general public (Putman-Casdorph

## Exhibit 14.6

### Pharmacologic Interventions for Dyspnea

#### Opiates: *Morphine Sulfate*

Nebulized (5 mg/2 cc 0.9 NS q4h) or parenteral (1–2 mg IV every 10–15 minutes; 2–5 mg SC initially)  
Orally or sublingually (5–10 mg, repeat as needed every 1 hour prn)  
Rectally (10–20 mg every 4 hours)

#### Antidepressants: *Selective Serotonin Reuptake Inhibitors*

Sertraline (Zoloft)

Oral

Treatment initiated at 25 to 50 mg/day. Seniors should start at 25 mg/day

Dose may be increased after 4 weeks if symptoms persist

#### Anxiolytics: *Benzodiazepines*

Lorazepam (0.5 mg orally or sublingually every 4 hours)  
Thorazine (25–100 mg orally tid or qid)

#### Diuretics: *Furosemide*

Administered orally, SC, IV, or IM for signs/symptoms of fluid volume excess 20–80 mg orally (per dose)  
20–40 mg IV/IM (per dose)

Source: From Kazanowski (2001).

et al., 2009). In COPD, depression rates range from 20% to 80% (Putman-Casdorph et al., 2009). Individuals who are African American, elderly, and of lower socioeconomic status experience a disproportionate incidence of depression (Putman-Casdorph et al., 2009). Depression in COPD interferes with the client's ability to participate in activities of daily living, pulmonary rehab, and breathing exercises. Depression may also impede the individual's ability to quit smoking, which is an integral component of care.

Due to the significant morbidity and mortality associated with depression in patients with COPD, it is imperative that clinicians screen patients for depression. Multiple tools have been developed to assess for depression, including the Geriatric Depression Scale, Patient Health Questionnaire-9 (PHQ-9), and the Primary Care Evaluation of Mental Disorders (PRIME-MD).

Although limited, studies to date indicate that antidepressants and psychotherapy may reduce a client's feelings of depression (Putman-Casdorph et al., 2009). Providers should encourage clients to discuss their feelings and proactively encourage communication throughout the continuum of care. Clients should be assessed

for depression and offered both antidepressants and/or cognitive/behavioral therapy and psychotherapy.

Norwood and Balkissoon (2005) have developed guidelines for screening and treating COPD patients who satisfy the criteria for major depression. Antidepressant therapy is recommended for all patients with major depression; most commonly, the classes of serotonin reuptake inhibitors (SSRIs) and tricyclic antidepressants (TCA) are prescribed. Although there are limited data to date on treatment of COPD patients, most studies suggest that there are fewer adverse effects associated with SSRIs. Studies have recently shown that patients with COPD who are treated with multiple, complex psychological and/or lifestyle interventions such as education, relaxation, counseling, problem solving, and cognitive-behavioral therapy have fewer symptoms of anxiety and depression (Coventry et al., 2013). Additionally, the GOLD Guidelines (2013) suggest that exercise may have beneficial effects in treating depression in patients with chronic illnesses in general.

Many providers are unaware that pain is a common symptom in COPD (Hardin et al., 2008). Often pain occurs as a result of both anxiety and depression, which are prevalent in this population. Due to the lack of knowledge, clients are not routinely assessed for pain, and their pain is often undertreated. Additionally, many providers are concerned that treating pain may depress the patient's respiratory drive or hasten their deaths. Common misperceptions and lack of knowledge may prohibit treatment of both pain and depression.

Mechanical ventilation is an intervention that involves the creation of an artificial airway in order to deliver oxygen. In the setting of end-stage COPD, it is not an option that offers many advantages. There is an increased risk of nosocomial infection in an already compromised host, such as the older adult with COPD (Hanania et al., 2010). It is difficult to wean a client with COPD from the ventilator because of diaphragmatic muscle weakness and, in the older adult, a decreased physiologic response to hypoxemia and hypercarbia (Phelan, Cooper, & Sangkachand, 2002). Mechanical ventilation also increases the risk of cardiac problems, aspiration, and barotrauma (Hanania et al., 2010). All oxygen delivery options should be offered to the client and family, along with the risks and benefits associated with treatment. In the setting of PC, the least invasive and intrusive therapies will promote comfort (Curtis, 2008).

### **Complementary Therapies for Patients With Chronic Obstructive Pulmonary Disease**

Complementary therapies, when incorporated into the practice of nursing, can increase the repertoire

of interventions available to older adult clients (Frisch, 2002). For those clients who are receiving symptom relief at the EOL, complementary therapies can positively enhance what is already being done. Complementary therapies enable the nurse to create care that is client-centered and holistic (Frisch, 2002). There is increasing demand by consumers to receive holistic care that takes into account the mind, body, and spirit (Kreitzer & Jensen, 2000). Complementary therapies are already available in the community. The use of complementary therapies can give clients and their families control over their care decisions (Kreitzer & Jensen, 2002); most complementary therapies can be utilized in the home. Examples of complementary therapies include guided imagery, relaxation, massage, and music therapy.

Rest is necessary in order to decrease the intensity of dyspnea; it can also decrease the work of breathing. Promoting rest and sleep can also decrease anxiety. Assessment of the older adult's sleep habits can be a helpful starting point to the promotion of restful sleep (Tullmann & Dracup, 2000). Assisting the client into a position of comfort can promote sleep (Tullmann & Dracup, 2000), and in the case of the client with COPD, this generally means elevation of the head of the bed, which also facilitates diaphragmatic expansion.

Guided imagery is a technique that can be utilized to promote sleep in the client with COPD (Tusek & Cwynar, 2000). Guided imagery can also assist the client through a stressful experience (Tusek & Cwynar, 2000). The older adult can practice guided imagery with a partner or via audiotape. Clients focus on the present and then are taken to a safe place in their mind.

Massage can also be explored as an option for sleep promotion (Richards, Gibson, & Overton-McCoy, 2000). Prior to initiating massage, the nurse must first determine that the elder is comfortable with being touched (Richards et al., 2000). In the client at the end stage of COPD, there are no contraindications to massage being utilized for the promotion of rest and sleep.

Music can also be added to the therapeutic plan for the promotion of rest and sleep (Chlan, 2000; Richards et al., 2000). Music therapy can be helpful in elders with COPD who tire easily; however, music should be selected to their personal preference (Chlan, 2000). Anxiety reduction can also be facilitated through the use of complementary therapies such as massage (Richards et al., 2000), guided imagery (Tusek & Cwynar, 2000), and music therapy (Chlan, 2000). Reducing anxiety can also result in the reduction of dyspnea in the client with COPD.

Clients or their significant others may ask the nurse about the utility of herbal remedies in the treatment of COPD. There are several herbs that are used in



the treatment of respiratory ailments. Chaparral, cinnamon, horehound, and pansy have been used in the treatment of bronchitis, although Chaparral can cause severe liver damage and cinnamon can precipitate shortness of breath (Skidmore-Roth, 2001). Anise and astragalus have been used in the treatment of COPD. For general respiratory care and cough, lobelia and wild cherry have been used (Skidmore-Roth, 2001). Lobelia is contraindicated in a client who has congestive heart failure or dysrhythmias, and wild cherry is contraindicated in a client who has respiratory or cardiovascular depression (Skidmore-Roth, 2001). If the client is self-medicating with ginseng, tachycardia and hypertension can result if he or she also ingests caffeinated beverages, such as coffee or tea (Kuhn, 2002). St. John's wort taken in combination with theophylline can decrease the serum level of theophylline, making it less effective as a bronchodilator (Kuhn, 2002). Theophylline should not be used concurrently with the herb guarana, as it also contains theophylline (Kuhn, 2002). The benefits of herbal interventions should be weighed against the harmful side effects that could exacerbate COPD or the complications of cor pulmonale and respiratory failure.

More research is needed regarding the benefits of complementary therapies in the treatment plan of end-stage COPD. Spirituality also plays a role in fostering a positive attitude in the client and the maintenance of hope in family members. PC of the older adult encompasses the physical, psychological, and social domains of care. Complementary therapies can be incorporated with other pharmacologic and nonpharmacologic modalities in the care of the older adult with end stage of COPD.

### Death of the Older Adult With Chronic Obstructive Pulmonary Disease

The death of the elder client with COPD is commonly the result of respiratory failure (Barnes, 2001). Respiratory failure can be due to the development of either hypoxemia or hypercapnia. The older adult may initially present with dyspnea, disorientation, or confusion. Vague symptoms such as tachypnea, tachycardia, and restlessness can occur. If respiratory failure is due to hypercapnia, the client may become stuporous or lapse into a coma (Barnes, 2001). Cyanosis is a late sign of respiratory failure. Therapeutic interventions are based on the etiology of the respiratory failure. Supplemental oxygen may be delivered either noninvasively or via mechanical ventilation. Dyspneic symptoms are treated with opiates, bronchodilators, and anxiolytics.

Due to the unpredictable and variable trajectory in patients with COPD, few of these patients are offered hospice care at the end of their lives (Curtis, 2008).

## Exhibit 14.7

### National Hospice and Palliative Care Organization; Criteria for Admission to Hospice in Patients with COPD

#### Primary

1. Disabling dyspnea at rest
2. Progressive pulmonary disease
3. Increasing emergency department visits or hospitalizations
4. Hypoxemia at rest on supplemental oxygen  
 $PO_2$  less than 55 on  $O_2$   
 $O_2$  sat less than 88 on supplemental  
 $O_2$   
 Or  
 Hypercapnea:  $PCO_2$  greater than 50.

Source: Adapted from Weiss and Lee (2010).

With greater education for patients and families, EOL discussions and optimal care will be improved. Criteria for admission to hospice has been delineated by the National Hospice and Palliative Care Organization and are listed in Exhibit 14.7.

In order to support the family through the death of their loved one, an honest discussion about the dying process needs to occur (Meier et al., 1998). Dyspnea is a symptom that is seen during the dying process of a client with COPD. Family members may panic when these dyspneic episodes occur (Tarzian, 2000). Due to the fact that the patient with COPD has no control over his or her breathlessness (Tarzian, 2000), educating the family and including the family in the management of dyspneic episodes can decrease his or her sense of panic and increase his or her sense of control.

## CONCLUSION

COPD is the third leading cause of death in the United States and it is the leading cause of death due to a respiratory cause; development of this disease occurs as the result of cigarette smoking and exposure to environmental pollution. These factors place older clients at particular risk for developing COPD because they have been exposed to smoking and pollution for an extended period of time. In addition to this, the normal physiologic changes due to the aging process places the older adult at increased risk for the

development of complications, such as cor pulmonale and pneumonia. In order to reduce the risk of developing the complications of COPD, smoking cessation is recommended to the older adult. Pharmacologic modalities focus on improving ventilation, reducing inflammation, and preventing complications. Nonpharmacologic interventions including exercise,

rest, and improved nutrition can be valuable adjunctive therapies in the care of patients with COPD.

PC, integrated throughout the continuum of the disease from diagnosis to EOL, may help to provide comprehensive care that improves QOL, reduces symptoms, and eases suffering for both patients experiencing COPD and their family members.

## CASE STUDIES *Conclusion*

### Mr. H.

Upon diagnosis, Mr. H. was educated about COPD, the progressive nature of the disease, and the variable course of illness. At that time, Mr. H. expressed a need to focus on disease-directed therapy and life-sustaining treatments. The interprofessional team emphasized improvements in QOL. He was started on NRT and successfully stopped smoking 2 years ago. A Tiotropium inhaler was initiated and he reported decreased symptoms of shortness of breath with exertion. Mr. H. also visited with his minister twice a month and enjoys their regular discussions. He began a pulmonary rehabilitation program, with noted improvement in his mood over several months. The interprofessional team continued to work with Mr. H to address his emotional, physical, psychosocial, and spiritual needs. At that time, Mr. H. was interested in aggressive resuscitation efforts including cardiopulmonary resuscitation and intubation in the event his condition deteriorated precipitously. The PC team continued to assess Mr. H.'s goals of care.

### Mrs. S.

The EOL discussions were initiated approximately 2 years ago when Mrs. S. started on home oxygen. At that time, Mrs. S. determined that she did not want intubation or cardiopulmonary resuscitation. An advanced directive was signed. She complained of increased feelings of sadness and depression and was prescribed Zoloft, a SSRI. Mrs. S. developed increased episodes of lethargy, confusion, and dyspnea. Morphine was added to her treatment regimen to ease her breathing. Mrs. S. died at home with her family in attendance 4 months after entering the hospice program.

## Evidence-Based Practice

Stead, L. F., Perera, R., Bullen, C., Mant, D., Hartmann-Boyce, J., Cahill, K., & Lancaster, T. (2012). Nicotine replacement therapy for smoking cessation. *Cochrane Database of Systematic Reviews*, 11, 1–264. doi:10.1002/14651858.CD000146.pub4

### Research Problem

Cigarette smoking contributes to one in every five deaths in the United States (CDC, July 19, 2013). The toll on patients with COPD is even greater with 90% of deaths attributable to cigarette smoking (CDC, 2013). NRT has been used to promote smoking cessation with preliminary evidence revealing that all forms of replacement



therapy contribute to successful quit rates. NRT provides alternative sources of nicotine to assist clients with withdrawal symptoms.

### Design, Sample, Setting, and Methods

This study is a systematic review and meta-analysis exploring the effect of NRTs on the smoking cessation rates at 6 months and 1 year. A comprehensive search was performed by the investigators using search terms “NRT,” and “nicotine” and searching through Medline and Cochrane Library, in addition to Cancerlit and Smoking and Health electronic databases. One hundred and fifty randomized controlled trials and quasirandomized trials were included in the review with over 50,000 participants. Although most of the trials were conducted in primary care clinics, 10 of the trials enrolled clients from inpatient or outpatient facilities. The average age of participants in the trial was between 40 and 50 years and most of the individuals who were recruited smoked a minimum of 15 cigarettes/day. An intention-to-treat strategy was used so that clients who were lost to follow-up were classified as continuing smokers who were not abstinent. The quality of the included studies was marred by some inadequate reporting of allocation procedures and suboptimal randomization procedures. However, a sensitivity analysis excluding trials of unclear risk did not alter the findings.

### Results

The success of smoking cessation was increased by 50% to 70% with the use of NRTs. When all different types of NRT were included, the risk ratio for abstinence was reported as 1.60 (95% confidence interval [CI 1.53, 1.68]). Fifty-six studies evaluated the use of nicotine gum compared with placebo and revealed a risk ratio for smoking cessation of 1.49 (95% CI [1.40, 1.60]). Similar results were found with the nicotine patch with 43 studies finding a risk ratio for abstinence of 1.64 (95% CI [1.52, 1.78]). Although a fewer number of trials explored the use of nicotine tablets, lozenges, intranasal spray, and inhalers, the success associated with these therapies was greater than with either the nicotine gum or patch. Adverse effects of the nicotine products revealed significantly greater risk of palpitations and chest pains.

### Implications for Nursing Practice

All clients who smoke should be assessed at each visit and offered NRT to assist with smoking cessation.

### Conclusion

Strong research supports the use of NRTs to help patients stop smoking. All forms of NRTs are successful; patients may want to choose among the different forms including gums, patches, inhalers, intranasal spray, lozenges, and sublingual tablets.

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# Neurological Disorders

## CHAPTER

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### KEY POINTS

- A growing body of evidence supports that symptoms associated with severe stroke and chronic neurological disorders are amenable to palliative treatment and that quality of life is increased from multidisciplinary approaches to care.
- Common problems faced by patients with these disorders include impairments in cognition, communication, sleep, swallowing, breathing, and mobility, as well as pain, fatigue, and depression.
- To improve treatment choices and end-of-life (EOL) decision making, research is needed to disentangle some difficulties with prognostic criteria for receiving hospice benefits and the accuracy of newer technologies in determining irreversible brain death.

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### CASE STUDY

Mrs. Cohen is an 84-year-old woman in the late stages of Alzheimer's disease (AD). Her dementia has severely impaired her short- and long-term memory as well as her functional ability. Her physical assessment is unremarkable, except for stiff inflexible muscles, arthritic changes, and the start of some contractures. She lives in a nursing home and spends most of her day in her bed repetitively grunting and tapping the side of the bedrails. She verbalizes few intelligible words, continually picks at her clothes, grimaces, and rocks her body. When approached, she yells; when bathed, she screams and exhibits aggressive behavior. Attempts to bring her to the dining room or to therapeutic activities are met with resistance and screaming. Staff has responded by leaving her alone in the room, providing stimulation by keeping the TV on in her room, and hanging a mobile of flowers in her line of vision.

How might Mrs. Cohen's current activity schedule enhance or impede her QOL?

What components should be included in an assessment of Mrs. Cohen?

What drug and nondrug interventions would you suggest to treat Mrs. Cohen?

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This chapter focuses on management of people with stroke, chronic neurological disorders (CNDs), coma, and brain death. Stroke and CNDs, while unique and individualized in many respects, share a cluster of common symptoms and treatment needs. While some people who suffer a stroke recover completely or nearly completely from the event, people with CND often exhibit unresponsiveness or only slight or temporary responsiveness to curative treatments. Symptoms associated with severe stroke and CND are amenable to palliative treatment, and a growing body of evidence supports that QOL is increased from multidisciplinary palliative care (PC) approaches to symptom management (Bede et al., 2011; Blackhall, 2012; Blacquiére, Gubitzi, Dupere, McLeod, & Phillips, 2009; Burton & Payne, 2012; Campbell, Jones, & Merrills, 2010; Higginson et al., 2009; Kuhn & Forrest, 2012; Lökk, 2011; Martin & Sabbagh, 2011; Miller et al., 2009; Miyasaki et al., 2012).

This chapter presents a description of common symptoms experienced from stroke and CNDs, including Alzheimer's disease (AD), and related disorders, Parkinson's disease (PD), multiple sclerosis (MS), and amyotrophic lateral sclerosis (ALS). Comorbid conditions that frequently accompany the latter stages of these illnesses are described as well, as interventions aimed to provide symptom management. Due to the unique assessment and management issues that accompany coma and brain death, these problems and their management are presented in separate sections of the chapter. Issues unique to pediatric coma and brain death are also discussed. All disorders discussed in this chapter except MS are more likely to occur in older adulthood; thus, gerontological issues are incorporated throughout the chapter.

## ■ PREVALENCE, DISEASE TRAJECTORY, AND PATHOGENESIS

### Stroke

Stroke is the fourth leading cause of death and the leading cause of severe long-term disability in the United States. Every 40 seconds, someone in the United States has a stroke. It is estimated that each year 795,000 people will experience either a new stroke (77%) or a recurrent stroke (23%). Eighty-seven percent of strokes are ischemic, 10% are hemorrhagic, and 3% are a subarachnoid hemorrhage (Members et al., 2012). The prevalence of stroke is higher in older adults, African Americans, American Indians/Alaska Natives, persons with lower levels of education, and persons living in the southeastern

United States (Go et al., 2013). Seventeen percent of all strokes occur in people who are older than 85 years (Go et al., 2013). The incidence of stroke is higher in men than women between the ages of 45 and 84 years. However, this changes after the age of 85 years with women having a higher incidence of strokes than men (Go et al., 2013). While stroke is most common in older adults, it does occur in teenagers, children, infants, and unborn babies. Estimates of the overall incidence of stroke in children 15 years of age and younger is 6.4/100,000. In contrast to adults, children have as many ischemic as hemorrhagic strokes (Go et al., 2013). Most people with stroke will survive the initial illness. As a result, there are an estimated 6.8 million stroke survivors in the United States with a projection of an additional 4 million by the year 2030 (Go et al., 2013). The annual death stroke rate fell 36.9% from the year 1999 to 2009. Stroke accounted for approximately 128,931 deaths in the United States in 2011 (Hoyert & Xu, 2012).

The term "stroke" or "brain attack" refers to the sudden onset of a focal or global neurological deficit that lasts longer than 24 hours and is caused by disrupted cerebral vascular circulation. Signs of impairment may be perceptual, motor, cognitive, or speech related. Risk factors include hypertension, disorders of heart rhythm, high blood cholesterol and other lipids, diabetes mellitus, physical inactivity, family history and genetics, chronic kidney disease, and smoking (Members et al., 2012). There are two types of stroke: ischemic and hemorrhagic. Both result in injury to the brain tissue, but the mechanism involved is different. In ischemic stroke, there is decreased or absent circulation to an area of the brain due to an occlusion of a cerebral artery by blood clots (emboli) or by a gradual buildup of plaque and other fatty deposits (thrombi). The majority of occlusions occur from the formation of a thrombus. In a thrombotic event, atherosclerotic blood vessels cause complete or partial blockage of blood flow to a local area in the brain. In an embolic event, however, a clot forms elsewhere in the body, such as in the heart, breaks off and travels through the arterial system and lodges in a cerebral vessel blocking blood flow. Atherosclerotic plaques tend to occur at the arterial bifurcations. Common sites for plaque formation include the internal carotid and vertebral arteries, and the junctions of the basilar and vertebral arteries (Book, 2009).

In contrast to an ischemic stroke, a hemorrhagic stroke is the result of a ruptured intracerebral vessel with leaking of blood into the brain. Ruptured intracerebral vessels occur as a result of hypertension, aneurysm, trauma, erosion of vessels by tumors, arteriovenous malformations, blood coagulation disorders, vasculitis, or drugs. The bleeding that occurs within the brain tissue causes increased



pressure within the skull, resulting in brain cell death. Hemorrhagic stroke can progress rapidly, resulting in coma and frequently death (Book, 2009).

The effects from an acute stroke are dependent upon the site and the extent of the brain damaged. Some of the effects include paralysis, cognitive deficits, speech problems, emotional difficulties, problems with activities of daily living (ADLs), and pain (National Institutes of Health [NIH], 2013). Recovery after stroke is complex and varies in terms of outcomes. The greater the initial damage, the longer and more difficult the recovery and residual disability. Neurologic function begins to improve within a few days after the onset of a stroke, with the greatest gain occurring within the first 4 to 5 weeks (Kreisel, Hennerici, & B  zner, 2007). Neurologic and functional gains can continue over 3 to 6 months; however, they will do so more slowly, “plateauing” (Langhorne, Bernhardt, & Kwakkel, 2011). The National Heart, Lung, and Blood Institute’s Framingham Heart Study reported that among stroke survivors 65 years of age or older at 6 months after discharge, 50% had some hemiparesis, 35% had depressive symptoms, 30% were unable to walk without assistance, 26% were dependent in ADLs, 26% were institutionalized in a nursing home, and 19% were aphasic (Go et al., 2013). The percentage of people dead at 1 year after stroke ranges from 14% to 19% for 45- to 64-year-olds and 23% to 28% for those older than 65 years of age. The percentage of people who die increases at 5 years, with a range from 26% to 41% for 45- to 64-year-olds and 50% to 57% for those older than 65 years of age (American Heart Association [AHA], 2013).

### Chronic Neurological Disorders (CNDs)

AD is the sixth leading cause of death in the United States, accounting for 84,691 deaths in the year 2011 (Hoyert & Xu, 2012). Approximately, 5.4 million people of all ages are living in the United States with AD and this number is expected to increase as the population ages (Alzheimer’s Association, 2012). There are more women than men with AD because women tend to live longer. The greatest risk factor for AD is advancing age (Alzheimer’s Association, 2012). It is estimated that dementia of the Alzheimer’s type affects over 13% of adults older than 65 years or one out of eight people (Alzheimer’s Association, 2012). By 2050, the number of people age 65 and older with AD is projected to almost triple, from 5 million to a projected 13.8 million (Alzheimer’s Association, 2014).

AD is a chronic progressive incurable neurodegenerative disease that is characterized by cognitive loss and neuronal death with significant cortical atrophy

(Kawczynski Pasch, 2009). Known risk factors for AD are increasing age, family history, and genetics; however, biological and lifestyle factors have also been associated with AD (National Institute on Aging [NIA], 2013). The pathophysiological processes that trigger the development and progression of AD remain unclear and complex. There’s no single event identified to date that explains the development of AD; rather, it is heterogeneous (Querfurth & LaFerla, 2010). The hallmark microscopic features of AD are the presence of beta-amyloid containing neuritic plaques and neurofibrillary tangles in the brain (Kawczynski Pasch, 2009). Neuritic plaques occur as a result of an abnormal accumulation and clumping of the beta-amyloid protein between the nerve cells early in the disease process. The clumping by the beta-amyloid protein in the brain is thought to be responsible for blocking cell-to-cell signaling at synapses and triggering inflammation leading to neuronal dysfunction and death. Neurofibrillary tangles form when a different protein called tau twist around each other in a helical fashion inside of abnormal neurons. The neurofibrillary tangle development causes disruption inside the neuron and later neuronal death (Querfurth & LaFerla, 2010). Neuritic plaques and neurofibrillary tangles are found in the hippocampus and other areas of the cerebral cortex. The hippocampus area controls information processing, acquisition of new memories, and retrieval of old memories. In contrast, the cerebral cortex is involved in thinking and decision making (Book, 2009). As a result, people with AD experience progressive memory loss, loss of executive function, language difficulties, psychiatric and behavioral disturbances, and impairment in ability to carry out ADLs (Burns & Iliffe, 2009).

AD progression and rate of decline varies from person to person. People with AD die an average of 4 to 8 years after diagnosis; however, the disease can last for as many as 20 years (Alzheimer’s Association, 2012). The underlying pathophysiological process of AD has been purported to begin years, if not decades, before the clinical symptoms are apparent (Sperling et al., 2011). In 2011, new recommendations from the NIA and the Alzheimer’s Association issued new criteria and guidelines for the diagnosis of AD. One of the decisions was to consider AD a disease with three stages. Stage 1 (preclinical AD) is the period prior to clinical symptoms; however, changes in the brain, cerebrospinal fluid, and/or blood are occurring and can be measured. Stage 1 can last as long as 20 years. Stage 2 (mild cognitive impairment due to AD) involves mild, but measurable changes in thinking with some memory problems. A person in Stage 2 is aware of the change in thinking/memory and this change is noticed by family and friends, sometimes

warranting a visit to the physician. Stage 3 (dementia due to AD) is evident when the person's ability to carry out the functions of daily living is impaired due to memory, thinking, and behavioral symptoms (Alzheimer's Association, 2012).

PD is the second most common progressive neurodegenerative disorder after AD, affecting approximately 1 million people in the United States, with as many as 60,000 new cases appearing each year (Parkinson's Disease Foundation, 2013). This estimate may be low because diagnosis is uncertain and may take several years to conclude PD. Life expectancy for people with PD is not as good as once thought. Willis et al. (2012) found in her study of 138,000 Medicare beneficiaries with PD in 2002, only 35% survived more than 6 years with the condition. Those with dementia (69.6%) were associated with a higher death rate (Willis et al., 2012). PD is the 14th leading cause of death in the United States. The age-adjusted death rate for PD increased 2.9% from 2010 to 2011 (Hoyert & Xu, 2012). PD symptoms mimic other conditions and there is no biomarker for PD. These figures are projected to grow as the age of the population increases. The average age of onset of PD is 60 years; however, 5% to 10% are diagnosed younger than the age of 50. Statistics have shown that men are affected more often than women (National Institute of Neurological Disorders and Stroke, 2013b).

Like AD, the exact etiology of PD is not known. The only known definitive risk factor to development of idiopathic PD is aging. Scientists suspect that both genetics and environmental factors play a role in the development of PD; however, they are unsure of the pathogenic role each plays and in what combination and/or dose. Most cases of PD occur without obvious genetic cause (Parkinson's Disease Foundation, 2013). Possible environmental toxins that have been connected to PD are pesticides/herbicide, exposure to metals, solvents and polychlorinated biphenyls (PCB's), 1-methyl-4-phenyl-1,2,3,6-tetrahydropyridine (MPTP) found in some synthetic forms of heroin, and viruses (National Institute of Neurological Disorders and Stroke [NINDS], 2013b). The hallmark features found in PD are the loss of dopaminergic neurons in the substantia nigra and the presence of Lewy bodies. PD develops when brain cells in the substantia nigra begin to degenerate and die, resulting in progressive development of motor and non-motor symptoms (NINDS, 2013b). This structure makes and stores the neurotransmitter dopamine; the degenerative process results in depletion of dopamine, a compound involved with communication between brain cells. Approximately 60% to 80% of dopamine cells are lost before clinical symptoms start to appear. The four primary motor symptoms are

bradykinesia (i.e., slowness of movement), rigidity, postural instability or balance problems, and resting tremor (NINDS, 2013b). Nonmotor symptoms associated with PD are many, some minor while others debilitating, including depression, emotional changes, difficulty with swallowing and chewing, loss of sense of smell, speech changes, urinary problems or constipation, skin problems, sleep problems, dementia, orthostatic hypotension, muscle cramps and dystonia, pain, sexual dysfunction, and fatigue and loss of energy (NINDS, 2013b). The progression of PD symptoms manifests differently from person to person. In some people, the disease progresses more quickly and in others it may take 20 years or more (NINDS, 2013b). Symptoms usually begin on one side of the body and eventually progress to both sides of the body, causing balance problems and severe disability. In the late stage of PD, people are bedbound and are commonly afflicted by complications such as choking, pneumonia, and falls that can be the contributing factor leading to death (NINDS, 2013b). Currently, there are no curative treatments; however, treatments can markedly reduce symptoms and effectively limit the disability associated with PD (Seppi et al., 2011).

MS is an incurable, inflammatory demyelinating disease that affects the neuronal transmission of the central nervous system (CNS; Rejdak, Jackson, & Giovannoni, 2010). Many researchers believe that MS is an autoimmune disease (NINDS, 2013b). Approximately 250,000 to 350,000 people in the United States are living with MS, with an estimate of 200 new cases a week (NINDS, 2013b). MS can occur between the ages of 10 and 80 years; however, a majority are diagnosed with their first attack between the ages of 20 and 50 years. Women are two to three times more commonly affected than men. The disease is more common in Whites, especially those of northern European ancestry. There is a strong genetic link, especially for first degree relatives where there is approximately a 1 in 40 chance of developing MS (National Multiple Sclerosis Society, 2013). Most people with MS have a normal life expectancy. However, a rare form of the illness can be fatal within weeks (National Multiple Sclerosis Society, 2013).

The exact cause of MS is unknown. MS is thought to be caused by genetic vulnerabilities combined with environmental factors, which subsequently trigger an autoimmune attack on the myelin, nerve fibers, and neurons in the brain and spinal cord (NINDS, 2013b). Scar tissue forms hard sclerotic plaques in multiple regions of the CNS. Early in the illness the myelin sheath is affected; however, the nerve fiber is not allowing nerve impulses to transmit signals through the nerve. As the damage to nerves progresses, the



nerve axons become destroyed and nerve impulses are totally blocked, resulting in permanent loss of function (NINDS, 2013b).

MS is highly unpredictable from person to person. There's no set pattern to nerves affected, thus making it difficult to predict the disease course (NINDS, 2013b). There are four main patterns to the presentation of MS. Relapsing-remitting is the most common form of MS and is characterized by flare-ups that appear for several days to weeks followed by remissions during which not all symptoms resolve completely. Primary-progressive MS is a less common form, in which the disease manifestations gradually worsen over time without periods of remission. The secondary-progressive MS form starts out as a relapsing-remitting course but later progresses to primary-progressive MS. Progressive-relapsing MS is the least common form that is progressive from the beginning with episodes of acute increased worsening of existing symptoms or new ones (National Multiple Sclerosis Society, 2013). Symptoms of MS are not the same for everyone; it depends on the location and extent of damage to the myelin in the CNS. Symptoms can come and go, range from mild to severe, and differ greatly between one relapse to another (National Multiple Sclerosis Society, 2013). Most common symptoms are fatigue, numbness, walking balance and coordination, bowel and bladder dysfunction, vision problems, dizziness, sexual dysfunction, pain, cognitive dysfunction, emotional changes, depression, and spasticity (National Multiple Sclerosis Society, 2013).

ALS or Lou Gehrig disease is a rare but rapidly progressive neurodegenerative disease that affects both upper and lower motor neurons leading to progressive muscle atrophy of the voluntary muscles in the arms, legs, and trunk (NINDS, 2012). The incidence of ALS is higher in men than women and typically strikes people between 40 and 60 years of age (NINDS, 2012). Roughly, 20,000 to 30,000 Americans are living with ALS at any given time with approximately 5,000 new cases diagnosed each year. ALS is a fatal disease; most die from respiratory failure. The average life expectancy after onset of symptoms is 3 to 5 years; however, approximately 10% will survive 10 or more years (NINDS, 2012).

The etiology and pathogenesis of ALS remains unclear and multifactorial, possibly involving both genetics and environmental exposures. However, over the years researchers have only identified a few possible pathogenic processes that occur after symptom onset, such as mitochondrial dysfunction, protein aggregation, generation of free-radicals, excitotoxicity, inflammation, and apoptosis (Gordon, 2011). In addition, only 5% to 10% of the cases are

of the inherited type, leaving 90% of the cases classified as sporadic or meaning there is no clear cause (NINDS, 2012). Diagnosis is made primarily on the medical history and the physical and neurological exam showing upper and lower motor neuron damage that cannot be attributed to other diseases (NINDS, 2012). The sense of sight, touch, hearing, taste, and smell are not affected, while ocular movements, bowel and bladder function, and cognitive abilities are occasionally affected (NINDS, 2012). ALS symptoms can vary from person to person, but the disease always starts off with limb weakness in approximately 65% of the patients (Gordon, 2011). Initial symptoms commonly include twitching, cramping, or stiffness of muscles, muscle weakness affecting an arm or a leg, slurred and nasal speech, or difficulty chewing or swallowing. As the disease progresses, muscle weakness and paralysis spreads to the muscles of the trunk of the body. Eventually, in the more advanced stage of the disease, muscles that control vital functions are impaired, causing difficulties in speech, swallowing, and breathing. Respiratory failure is the cause of most deaths (NINDS, 2012).

## Coma

Coma is the result of injury to the brain and is characterized as a deep state of unconsciousness in which a person cannot be awakened and does not purposefully respond to stimuli (NINDS, 2013a). Those in the deepest coma are not conscious of self or their environment; they show no sleep-wake cycles, no auditory or visual responses, and have reflex and postural responses only to external stimuli (Posner, Saper, & Schiff, 2007). To date, precise estimates of the incidence and prevalence of coma in the United States are not available due to lack of surveillance, incomplete diagnostic codes for stages of recovery, and misdiagnosis in the assessment of disorders of consciousness (McNamee, Howe, Nakase-Richardson, & Peterson, 2012). However, prevalence estimates for vegetative state (now known as unresponsive wakefulness syndrome) and minimally conscious state (MCS) range from 25,000 to 420,000 and 112,000 to 280,000, respectively (Hirschberg & Giacino, 2011). The state of arousal and wakefulness is dependent upon functioning cerebral hemispheres and the brainstem's regulatory system called the reticular-activating system (RAS; Posner et al., 2007). The RAS is located at the core of the brainstem. Damage to either the RAS area or both cerebral hemispheres will result in an altered level of consciousness or coma (Posner et al., 2007). Coma etiology can be classified into one of three main categories: supratentorial lesions,

infratentorial lesions, and metabolic encephalopathy. Supratentorial caused coma results from the formation of a mass (i.e., brain tumor, stroke, head trauma with brain swelling, brain abscess) that expands, producing brain herniation through the tentorial opening into the tentorial compartment, causing fatal brainstem hemorrhages and ischemia (Davis, King, & Schultz, 2005). Infratentorial type coma occurs when a tumor or ischemic stroke involving the brainstem or cerebellum damages or compresses the reticular formation. Metabolic encephalopathy type coma results from a variety of sources that affect the brain chemistry (i.e., drugs, hypoxia, blood glucose abnormalities, organ diseases, B vitamin deficiencies, poor cerebral perfusion, toxins, etc.). Metabolic coma develops acutely and is often reversible if the underlying disorder is treated (Davis et al., 2005). Many comatose patients progress to being brain dead. Diagnosing brain death remains challenging; to date, there is no one specific protocol to determine clinical criteria of brain death (Hills, 2010). Brain death is defined as the irreversible loss of function of the brain, including the brainstem (Posner et al., 2007).

The differential diagnosis for coma includes a structural lesion (stroke, head trauma, tumor), meningeal irritation (infection or bleeding), metabolic encephalopathy (organ failure, drugs), and seizure (Simon, 2000). Getting a history from witnesses or significant others is helpful in making a differential diagnosis. If the coma was preceded by a period of confusion or delirium, this is more consistent with infection or metabolic etiologies, whereas sudden loss of consciousness suggests an intracranial bleed or infarct.

Some of the causes are treatable and reversible and others are not. The prognosis depends upon the cause, the severity of damage, and the site of neurological damage (NINDS, 2013a). A coma usually lasts only a few days to a few weeks and it is rare that a coma would last more than 2 to 4 weeks. However, some comas can last for years (NINDS, 2013a). The most critical factors involved in determining prognosis is etiology of the coma, the clinical depth of coma, and the length of time the person remains comatose. Other factors include age of the person, the neurological findings, and concurrent medical complications (Posner et al., 2007). Poor prognostic signs are when the coma follows cardiac arrest or if the patient has not regained pupillary function or purposeful movement after 72 hours. Coma, due to traumatic head injury, has a worse prognosis in older patients, with patients older than 60 years being three times more likely to die than patients younger than 20 years (Simon, 2000). Most comatose stroke patients do not survive. Medical comorbidities, advanced age,

and complications all negatively affect survival. The majority of coma patients will die in the acute care setting, except for those whose coma is persistent. They are transferred to a long-term care facility for supportive nursing care. Similar to stroke, they may die from the initial damage to the brain, which precipitated the coma or from subsequent complications or comorbid conditions.

After the coma phase, some people gradually recover, some progress into a vegetative state, and others become brain dead. People who do emerge from a coma may have problems with complex thinking, emotional stability, and physical difficulties. The most common cause of death for someone in a persistent vegetative state is infection, such as pneumonia.

The common causes of pediatric coma are injury, shock, metabolic disorders, ingestions, and CNS infections. Altered mental status in children covers a range of behaviors, and irritability, lethargy, changes in feeding or sleeping habits, and other subtle behavioral changes can be indicative of impairments in the child's CNS. History from the caregiver is critical. One recent study suggests that studying reactive encephalographic patterns in comatose children may be useful in prognostication of morbidity and mortality outcomes (Ramachandranair, Sharma, Weiss, & Cortez, 2005).

## ■ COMORBIDITIES

Many of the predisposing factors for stroke, AD, and vascular dementia overlap with cardiovascular disease and include hypertension, diabetes, cigarette smoking, high cholesterol, and African American ethnicity. This can lead to complications with unstable blood pressure, angina, congestive heart failure, myocardial infarction, and arrhythmias (Cechetto, Hachinski, & Whitehead, 2008; Ostwald, Wasserman, & Davis, 2006).

As previously stated, the risk of stroke and most CNDs increases with age and the older patient is also more likely to have coexisting chronic illnesses. People with MS are likely to be younger at age of onset and thus have fewer coexisting chronic problems. Any limitations associated with comorbid conditions can impede functional status and complicate management. Comorbid illnesses have consistently been shown to affect function, mortality, and utilization of services (Studenski, Lai, Duncan, & Rigler, 2004).

People with stroke and CND are susceptible to secondary complications, including pressure sores, malnutrition, venous thrombosis, contractures, pneumonia, conjunctivitis, depression, and problems with



bowel and bladder function. These complications are frequent enough that they should be anticipated, and nursing care should be aimed at prevention, early recognition, and treatment of problems.

In addition, anti-Parkinson drugs are associated with the development of dyskinesias, including on–off phenomena of recurring, sudden changes from dopamine-deficient akinesia to dopamine-induced dyskinesia. Anti-Parkinson drugs may also cause impaired thinking, delusions, and hallucinations.

## ■ COMMON SYMPTOMS AND TREATMENTS

Symptoms vary greatly among people who have had a stroke or neurodegenerative illness, depending on the locations and severity of damage or pathology. Specific chapters in this book that cover management of symptoms such as dyspnea, pain, immobility, and gastrointestinal symptoms should be consulted for an overview of treatment options. This section focuses on some of the PC issues and their management for individuals with stroke and chronic neurodegenerative diseases such as cognition and communication, affect and behavior, recognizing and treating pain, eating and swallowing, dyspnea and air hunger, sleep, and infection.

### Cognition

There is great heterogeneity in cognitive deficits following a stroke. The person can exhibit reduced level of consciousness, attention deficits, and an array of perceptual deficits that commonly impact functional ability. For example, some patients develop neglect or a loss of awareness of their affected limbs. It is associated with right hemispheric strokes and, in the extreme, can result in patients being completely unaware of the left side of their body or to stimuli coming from the left side of their environment. Patient safety is compromised as neglect can increase the risk of injury and falls.

Neurodegenerative illnesses are associated with the development of cognitive deficits; symptoms worsen as the illness progresses. Early in AD, short-term memory, judgment, and visuospatial problems are common. During later stages, the person has severe impairment of all cognitive functions and may no longer recognize family members. Attention, orientation, and short- and long-term memories are impaired. In PD, it is more common to have impairment of learning and free recall of new information while recognition memory is relatively well preserved (Demakis, 2007). Cognitive changes for people with MS occur in 40% to 60% of cases and mainly affect attention, information processing speed, and episodic memory

(Houtchens et al., 2007; Minden, 2000). Executive dysfunctions are the most common areas affected in those with ALS (Bede et al., 2011).

There is evidence that memantine and cholinesterase inhibitors are modestly effective in decreasing the severity of cognitive deficits in AD and PD. Cholinesterase inhibitors are used in mild to moderate dementia, and memantine alone or in combination with cholinesterase inhibitors is used in the late stages of the illness (Lokk & Delbari, 2012). Reality orientation is not recommended for people with AD, but the use of environmental cues and decreasing visual clutter are recommended. Pleasant music has been found to improve visual attention in patients with unilateral neglect after stroke (Chen, Tsai, Huang, & Lin, 2013).

### Communication

Impairments in communication are common with all disorders discussed in this chapter. Strokes occurring in the left hemisphere, in particular, can impair the ability to communicate. Voice disorders can be grouped into dysarthria and dysphonia. Dysarthria is caused by neurologic damage to the motor components of speech. Impairments in neuromuscular function cause dysarthria in people with PD, MS, and ALS. Dysphonia is disordered sound production at the level of the larynx and may have a neurologic, structural, or functional etiology (Cohen, Elackattu, Noordzij, Walsh, & Langmore, 2009).

Cognitive deficits are associated with receptive and expressive aphasia in the CNDs. As AD progresses to late stage, the number of words in the person's vocabulary is usually limited to 20 or less. Those individuals with expressive aphasia may comprehend spoken language but are unable to express themselves verbally to varying degrees. Receptive aphasia is the result of deficits in receiving the message/auditory perception or retaining it. Due to difficulty expressing their needs or interpreting what is going on around them, aphasic patients may become noncompliant, angry, fearful, or withdrawn.

Difficulty communicating severely reduces QOL. Voice amplifiers may be helpful in the final stages of illnesses in which nerve damage or reduced respiratory support for speech contribute to a soft voice. Surgically placing a tracheoesophageal prosthesis and augmenting an atrophic vocal fold with collagen can palliate the dysphonic patient (Cohen et al., 2009).

The nurse should develop a plan with the interprofessional team for providing meaningful communication and socialization that considers the wishes of the individual and the accommodations needed because of communication deficits. A consistent caregiver or family member is often able to understand speech that

others consider unintelligible. Supporting the remaining demonstrations of attempts to communicate enables the patient to feel connected and accepted; he or she may begin using many more nonverbal cues to communicate needs.

Behaviors listed in Table 15.1 may be used by patients to communicate to the caregiver that there is an unmet need such as pain, hunger, or the need to eliminate or change positions (Kovach et al., 2012). An effective evidence-based intervention for treating pain and other unmet needs in people with dementia who no longer clearly or consistently verbally communicate unmet needs is presented in the “Evidence-Based Practice” section.

Anticipating physical needs decreases frustration for the person who is unable to clearly or consistently verbalize needs. Nonverbal communication through touch, massage, and eye contact should be used. Gestures are a three-dimensional language of communication; waving hello, pointing, beckoning with outstretched hands, and hugging used judiciously by the caregiver may be effective communication tools. Presence of a family member or caregiver conveys to the individual that he or she is not alone and that the individual is respected.

**TABLE 15.1 Behavioral Symptoms of Unmet Needs in People With Impaired Communication and/or Cognition**

■ Any change in behavior
■ Restless movement
■ Moaning
■ Tense muscles
■ Facial grimace
■ Agitation
■ Combative/angry
■ Pulling away
■ Changes in mobility
■ Rubbing/holding or bracing of a body part
■ Crying/tears in eyes
■ Change in sleep
■ Confusion
■ Changes in appetite
■ Verbal perseveration
■ Withdrawal/quietness
■ Increased pulse or respiration

When cognitive impairment is present, the strategies outlined in Table 15.2 may be useful to facilitate communication. A calm, gentle voice communicates safety and security. Listening to the person, even if the message is unclear, communicates respect. Compared to those with mild cognitive impairment, the individual who is severely impaired may require more focused stimulation to elicit a response. Making a compassionate and meaningful connection with a person who has severe dementia will often soothe a troubled anxious state.

## Affect and Behavior

The development of depression, apathy, mood disorders, and anxiety associated with stroke and neurodegenerative illnesses are common. Frontal lobe pathology and disturbed neurotransmitter metabolism increase a person's susceptibility to depression. Also, adapting to the loss of physical or cognitive abilities can be overwhelming. The individual's premorbid personality, coping skills, and resources are all factors in making this adaptation. Medications can contribute to depressive and psychotic symptoms. In people with MS, frontal lobe symptoms of euphoria and pathological laughing and weeping are thought to result from demyelination of nerves (Minden, 2000).

People with CND are both underdiagnosed and inadequately treated for mood and anxiety disorders (Hallford, McCabe, Mellor, Davison, & Goldhammer, 2012). People with neuromuscular problems may appear less animated at baseline, so flat affect and decreased involvement in activity are not useful cues for depression or mood disorders.

A systematic literature review using Cochrane methodology found a lack of evidence of an association between the severity of AD and the prevalence of comorbid depressive symptoms or depression (Verkaik, Nuyen, Schellevis, & Francke, 2007). This review suggests that prevention and intervention strategies for depression should be aimed at all people with AD regardless of their disease severity. Geropsychiatry consultations are often needed to competently assess and treat those with more complicated symptomatology.

There are few systematic studies of psychotherapy and pharmacotherapy in individuals with CND. Evidence supports the use of selective serotonin reuptake inhibitors (SSRIs) as the drugs of choice for depressive disorders because of their safer drug profile, and anxiety disorders may be treated effectively with combined drug and nonpharmacological therapy (Chan, Cordato, & O'Rourke, 2008; Lokk & Delbari, 2012).



**TABLE 15.2 Communication Strategies With the Cognitively Impaired**

■ Make sure the person knows you are present before communicating to avoid startling or frightening the person.
■ Touching the person gently may be used to begin the communication. A conventional handshake may be well tolerated. Assess the person's reaction and gradually increase the use of appropriate touch, if tolerated.
■ Keep voice, facial expression, and body movements calm, slow, clear, and positive.
■ Use short, simple, adult sentences.
■ Use the name of the person most familiar to them. Avoid the use of pronouns.
■ Use visual cues to augment verbal message.
■ Limit choices to two options to avoid overwhelming the person's cognitive ability.
■ Avoid "why" questions which may be perceived as threatening.
■ Avoid negative feedback statements such as "don't..."
■ Avoid working to teach or orient the person. Since short-term memory is severely impaired, this is ineffective.
■ Listen to the person's verbal message attentively and allow enough time for the person to communicate with you.
■ Validate the feelings behind the words. For example, "I hear that you are upset and I am here to help" or "I'm glad you're okay."
■ Tapes of family members may be used to provide simulated presence therapy.
■ End all interactions with positive feedback such as "I appreciate this time with you," or "It was nice to visit with you today."

Behaviors listed in Table 15.1 are common in people with dementia and may indicate an underlying need such as pain or hunger. People with dementia are very sensitive to and reactive to stressful stimuli in the environment though this behavioral response is somewhat less evident in later stages. The person may have active hands and repetitive movements or vocalizations (i.e., perseverance). Delusions and hallucinations may be present and the person may display agitation, wandering, aggressive outbursts, and spontaneous screaming.

The person who has decreased competence, particularly cognitive competence, is more affected by stressors from the environment and has a decreased threshold for tolerating stressors from the environment (Kovach, 2000). Consideration of this environmental vulnerability creates the need for two foundational interventions:

- Provide a positive environment with few environmental stressors.
- Balance sensory stimulating and sensory calming activity throughout the day. (Kovach et al., 2004)

High decibel sound is associated with higher levels of agitation in people with dementia (Joosse, 2012). Health professionals should conduct a noise assessment by listening at various times of the day for sources of noxious or extraneous noise. Eliminate echo, background conversations, and television used

for background sound. Provide brief periods of music listening with selections that are pleasing to the patient (Padilla, 2011). The visually accessible environment may be quite circumscribed, so it is important that it be pleasant and as stress-free as possible. Avoid fluorescent lighting that often creates a glare. Keep some items that are familiar to the person in the immediate area; for example, pictures, afghans, and pillows may convey home and familiarity. Spaces that are too big or too small, as well as cluttered areas, should be avoided. One or two plants or flower arrangements are preferred to an overwhelming clutter of flora. Avoid tactile stressors by keeping the room temperature comfortable. Avoid itchy skin by keeping the skin well lubricated and treating with medicated emollients; flannel sheets and silk pillowcases may provide some comfort.

In addition to decreasing environmental stress, there is a need to balance sensory stimulating and sensory calming activity (Kovach et al., 2004). As the illness progresses, there may be a need for more sensory calming time, and the person will probably tolerate less than 1 hour of activity before needing a decrease in environmental stimulation. Often, only brief visits of 10 minutes or less will be tolerated. The person may need to engage in frequent inner retreat by withdrawing from others. This need should be explained to family so they do not feel shunned; if the patient shuns socialization, allow him or her some solitary time and approach again later.

Agitated behaviors are associated with cognitive impairment and increase in frequency as dementia progresses (Chen, Ryden, Feldt, & Savik, 2000). Social contact and focused, therapeutic stimulation have been associated with decreases in agitated behavior (Draper et al., 2000; McGonigal-Kenny & Schutte, 2006). Stimulation of multiple senses may enhance engagement in the activity. Friendly visiting, hand massage, music listening, and pet therapy are just a few examples of therapeutic activities. Multiple activity therapy books provide suggestions for therapeutic activities that accommodate any level of cognitive or functional deficit and enhance QOL.

Perseverant behavior, defined as repetitive movement or verbalization, may also occur in patients with CND. Perseverance may indicate boredom, discomfort, or an unmet need; it may also be a simple tension reduction mechanism. Calm repetitive movements or verbalizations may be a coping mechanism and not require treatment. It is important to determine if environmental stress needs to be decreased or, alternatively, if stimulating activity should be provided. Health professionals should assess for basic comfort needs: offer a drink, be certain elimination needs have been met, provide a warm blanket or sweater, check for pressure points, and ensure good positioning. If pain is suspected, administer an analgesic.

Aggression and resisting care may also be present. Resisting care may indicate that pain control is inadequate. This behavior is often temporary and so the caregiver should repeat the attempt to provide care following a short break. Paratonia is a primitive reflex that may be present and is often mistaken for resisting care. Paratonia is involuntary resistance of an extremity in response to sudden passive movement. A caregiver who moves a patient's arm may evoke this movement that appears to be resistance to care. Slow and gentle touch decreases the likelihood of inducing paratonia.

Delusions and hallucinations, when present, are a real part of the person's mental life and can be very disconcerting. These alterations in perception often respond well to psychotropic drugs. Caregivers should not agree or disagree with the false perception, but there is a need to provide comforting intervention. For example, saying, "I hear that you are afraid and I will keep you safe," validates feelings and provides reassurance. Distraction or provision of a comforting intervention such as friendly visiting will often soothe the person's troubled state. Also, check to be sure the person's glasses and hearing aid are in place and functioning properly. Many suspected delusions are actually mixed messages resulting from impaired hearing.

## Eating and Swallowing

Dysphagia and aspiration are problematic in stroke and neurodegenerative illnesses. Dysphagia resulting from stroke is temporary in 90% of cases but is a part of general progress of the illness for CNDs discussed in this chapter (Broadley et al., 2005). Dysphasia can occur in oropharyngeal or esophageal phases of swallowing. The oropharyngeal phase is voluntary and depends on motor and sensory pathways triggering a series of movements that move food posteriorly to the oropharynx. Oropharyngeal dysphagia has a neurological cause in 75% of cases (Ertekin & Aydogdu, 2003). Esophageal dysphagia is more likely caused by obstruction (White, O'Rourke, Ong, Cordato, & Chan, 2008). Patients with swallowing disorders are at risk of aspiration pneumonia. Sialorrhoea, or an excessive secretion of saliva, is common for those with PD, ALS, and MS (Andersen et al., 2012). Low food consumption, food pocketing, difficulty manipulating food on the plate and transporting it to the mouth, weight loss, and nutritional impairments are common in PD (Westergren, Ohlsson, & Hallberg, 2002).

The swallowing mechanism is quite complex, involving 26 sets of muscles and six nerves, and is dependent on critical timing of several phases and highly coordinated movement (Shapiro & Downe, 2003). Individuals in the late stages of neurodegenerative diseases will have dysphagia and be at risk of aspiration and malnutrition (Langmore, Grillone, Elackattu, & Walsh, 2009). Management strategies are important in preventing morbidity. All stroke patients should be evaluated by speech therapy to determine if feeding by mouth is safe and if aspiration precautions are needed. Techniques commonly used to assist individuals with dysphagia to swallow safely will be reviewed. Other options for managing eating problems will be discussed.

Prior to the meal, several interventions may be helpful. For example, oral hygiene is important in maintaining a normal viscosity to the saliva, and aggressive oral care may reduce the risk of pneumonia (Marik & Kaplan, 2003). If the person is taking medications that dry the mouth, artificial saliva products should be used. Safe swallowing methods include upright posture, chin-tucking, careful slow swallowing, and specific maneuvers designed to improve swallowing (Marik & Kaplan, 2003). For the person with dementia, providing some cueing that mealtime is coming is helpful. For example, in a long-term setting on units for individuals with late-stage CND, in the late afternoon a tablecloth and vase of flowers are placed on each table to signal that it is the start of evening mealtime. The residents and staff enjoy a glass of nonalcoholic wine together



while listening to relaxing music. It is important to reduce distractions during mealtime, so the focus is on eating and swallowing. If the person is in a long-term care facility, the dining room should optimally seat 16 or fewer residents to decrease the potential for overstimulation. Turning up lights, increasing visual contrasts, and improving acoustics have been suggested to enhance mealtimes in group dining rooms (Brush & Calkins, 2008). Be certain the person is comfortable and that the environment is comfortable and free from odors.

Provide verbal cueing to assist the person to eat; for example, say “the food is coming,” and “swallow now.” Do not rush the person to eat and swallow too quickly, but be aware that excessive time spent at the task may lead to fatigue and decreased eating. Provide positive encouragement during the meal. Plastic utensils should not be used because a biting reflex may occur, especially if the gums or teeth are touched with the utensil. Applying gentle pressure on the jaw and cheek muscles may break the biting reflex. The following feeder behaviors may help to sustain eating behaviors of the patient: talking and reorienting the person to the meal, offering drinks between bites, holding the spoon ready for a bite, and warmly touching the person.

There is a need for research on drugs used to stimulate appetite and promote weight gain in anorexic individuals with neurological illnesses. Dronabinol is a cannabis derivative, which in one study of people with AD was associated with a 0.5 to 1 kg greater weight gain than was placebo (Chapman, 2007).

The person with dysphagia will require alterations in diet. Dieticians can suggest foods that are easier to swallow. Calorie-dense pureed diets and thickened liquids may be used. One large randomized controlled trial found that honey-thick liquids were more effective than nectar-thick liquids, and chin-tucking was least effective. All three interventions were more effective in people with PD than with AD (Logemann et al., 2008). Smaller, more frequent meals are used, and the person often takes in more food at meals earlier in the day. For some people, the stimulation of a soft bolus of food, such as mashed potatoes, may provide more stimuli for swallowing than liquids. The person should drink sufficient liquid to produce straw-colored urine. Consuming 20 to 35 g of fiber each day can help to manage constipation (Shagam, 2008).

For patients who have had a stroke, enteral feedings may be seen as a temporary intervention to allow time for rehabilitation and recovery or as a permanent intervention to prolong life. For those with CND, oral feeding may eventually become impossible and a person should never be force-fed.

The decision to tube-feed is complex and controversial; in addition, the courts have recognized tube feeding as a medical treatment that can be refused. Prior decision making by the patient relative to the desire to initiate assisted feeding is helpful. There are no randomized clinical trials examining the outcomes of tube feeding. In the case of ALS, percutaneous gastrostomy (PEG) tube placement is common and evidence suggests that nutrition and QOL are improved and survival is prolonged (Andersen et al., 2012). There is no evidence that tube feedings reduce incidence of aspiration pneumonia, prolong life, or improve QOL for people with advanced dementia (Gessert, Mosier, Brown, & Frey, 2000). Other possible problems associated with tube feeding include diarrhea, and the need for physical restraints if tubes are pulled, wound infection occurs, and skin breaks down.

## Dyspnea

In people with chronic neurological disease involving motor systems, respiratory insufficiency is common late in the illness. Chronic nocturnal hypoventilation is also common. Weakness of the respiratory muscles produces a restrictive ventilatory defect with resulting atelectasis and a feeling of dyspnea or increased work of breathing. Expiratory weakness is generally more prominent than inspiratory and may contribute to impaired coughing, aspiration, and the development of pneumonia. Thick respiratory secretions may be difficult to manage and uncomfortable. Respiratory insufficiency is particularly severe in ALS and MS.

In people with chronic neurological disease involving motor systems, respiratory insufficiency may cause chronic nocturnal hypoventilation and sleeplessness. Respiratory management of these patients has evolved from no treatment to the use of strategies to avert respiratory failure and to permit the extubation of unweanable patients without a tracheostomy. An international panel, experienced in continuous noninvasive intermittent positive pressure ventilatory support (CNVS), reviewed the strength of evidence for the efficacy of interventions and made recommendations for achieving prolonged survival by CNVS. Controlled studies demonstrated prolongation of survival for several months using nocturnal bilevel positive airway pressure (PAP). Daily air stacking involves the glottis and holding consecutively delivered air volumes from a volume cycled ventilator or a manual resuscitator until no more can be held (maximal insufflation capacity), and is recommended once the vital capacity is lower than 80% of normal. Following air stacking,

a cough-timed abdominal thrust was demonstrated to significantly increase cough peak flow. Because bilevel PAP cannot be used for air stacking, expiratory PAP is counterproductive for assisting weak respiratory muscles and, because portable ventilators eventually become necessary for CNVS, the panel recommended that all patients with the ability to air stack use nocturnal noninvasive intermittent positive pressure ventilation rather than bilevel PAP. The panel unanimously recommended tracheotomy only for patients who cannot maintain a  $\text{SpO}_2$  of greater than or equal to 95%, despite CNVS and mechanically assisted coughing (Bach et al., 2012). One study showed that people with ALS who choose tracheotomy demonstrated a strong attachment to life from the point of diagnosis (Albert et al., 2009). Clinicians are challenged to support this strong desire to live while providing appropriate expectations for life after tracheostomy.

Supplemental oxygen therapy for patients with respiratory muscle weakness is not recommended because it has been found to decrease ventilator drive and worsen high  $\text{CO}_2$  levels, decrease effectiveness of nocturnal bilevel PAP and NIV, and render oximetry ineffective as a gauge of hypoventilation, airway mucus congestion, atelectasis, and pneumonia (Bach et al., 2012).

People who choose to not receive ventilator support need to be given information regarding the mechanism of terminal hypercapnic coma and the resulting peaceful death, so that fear is decreased. Medications discussed in the chapter on dyspnea need to be administered skillfully to successfully prevent the feeling of “choking to death.”

### **Fatigue, Activity, and Sleep**

Fatigue is a subjective feeling of early exhaustion that impacts an individual's ability to interact mentally or physically with his or her environment. It is a commonly reported symptom and can be overwhelmingly debilitating, especially for people with MS (Caminero & Bartolomé, 2011). Research is only beginning to investigate a possible correlation between fatigue and location of damage, such as brainstem and thalamic regions that impact the RAS (Staub & Bogousslavsky, 2001). An understanding of the relationship among fatigue and depression, sleep disturbances, and specific deficits is needed in order to better recognize and treat fatigue.

Sleep disruptions and insomnia are common in people with stroke, dementia, and other neurodegenerative illnesses (Brass, Duquette, Proulx-Therrien, & Auerbach, 2010; Subramanian & Surani, 2007). People with dementia show great alterations in the sleep-wake cycle with increased nighttime

awakenings, decreased time spent awake versus time spent in bed, increased daytime napping, and changes in the amount of rapid eye movement and nonrapid eye movement sleep (Ancoli-Israel & Cooke, 2005; Subramanian & Surani, 2007). Sleep-disordered breathing has been reported in 33% to 70% of people with AD, and obstructive sleep apnea is associated with agitation (Gehrman et al., 2003). Sleep is greatly impaired by involuntary movements and muscle spasms for those with PD and MS, and dyspnea during the night for those with ALS and MS.

Patients should be carefully evaluated for factors that could be contributing to their fatigue, such as anemia, pain, occult infections, hypothyroidism, medications, malnutrition, and sleep apnea (Oken et al., 2006). Adapting the environment to promote sleep, pacing activities, treating pain, and eliminating or reducing any offending medications should be considered possible interventions for people with CND. Relaxation techniques such as breathing exercises, massage, imagery, or music may also promote sleep and reduce fatigue.

Light and fragmented sleep impairs QOL. Nocturnal hypoventilation is discussed under dyspnea. It is important to keep a consistent schedule so that the diurnal rhythm is encouraged. Most people will need an afternoon nap, but keeping the person engaged in some activities during the daytime might help to improve nighttime sleep.

An increase in agitated behavior in the late afternoon or early evening is called sundown syndrome and occurs in some people with dementia (Yevchak, Steis, & Evans, 2012). This often indicates there is a need to improve the balance between sensory stimulating and sensory calming activity earlier in the day (Kovach et al., 2004). Specifically, there may be a need for more physical activity early in the day, followed by an afternoon nap. Then, during the usual sundowning period, the person should be engaged in a quiet one-on-one activity. Also, because of the severe sleep variations experienced by people with CND, try to keep diurnal rhythms intact by keeping lighting low during the night and up during the day. This may require increasing use of artificial light beginning in the late afternoon.

### **Movement**

Stroke and neurodegenerative disease affect movement. These symptoms can severely impact functional ability and QOL. People who suffer from a stroke may display hemiparesis and a variety of symptoms, depending on location and severity of the damage. People with neurodegenerative disease have slowed movement and gait disturbances, which progress so that the person becomes chair-bound or bed-bound.



People with late-stage AD may display primitive reflexes such as hand grasping, sucking reflexes, and paratonia. Paratonia is the involuntary resistance of an arm or leg to movement of the limb by another person. This may be misinterpreted by a caregiver as aggressive behavior, but is actually a reflexive process. Resting tremor may be present as well as muscle rigidity (Kurlan, Richard, Papka, & Marshall, 2000; Wilson et al., 2000).

Late in PD, motor problems result from drug therapy and include dyskinesias (involuntary movements), shorter duration of benefit or lack of benefit from medication, and end-of-dose deterioration. Severe muscle rigidity and hypokinesia contribute to the person becoming bed or chair bound. When movement does occur, the person often needs physical help initiating the movement. Akinesia or freezing of movement becomes debilitating. Giving short-acting levodopa/carbidopa every 3 to 4 hours with catechol-o-methyl transferase (COMT) inhibitors is recommended to minimize episodes of hypokinesia. This regimen causes the least variation of levodopa in blood levels, with less off-time, more on-time, and better QOL (Lokk & Delbari, 2012).

For people with MS, problems with walking, or gait, can arise from muscle weakness or stiffness, numbness, poor balance, spasticity, lack of ability to coordinate muscle movements, extreme fatigue, or visual disturbances. Depending upon the type of MS, symptoms can become progressively worse or come and go over time. People with ALS experience weakness, particularly of the upper limbs, and progressive muscle wasting. The person loses muscle strength, muscle mass, and mobility, until becoming completely dependent. Riluzole has antiglutamate properties and has been shown to slow the course of ALS. It is not considered useful in the later stages (Andersen et al., 2012).

Physical exercise is a cornerstone of rehabilitation following stroke. However, evidence is inconclusive regarding the benefits of cardiovascular exercises on disability, ADLs, QOL, and death (Meek, Pollock, Potter, & Langhorne, 2003). The goals of treatment of PD are to slow progression of the illness and to reduce disability without inducing long-term complications. Motor symptoms associated with PD are disabling. While levodopa/carbidopa is the cornerstone of treatment of motor symptoms of PD, optimal response only lasts 5 to 7 years. The classes of drugs approved for the treatment of PD include dopamine agonists, COMT inhibitors, monoamine-oxidase type B (MAO-B) inhibitors, and anticholinergics. These drugs do not prevent neuronal degeneration but decrease motor symptoms (Lo, Leung, & Shek, 2007). Research is currently focused on developing neuroprotective drugs that will slow or halt progression of PD. Surgical options such as deep brain stimulation

are options for some patients with PD who are not effectively managed through drug therapy.

Research on exercise for people with AD and related disorders has shown maintenance of motor skills, decreased falls, reduced rate of cognitive decline, and improved mood (Teri et al., 2003). A systematic review and meta-analysis showed that strengthening and balance exercises in PD provide benefits to physical function, strength, balance, gait speed, and health-related QOL (Goodwin, Richards, Taylor, Taylor, & Campbell, 2008). Rhythmic auditory stimulation, in which rhythms of sounds function as a cue to stabilize and enhance the organization of movement, may be beneficial for improving gait parameters in stroke patients, including gait velocity, cadence, stride length, and gait symmetry (Bradt, Magee, Dileo, Wheeler, & McGilloway, 2010). For people with ALS, exercise can help to maintain flexibility of muscles but it will not strengthen muscles that have been weakened by ALS. For people with MS, exercise may decrease symptoms but it must be done judiciously as overheating or oversteering the body can actually exacerbate symptoms. Occupational therapy may help patients to maintain independence for longer periods of time as the CNDs progress.

## Pain

Spasticity due to increased muscle tone is common, especially poststroke, with MS and PD and presents as resistance to passive range-of-motion. Brain lesions can interfere with the descending CNS pathways that regulate muscle tone (Barnes & Campbell, 2010). For people with ALS, spasticity can actually be helpful in maintaining function as the rigidity helps replace normal muscle strength, but it causes jerky, hard-to-control movements.

Shoulder pain after stroke is common, affecting from 16% to 72% of patients (Walsh, 2001). Both flaccidity and spasticity in the paretic arm can cause subluxation (partial separation), instability of the shoulder joint, pain, and increased risk of subacromial bursitis. Shoulder hand syndrome or reflex sympathetic dystrophy is due to autonomic dysfunction in the affected upper extremity. Paresis in the shoulder and arm can lead to joint instability and trauma that may trigger overstimulation of the sympathetic nervous system. It develops in stages; typically, there is vasoconstriction in the affected arm with complaints of burning pain. If it progresses beyond 3 months, the limb may develop trophic changes with decreased hair, thin shiny skin, increased or decreased sweating, edema, and bone demineralization. Movement and touch usually cause pain and patients tend to guard the limb, leading to further dysfunction. After

9 months, atrophy and contractures may also occur. Central poststroke pain (CPSP) is described as a neuropathic pain in all or part of the body affected by the stroke that may develop immediately or up to 2 years after the initial stroke (Frese, Husstedt, Ringelstein, & Evers, 2006). It is associated with sensory deficits and tactile allodynia (pain elicited by a normally non-painful stimulus). This often prompts patients to lie perfectly still in order to avoid discomfort.

Pain in MS occurs both as a consequence of the disease process and the resulting disability. Prevalence of pain in patients with MS is nearly 50%, and approximately 75% of patients report having had pain within 1 month of assessment. The presence of pain in patients with MS is associated with increased age, duration of illness, depression, degree of functional impairment, and fatigue. Pain in MS may originate from trigeminal neuralgia, headache, facial pain, tonic seizures, and limb pain. The pain may indicate an underlying inflammatory process or demyelinating lesion affecting a pain pathway (O'Connor, Schwid, Herrmann, Markman, & Dworkin, 2008). Pain associated with optic neuritis is caused by traction of the meninges surrounding the swollen optic nerve (Maloni, 2000).

Dysesthetic extremity pain in people with MS is a result of demyelinating lesions and is described as persistent and burning. Most commonly affected are the legs and feet, but upper extremities and the trunk can also be affected. Pain is often worse at night and after exercise, and may be precipitated by changes in temperature, particularly the use of warm water. Joint pain and back pain are common, resulting from the disease process, steroid-induced osteoporosis, postural changes, immobility, and weakness with improper use of compensatory muscles (Maloni, 2000). Approximately 50% of patients in the late stage of ALS report pain as a result of immobility, ligament laxity, spasticity, fasciculations, muscle cramps, and associated problems (Miller, 2001).

Pain experienced by individuals with stroke and neurodegenerative illnesses may also arise from the medical conditions commonly prevalent in the older age group, or as a result of comorbid conditions such as pressure ulcers, urinary retention, constipation, and contractures. Older people more commonly suffer from arthritis, back problems, and other chronic conditions.

The consequences of untreated pain are far reaching and assessing for pain and treating it early may help to improve psychosocial and functional outcomes. Spasticity is a common problem that can be quite painful and contribute to the development of contractures (Gelber, 2002). While there is a growing interest in the use of cannabinoids for

palliation of refractory spasticity and neuropathic pain in CNDs, controversies remain over risks versus benefits (Peat, 2010). Early and continued range-of-motion exercises done at least twice daily to the affected areas and individualized splinting may reduce the risk of contractures. Given the risk of sedation and mental status changes, particularly in the older adult, the decision to treat pharmacologically must be weighed carefully. Drugs such as baclofen, tizanidine, benzodiazepines, or dantrolene each work slightly differently, but all patients using them must be closely monitored for side effects. Baclofen can also be administered intrathecally for spasticity. Nerve blocks with phenol or botulinum toxin to focal areas of spasticity can be effective for a number of weeks to months but need to be repeated for sustained symptom relief. In order to restore a functional position or facilitate hygiene, surgical tendon release or lengthening can also be an option in extremities with no voluntary movement. Nondrug treatments that may be helpful include the application of heat or cold to areas of spasticity but not if there is reduced sensation given the risk of injury. Gentle massage and relaxation techniques such as imagery or music may also promote comfort (Blatzheim, 2009; Gutsell et al., 2013).

Establishing the underlying cause of the shoulder pain in patients with stroke is necessary when choosing the appropriate intervention. The effect of electrical stimulation on shoulder pain is inconclusive, but it may offer relief for some patients. Intra-articular steroid injections can be helpful, especially with bursitis. Shoulder pain due to spasticity has also responded to intramuscular botulinum toxin injections. Nonpharmacological treatments such as ice, heat, transcutaneous electrical nerve stimulation (TENS), and ultrasound may also relieve pain in some patients. Range of motion exercises, proper positioning, and techniques to manage edema should be initiated immediately poststroke in the affected limb.

Treatment options used for neuropathic pain can include anticonvulsants (e.g., Gabapentin) and tricyclic antidepressants (e.g., amitriptyline and nortriptyline). The risk versus benefit of a trial of a tricyclic antidepressant in an older adult must be carefully considered given the anticholinergic side effect profile. Opiates play a relatively small role in the management of neuropathic pain. Vestergaard, Andersen, Gottrup, Kristensen, and Jensen (2002) found that the anticonvulsant, Lamotrigine, for patients with CPSP reduced pain scores by 30% and, at 200 mg/day, the drug was well tolerated. Another study found Gabapentin effective for paroxysmal pain experienced by people with MS (Yetimalar, Gürgör, & Basoglu, 2004). Adapting relaxation techniques



to assist patients in coping with neuropathic pain may be helpful.

It may be difficult to recognize pain in people who have dementia and/or communication impairment. While self-report remains the gold standard for assessing pain, for those who do not communicate pain verbally, it is important to be vigilant in assessing for potential causes of pain, to observe for changes in patient behavior that may be indicators of pain, to seek surrogate reports from caregivers, and to attempt an analgesic trial if pain is suspected (Kovach et al., 2012). Refer to Chapter 19 for further discussion of pain management.

### ■ ADDITIONAL ILLNESS-SPECIFIC SYMPTOMS

Autonomic nervous system symptoms are most common in MS and PD and can include postural hypotension, constipation bowel dysfunction, urine retention, urgency, and incontinence. Bowel dysfunction may result from both a delay in colon transit time and impaired muscle coordination in the anorectal area (Pfeiffer, 2000). Delayed gastric emptying, caused by reduced parasympathetic activity, can affect the timing of drug response. Damage to the sensory system in MS can cause or contribute to a variety of problems including loss of sensation and sexual dysfunction. Visual dysfunction is common including diplopia, vision loss, and nystagmus.

### Infection

Severe infection, commonly pneumonia and septicemia arising from the urinary tract, may be the cause of death in those with CND. Delayed diagnosis of infection may contribute to the severity of infection because of both altered clinical presentations for infection and inability to clearly report symptoms (Kovach, Logan, Simpson, & Reynolds, 2010). Nurses should work to prevent infection through common practices such as good hand washing, skin care, and adequate hydration. As the illness progresses, the question of how vigorously to treat infection or if one should treat infection at all is commonly raised. A comparison of nursing home residents with dementia in the Netherlands and Missouri found more aggressive treatment of lower respiratory tract infection and lower mortality rates in the Missouri homes. However, parenteral antibiotic treatment was not associated with better outcomes in residents with low to moderate risk of mortality (van der Steen, Mehr, Kruse, Ribbe, & van der Wal, 2007).

### ■ COMA

Initial priority in the emergency management of comatose patients is to evaluate and maintain respiratory and circulatory function and then to establish the underlying disease process. Timely diagnosis will improve the likelihood of reversing the coma, when this is possible, and reducing mortality. The Glasgow Coma Scale (GCS) is often used to assess and score the level of consciousness. Eye opening, verbal response, and motor response to stimuli are evaluated. The Consciousness Scale for Palliative Care (CSPC) is designed to assess consciousness in PC patients. It is easy to use and has good psychometrics with a Cronbach alpha of 0.99, intraclass correlation of 0.99, and correlation with the GCS of 0.82 (Gonçalves, Bento, Alvarenga, Costa, & Costa, 2008).

A pediatric version of the GCS is available (Reilly, Simpson, Sprod, & Thomas, 1988). The CHOP Infant Coma Scale or Infant Face Scale (IFS) may be more useful for children younger than 2 years of age. This scale relies on objective behavioral observations, assesses cortical as well as brainstem function, and is based on infant-appropriate behaviors. It can also be used with intubated patients and has better inter-rater reliability than the pediatric version of the GCS (Durham et al., 2000).

### ■ PALLIATIVE CARE ISSUES

The illness trajectory for patients with CNDs is often long and unpredictable. The prognostic uncertainty is associated with a host of patient, family, caregiving, and reimbursement challenges. Patients with CND have heavy physical and emotional care needs. Care in a hospice or long-term care facility may reduce the caregiving required of the family, but may lead to feelings of loss of control as well as feelings of isolation. Deciding on the preferred setting for EOL care is complex with many factors to consider; family members may disagree with each other or with the individual him- or herself. The nurse can serve as a nonjudgmental listener, can help to explore options, and can facilitate working through the process of decision making with family members.

Regardless of the setting of care, people with CND do not receive enough palliative or hospice care even though overall quality of care is rated highly by family members of decedents. Approximately 11.3% of patients receiving hospice care have a diagnosis of dementia (Mitchell et al., 2007). Health care providers often do not understand that hospice services are extremely helpful to those with noncancer diseases, nor do they understand the criteria or mechanisms

for establishing hospice services in their agencies or homes.

Guidelines established by the National Hospice Organization (NHO) for determining prognosis in selected noncancer diseases, including dementia, stroke, and coma, are designed to predict 6-month mortality so that the person can be entered into Medicare/Medicaid reimbursed hospice services. The accuracy of these guidelines at predicting mortality is debated. Because of the prognostic uncertainty in advanced dementia, the NHO criteria are restrictive and patients who are clearly terminal may still not qualify. Hospice criteria for dementia include (a) dementia severe enough to have reached Stage 7-C of the Functional Assessment Staging (FAST) scale; and (b) the presence of medical comorbid conditions of sufficient severity to warrant medical treatment, whether or not the decision was made to treat the condition. In the chronic phase after stroke, criteria for hospice include either (a) poststroke dementia equivalent to Stage 7-C of the FAST scale; (b) poor functional status, as evidenced by Karnofsky score of less than 50%; or (c) poor nutritional status as measured by weight loss and serum albumin. Patients in coma are eligible for hospice if they show any four of the following: (a) abnormal brainstem response; (b) absent verbal response; (c) absent withdrawal response to pain; (d) serum creatinine greater than 1.5 mg/dL; or (e) age older than 70 years (NHO, 1996).

Family members should optimally be a part of a continued process of decision making throughout the illness trajectory. In the case of illnesses that are associated with dementia, early discussions and assignment of trusted family members to decision-making roles when capacity is compromised are essential. With these illnesses, there is a lot of anticipatory grieving that occurs, and family members need to be supported in accepting their feelings. Acknowledging conflicting feelings, particularly both the dread and desire for the death to occur, as common and natural can be helpful. Early discussions about the typical course of the illness that are honest but sensitive are needed.

Coping with the late stages of chronic neurodegenerative illness is both physically and emotionally demanding. The patient's stress should not be amplified by an awareness of the burden on family or professional caregivers. Discussions about the burdens or problems of caregiving should be held away from the patient. The person should feel cared for and safe.

## Brain Death

Improved medical technology capable of sustaining life and organ transplantation protocols has created circumstances in which the individual may

have cardiopulmonary functions, but is brain dead. Toward the need to define and determine brain death, the President's Commission (1981) developed the Uniform Determination of Death Act that allowed brain death to be a legal definition of death. Declaring a person dead requires that either his or her heart function has ceased or his or her brain no longer functions due to irreversible damage. There is continued controversy and ongoing research to improve accuracy in determining irreversible brain death and a variety of confirming tests have been suggested. These include electroencephalography (EEG), computed tomographic angiography, MRI, and testing of cerebrospinal fluid (Owen, Schiff, & Laureys, 2009; Welschehold et al., 2012). Major differences exist in the guidelines used to determine brain death in major neurological hospitals in the United States (Lessard & Brochu, 2010).

Direct damage to the brainstem (head trauma, intracranial hemorrhage, infarcts, mass lesions) or diffuse damage to neuronal metabolism (drugs, renal failure, hypoglycemia) are the mechanisms by which irreversible brain death may occur. Patients who are being evaluated for brain death are most likely being treated in the ICU or ER. Families need significant education and support throughout the diagnostic evaluation and the process of treatment withdrawal. If brain death has occurred as the result of a long illness with multiple organ failure, they may have had time to absorb information and develop realistic expectations about their loved one's survival, as opposed to a sudden unpredictable trauma. It is important to have staff available who are comfortable discussing the implications of brain death, the need for withdrawal of treatment, and how to incorporate any previous wishes of the patient and requests by the family.

Truog and colleagues (2001) recommend that families be given a very straightforward but compassionate explanation that the patient died when his or her brain died and that treatment is being withdrawn from someone who is already dead. This may relieve feelings of guilt that withdrawal of treatment contributed to the patient's death. Due to the extent of the brainstem injury, brain dead patients do not feel pain. Reassurance that they are not suffering and that measures to ensure patient dignity are in place is important as well as incorporating any cultural or spiritual rituals. Nurses can help to establish an environment where the family feels supported and valued.

Before withdrawing life support, families should be offered adequate time to process and cope with the information they have been given and to spend time with the patient if requested. Discussion of any possible organ donation should be separate from the notification of brain death and should be done by those trained to have such discussions.



## Pediatric Brain Death

The concept of brain death, particularly in children, remains difficult. Because of the gravity of the outcome of the diagnosis of brain death, the process should never be rushed, requires the expertise of multiple clinicians in pediatric neurocritical care, and should be well documented (Mullen, 2013).

The 1987 guidelines for the determination of brain death in children (Guidelines for the Determination of Brain Death, 1987) were recently updated by an interprofessional team of experts (Nakagawa, Ashwal, Mathur, & Mysore, 2011). The patient's history must provide a proximate cause of the irreversible coma and potentially correctable conditions must be excluded. The guidelines include the need for the patient to have coma, absent brainstem function, flaccid tone and absence of spontaneous or induced movements excluding spinal cord reflexes, and meet apnea testing criteria. The period of observation varies by age of the patient (Mullen, 2013). Waiting periods for establishing brain death, particularly of infants and young children, require further research. Also, it is important to be aware of legal requirements specific to states as well as institutional policies regarding brain death and organ procurement.

## Palliative Care Nursing for Comatose and Brain Dead Patients

Assessing for signs and symptoms of discomfort is difficult due to the lack of response to stimuli from patients who are in a coma. It is possible that some comatose patients may feel painful stimulation, but be unable to respond in any meaningful way depending upon the depth of the coma. Physiological responses, such as changes in blood pressure, heart rate, respiratory rate and rhythm, diaphoresis, and decreased oxygen saturation levels, may be possible cues of pain sensation. Monitoring facial electromyography and electroencephalographic tracings have both been used, but they remain invalidated measures. Bispectral analysis using encephalographic signals to assess level of consciousness and comfort during withdrawal of life support has been attempted (Truog et al., 2001). This technology may assess level of arousal, but is not able to quantify pain. The use of analgesics to relieve potential pain in unresponsive patients with diagnoses consistent with pain or undergoing painful procedures should be considered.

Although brain dead patients, by definition, do not feel pain, they should be treated with the intent to maximize their physical integrity and minimize discomfort. Families may be comforted by touching and speaking to them and should be offered privacy to do so. Attention should be focused on the physical and

emotional needs of the family members throughout these events.

## Withdrawal of Life Support

By the time it is determined that any meaningful recovery is unlikely, health care providers may have had the opportunity to process the implications. Families, however, may require additional time and counseling to reconcile with the poor prognosis and the option of treatment withdrawal. It is always a difficult and emotionally charged issue to begin discussing the withdrawal of life support from a patient. Having consistent staff members communicating with families and ongoing opportunities to discuss diagnosis, prognosis, and QOL issues should help to prepare them for potential outcomes.

Information regarding the actual process for withdrawal of treatment can be reviewed to the extent that the family requests; in addition, input from all appropriate disciplines should be encouraged. The actual process of withdrawal needs to incorporate any preferences for timing, those who will be present, and religious and cultural rituals. This promotes the family's ability to infuse personal meaning into the experience. Ideally, this should occur in a calm environment with respect for privacy.

Protocols vary between institutions, and more evidence-based data are needed to determine the optimum management of patients during the withdrawal of life support. Prior to discontinuing mechanical ventilation, all other treatments that do not contribute to the patient's level of comfort and unnecessary electronic monitoring may be discontinued. An intravenous (IV) line may be maintained in order to administer medications. Rubenfeld and Crawford (2001) recommend that, given the uncertainty regarding the potential for pain and suffering in comatose patients, clinicians administer an appropriate level of sedation. However, due to the extent of their neurological injuries, sedation is not required in brain dead patients. Opioids and benzodiazepines are the primary drugs used for sedation and analgesia in comatose patients before and during the withdrawal of life support (von Gunten & Weissman, 2001) and these should be titrated up to effect or comfort.

After removing all other life supportive equipment, ventilator withdrawal in comatose or brain dead patients can be done by simply removing the endotracheal tube (extubation), or by gradually reducing the ventilator settings (terminal weaning). For unconscious patients unlikely to experience discomfort, Truog et al. (2001) suggest rapidly withdrawing ventilator support by removing the artificial airway or disconnecting the ventilator rather than the process of terminal weaning. For any distress during or after

extubation, Pendergast (2002) recommends midazolam (2–5 mg IV every 7–10 minutes) or diazepam (5–10 mg IV every 3–5 minutes) and/or morphine (5–10 mg IV every 10 minutes) or fentanyl (100–250 mcg IV every 3–5 minutes).

Following the withdrawal of supportive measures, the family may need time to share their feelings and have their decisions reaffirmed. Information on grief counseling should be offered to all who were involved in the person's care. Staff members should also have opportunities to debrief after withdrawing a patient from life support. Discussing reactions with coworkers can be therapeutic and lead to quality improvement initiatives.

### ■ RESEARCH IMPLICATIONS REGARDING CARE OF COMATOSE AND BRAIN DEAD PATIENTS

Future research is needed to develop technology that could better assess pain perception in unconscious patients. This same technology might be applied to patients with impairments in cognition or communication as well. Currently, protocols for withdrawal of life support vary within and among institutions. Analysis of staff competencies, perceived patient comfort, and family acceptance to different protocols would support evidence-based clinical guidelines for the care of comatose and brain dead patients. Putting the available resources of the health care system to the most appropriate use takes on added meaning with patients who require advanced technology for life support.

### ■ CONCLUSION

Patients and their families who are dealing with the consequences of stroke, coma, CNDs, or a diagnosis of brain death face enormous challenges and are ideal candidates for PC. Challenges may occur over a

period of hours in the acute care setting with immediate decisions to be made regarding prognosis and life support or they may be experienced for years and require lifelong coping strategies. Expert opinion has shifted toward recommending an earlier introduction of PC for people with neurological diseases (Gofton, Jog, & Schulz, 2009). From a PC perspective, nurses in all settings need to combine knowledge of the disease, its trajectory, and related symptoms with appreciation of the values and goals of the patient and his or her family. Comfort and QOL interventions have been found to greatly assist people to cope with an array of debilitating symptoms.

While nursing spends a good deal of time focused on pain management and symptom control, nurses are also responsible for addressing the QOL needs of patients who are at the end of their lives. Family members may need help learning how to avoid just sitting at the bedside in a “death watch” but rather share meaningful moments with their loved one. Family members and caregivers should still engage the person in activities designed to evoke feelings of pleasure, meaningfulness, and being socially connected. Warm conversation, music and pet therapy, massage, and activities designed to share beauty in the world and to maintain social connections should be a part of everyday life for the noncomatose patient. For families whose loved one is in a coma or determined brain dead, PC nursing can provide information and support along the illness trajectory and into the bereavement period. Such support is central in assisting families to cope effectively with illness and to find strength in facing their loss.

Since patients with serious neurological problems are often not able to advocate for themselves, it is the nurses' responsibility to continue to work to improve the care delivered to this population who are nearing the end of their lives. There is a need for the profession of nursing to develop a host of evidence-based interventions to meet the PC needs of people with serious neurological disorders.

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### CASE STUDY Conclusion

Mrs. Cohen's case, introduced at the beginning of this chapter, is unfortunately not atypical for people with late-stage AD. Her history revealed arthritis of the hands and knees though she currently was not taking any pain medication. Acetaminophen 500 mg was started on a twice a day schedule. The effect was a decrease in screaming and agitated behaviors but she still was resistant and agitated by physical contact. The television was turned off and the mobile was removed to decrease extraneous and potentially confusing environmental stimulation. Mrs. Cohen had a new activity plan that included



two 10-minute sessions of friendly visiting, soft massage and gentle range of motion, music therapy for 15 minutes, and pet therapy twice each week. She was also given a small silk pillow that she enjoyed feeling on her skin. Flannel sheets were applied to her bed to keep her joints warm. Mrs. Cohen was also transferred to a comfortable chair each day and ate at least one meal a day in the dining room. Though she did not participate, she attended the sing-a-long after lunch each day. Following these interventions, her appetite improved; verbalization was more coherent; her gaze often tracked events in the room; and she would smile in response to activities, such as pet therapy and massage. Her agitated behavior and repetitive vocalizations significantly decreased.

Mrs. Cohen had pain, social isolation, and boredom, and was receiving environmental stimulation that exceeded her stress threshold. All of these factors were compromising the quality of her life. Even though Mrs. Cohen was at the end of her life and would die soon, she could still engage in a range of positive activities and stay socially connected. While Mrs. Cohen did not have complex comorbid physical conditions, she clearly needed comprehensive nursing interventions to improve her comfort and QOL.

## Evidence-Based Practice

Kovach, C. R., Logan, B. R., Simpson, M., & Reynolds, S. (2010). Factors associated with time to identify physical problems of nursing home residents with dementia. *American Journal of Alzheimer's Disease & Other Dementias*, 25(4), 317–323.

### Research Problem

People with dementia are at increased risk for delays in recognition and treatment of symptoms, as well as new or exacerbating conditions, because of difficulties perceiving and communicating symptoms. Symptoms can also be more blunted or atypical in older adults. Early recognition and treatment of symptoms may decrease severity of symptoms, prevent comorbid problems, prevent hospitalization, and maintain both physical comfort and QOL. This study described problems developing over 6 weeks in a sample of nursing home residents with moderate to severe dementia. The authors examined the relationship of patient and nurse factors related to the onset of changes in resident symptoms to identification of the existence of the problem.

### Design

The study design was a secondary analysis of data from a randomized double-blinded experiment testing two versions of the Serial Trial Intervention protocol for assessment and treatment of unmet needs in people with advanced dementia who no longer clearly or consistently verbalized symptoms.

### Sample and Setting

Six long-term care facilities in one Midwestern state participated. There were 65 resident participants who had advanced cognitive and functional disorders, had no chronic psychiatric diagnosis other than dementia-associated diagnosis, and were enrolled at least 4 weeks postadmission. Fifteen nurses (11 licensed practical nurses [LPNs], four registered nurses [RNs]) working in the day shift participated.

## Methods

For 6 weeks, the nurse recorded, using a daily tracking form, the behaviors, problems, assessments, interventions, consultations, and new medical orders and diagnoses. Resident data extracted included physical signs, behaviors, and new problems. Nursing care data extracted included assessment skill, time to identify new physical problems, interventions delivered, the start date of a new intervention, and nurse time spent on problems.

## Results

Sixty-one participants (94%) developed new physical problems over 6 weeks and the majority had two or more new problems ( $n = 41$ ; 67%). The majority of these problems involved uncontrolled pain, new infections, and severe psychotic behavior. Musculoskeletal pain occurred frequently and four participants had uncontrolled pain from metastatic disease. Pneumonia, urinary tract infections, and cellulitis were common infections. The time it took from onset of change in condition to identification of the problem ranged from 0.5 days to 29 days and the median was 4 days. Quality of nurse assessment, ratio of new to standard interventions, and presence of specific physical symptoms were all statistically significantly associated with decreases in the days from symptom presentation to diagnosis. Increased length of stay was statistically significantly associated with an increase in days from symptom presentation to diagnosis. A one-unit decrease in nurse assessment skill was associated with a 54% increase in the time to identify new physical problems ( $p < .001$ ).

## Implications for Nursing Practice

Results suggest that the quality of a nurse's assessment may strongly impact the identification of symptom change and new physical problems among nursing home residents with dementia. Improving the vigilance and quality of nursing assessment provided to people with advanced dementia may lead to earlier identification and treatment which, in turn, can increase comfort and QOL, while decreasing costs of care.

## Commentary

Multiple measures were used in this study to ensure accuracy of data collected. The study did lack a comparison group and had a relatively small sample size. Research is needed to determine if better training, use of assessment protocols, or staffing nursing homes with advanced practice nurses is associated with more timely identification of problems, improved QOL, decreased pain, and reduced utilization of health care resources.

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# End-Stage Renal Disease

CHAPTER

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## KEY POINTS

- The incidence and prevalence of end-stage renal disease (ESRD) is increasing as the population ages, the median age of occurrence being 65 years.
  - Patients with ESRD have a high symptom burden and often have multiple comorbid conditions.
  - Patients with ESRD have a shortened life expectancy with a 5-year survival probability of 38, which are worse statistics than that of most cancer diagnoses. The survival rate for those older than 65 years is as low as 14%; however, life expectancy for children with ESRD has greatly improved.
  - The rate of palliative care (PC) and hospice use by patients with ESRD is around 14%, well below that of the general population.
  - Information is now available that suggests that patients who are typically expected to do poorly on dialysis may benefit as much from conservative management and PC, an option referred to as the nondialysis option, as they would from dialysis.
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## CASE STUDY

Gene lost his renal function from hypertensive nephrosclerosis. Years of poor blood pressure control caused irreversible scarring of the kidneys and finally ESRD. He initially declined dialysis because he simply could not see how, at age 62 years, he could tolerate being tied to any sort of technologic life support, but later agreed to a trial of dialysis. He would ultimately spend 10 years on dialysis.

He and his family adjusted to the 4-hour treatments three times a week. His wife became an expert in managing the various aspects of therapy required to compensate for loss of renal function. Both were kind and supportive to the other patients undergoing dialysis at the same time. They were deeply religious people who brought a sense of grace and peace to the dialysis setting.

Late one August, Gene told his family and the dialysis staff that he could no longer tolerate dialysis. His feelings were understandable but emotionally difficult to accept. Because of progressive severe peripheral vascular disease, he had begun to experience constant pain. The cause of the increasingly intense pain seemed to have been related to a revision of his hemodialysis (HD) graft, which necessitated stopping the Coumadin that he

took to treat chronic deep venous thrombosis (DVT). As his prothrombin ratio (PR) and international normalized ratio (INR) drifted into a nontherapeutic range, he began having problems with thrombosis and leg pain that did not resolve even after the coumadin was resumed. Soon, he was no longer able to participate in church and family events, and this made his quality of life (QOL) unacceptable to him. Each time he had to come in for dialysis, he experienced more pain than was tolerable and he was now wheelchair-bound with leg and foot ulcerations from ischemia. It became clear from his lab values that he was not eating adequately (albumin: 3.1 g/dL; blood urea and nitrogen [BUN]: 30 mg/dL; PO<sub>4</sub>: 3.0 mg/dL—these values should be higher in patients undergoing dialysis).

After extensive discussion with Gene and his wife, the dialysis care team arranged for him to be seen by PC. The doctor skillfully questioned him about what he found intolerable about his current situation. He determined that Gene was not amenable to amputation, which was the definitive treatment for intractable leg pain, and that his pain and subsequent inactivity were the reasons for his desire to withdraw support. He was offered a trial of several different types of pain control medications including oxycontin and fentanyl lozenges for breakthrough pain. Gene agreed to try these therapies for 1 month. If there was no relief at the end of that period, he wanted to withdraw from treatment. He also said that he only wanted to dialyze twice weekly. All understood and sadly agreed.

Miraculously, by the end of the month, the pain, with the help of powerful analgesics, had lessened greatly. Circulation to his legs also improved sufficiently for the ulcers to begin to heal. Gene was able to resume some of his church and family activities. He even decided to dialyze three times weekly. A good prognostic indicator was that his appetite and his lab values improved. Unfortunately, in a short period of time Gene's medical problems would take a turn for the worse and withdrawal from dialysis with hospice care would become necessary.

A diagnosis of end-stage renal disease (ESRD) is an ominous diagnosis, which means a patient has severe end-organ kidney damage and failure. ESRD is the final renal outcome of Stage-5 chronic kidney disease (CKD). Stage-5 CKD is defined as a glomerular filtration rate (GFR) of 0 to 15 mL/min, normal GFR being 60 to 90 mL/min depending on age and race. GFR is a measurement that is calculated from the serum creatinine level and is the accepted method of measuring kidney function (KDIGO, 2012). In ESRD, pathology is so extensive that the normally resilient kidneys finally reach a point where they no longer function well enough to remove fluid, balance electrolytes, stimulate red blood cell production, or accomplish the myriad other physical and chemical processes necessary to sustain life (Exhibit 16.1). ESRD requires renal replacement therapy (RRT) in the form of dialysis or transplantation, or death will occur within a relatively short time unless there is residual renal function (Holley, 2008).

The nursing care of ESRD patients is complex, as they typically have multiple disabling comorbidities that result in often serious complications. Most of the comorbidities such as the different forms that vascular disease can take, for example, myocardial infarction (MI), stroke, hypertension, or the end-organ complications of diabetes, can result in life-changing disability and premature death. Given that the mortality rate for patients with ESRD is high (23% per year) and death often does not occur before a spiral of worsening

symptoms and chronic overall decline, the care challenges that family and staff face are substantial.

When confronted with the extensive list of medical and psychological problems of ESRD patients, the temptation for health care professionals is to focus primarily on correcting laboratory values or on the numerous physical manifestations of ESRD. Not surprisingly, this approach is too simplistic, resulting in less than satisfactory outcomes. The goal for patients with ESRD cannot be simply to preserve life but also to promote QOL. These two goals can be in conflict and can certainly add to the complexity of care. The broader goal that incorporates QOL necessitates the presence of a holistic team committed to a shared decision-making approach, the importance of which is discussed later in the chapter. It is this approach that should prevail throughout the course of ESRD up to and including end-of-life (EOL) care.

In this chapter, palliative care (PC) will be discussed in relation to two groups of patients: ESRD patients who are being treated with ongoing dialysis and ESRD patients who are not being treated with dialysis either because they have decided not to have treatment or they want dialysis treatment withdrawn. QOL is crucial for both groups. In reading the chapter, the following questions should be considered: (a) How can PC improve QOL for ESRD patients? and (b) What makes ESRD unique regarding withdrawal of treatment and PC?



### Exhibit 16.1

#### Functions of the Kidneys

1. *Chemical and water equilibrium:* Kidneys regulate the volume and osmolarity of fluid in the body, as well as electrolyte content and acidity, by varying excretion of ions and water in the urine. Electrolytes excreted or preserved by the kidneys include sodium, potassium, chloride, calcium, magnesium, and phosphate. Numerous bodily functions depend on maintenance of optimal body fluid composition and volume, such as:
  - a. Cardiac output
  - b. Blood pressure
  - c. Most enzymes that function best within a narrow range of pH
  - d. K<sup>+</sup> concentration, which directly affects cell membrane potentials
  - e. Membrane excitability, which depends on calcium concentration in the body fluid
2. *Excretion of metabolic end products and foreign substances:* Kidneys excrete urea and creatinine as well as the end products of metabolized drugs and toxins
3. *Production and secretion of enzymes and hormones:*
  - a. Renin is a catalyst in the formation of angiotensin and a potent vasoconstrictor involved in sodium balance and blood pressure regulation
  - b. Erythropoietin stimulates maturation of erythrocytes in bone marrow and, when absent, causes anemia of chronic renal disease
  - c. 1,25-Dihydroxyvitamin D3 is a steroid integral in parathyroid hormone function and in regulating calcium and phosphorus

Source: Adapted from Schena (2001).

## ■ INCIDENCE AND PREVALENCE

The occurrence of ESRD has reached almost epidemic proportions. In the United States in 2010, the incidence rate was 11,083 new cases per year, well over previous rates. From 1988, the prevalence rates have more than tripled to 415,000 when peritoneal and hemodialysis (HD) patients are combined. The incidence and prevalence rates for ESRD are finally stabilizing after years of dramatic increases; however, the size of the population is still significant. The median age of onset of adult ESRD is 65 years, and not surprisingly the highest rate of occurrence is in the 45- to 64-year age group (38%) with incidence rates increasing in all age groups. As expected, ESRD rates are being driven up proportionate to the overall rate of increase in kidney disease but at a slower overall rate than in the past (U.S. Renal Data

System [USRDS], 2012). The scope of the problem is massive given that an estimated 20 million adults age 20 or older (10% of adult population) have evidence of CKD defined as moderate to severe reduction in GFR (USRDS, 2012). It is believed that a substantial number of these patients will progress to ESRD. The increase in ESRD is also of concern for economic reasons, as it is the only disease entity in the United States that is reimbursed primarily with public funds. Medicare pays for 80% of all costs of care for patients diagnosed with ESRD. This averages around 60,000 dollars per patient per year (USRDS, 2012).

The increase in ESRD is not simply a health problem of the United States. In 2010, it was estimated that the global maintenance dialysis population was just under 2 million, this is an increase of approximately 10% per year (USRDS, 2012). In 2002, Lysaght stated,

If current trends in ESRD prevalence continue, the [world] ESRD population will exceed 2 million patients by the year 2010. The care of this group represents a major societal commitment. The aggregate cost of treating ESRD during the coming decade will exceed \$1 trillion globally, a thought-provoking sum by any economic metric. (Lysaght, 2002)

He was prophetic in his estimate.

Even though ESRD is an international health problem, dialysis is predominantly a phenomenon of highly industrialized societies, with the United States, Great Britain, and Japan accounting for almost 80% of all dialysis treatments worldwide. Developing nations cannot begin to afford the price tag attached to providing RRT when access to basic food and shelter is a daily challenge. To understand the societal scope of the problem, it is important to look at more than incidence and prevalence rates. Survival statistics for ESRD are informative as well. Although the life span of a particular individual with ESRD cannot be reliably known, survival data are eye-opening for the group as a whole. The 5-year survival rate for the U.S. ESRD dialysis population is 32% (USRDS, 2012), which is worse than the 5-year survival rate for many cancer diagnoses, including breast cancer Stages 0 to 3 (93%–41%), colon cancer Stages 1 to 3b (74%–46%), and melanoma Stages 1 to 3b (95%–43%). The death rate among ESRD patients is only slightly lower than the deadliest cancer killers (lung, liver, and pancreas; SEER, 2012). Compared to the general population, ESRD patients live about one-third as long as individuals without ESRD of the same age and gender (Henrich, 2009). In summary, statistics point to the reality that ESRD patients have a shortened life expectancy, thus solidifying

the argument that PC should be a common consideration for this patient population in order to maximize QOL.

## ■ PATHOGENESIS

ESRD can be caused by any disease process that can damage the kidney; however, some diseases are more likely than others to cause irreversible damage and kidney failure. We know that glomerular diseases are the primary cause of ESRD but the reason why diseases cause glomerular destruction still remains unclear. The cause can be diseases that originate in the kidney, or they can be diseases in which kidney involvement is part of a systemic disorder that involves other organs and tissues (Brenner & Rector, 2007). The most common etiologies are diabetes, hypertension, glomerular-nephritis (GN), autoimmune diseases, lupus, and HIV. There are other causes, but they make up a fraction of the etiology of ESRD. Almost 44% of all adult patients are on dialysis because of diabetes. Another 27% are being dialyzed because of uncontrolled hypertension. Sadly, in the case of both these diseases, that is, diabetes and hypertension, if they had been treated aggressively in the early onset phase of the disease, most patients would not end up losing their kidney function. Given that diabetes accounts for almost 50% of the cases of ESRD, the really alarming statistic is that the incidence of diabetes is increasing exponentially worldwide. Recent statistics set the rate of diabetes in the United States at 25.8 million or slightly over 8.3% of the population (Center for Disease Control, 2010).

The underlying renal pathology of ESRD varies according to the etiology. For example, in the case of diabetic kidney disease, the renal lesion includes changes in the afferent and efferent arteries, tubular fibrosis, and thickening of the basement membrane with impingement on the filtration surfaces of the glomerulus. These changes progress as hyperglycemia persists and the resultant proteinuria contributes to hyperfiltration and high GFR and ultimately GFR decline (Eberhard & Wolf, 2010). Each disorder that causes ESRD will have a different histopathologic look, but all will have one thing in common; that is, sufficient destruction of the nephron in one form or another which, if left unchecked, will cause cellular death and ESRD.

In the pediatric population, the most common diagnoses that lead to ESRD differ from those of adults. They include, in order of frequency, GN, vasculitis, and familial including cystic disease, with GN having the best prognosis. The mortality rate for children regardless of cause is 55.3/1,000 patient years, which

is better than that of adults (226/1,000 patient years). The most recent statistics demonstrate an encouraging trend of progress in the 5-year survival rate for children. As with adults, the most common cause of death for children with ESRD was cardiovascular disease, at 25% (USRDS, 2012).

## ■ DISEASE TRAJECTORY

We know, after 30+ years of caring for ESRD patients treated with RRT, that the disease trajectory involves brief stable periods followed by intervals of steady decline and death usually within 5 years of starting dialysis (Holley, 2007). The explanation for this compressed life span includes several speculative considerations and, truthfully, no concrete conclusions. There is simply not enough research available on patients undergoing dialysis at this time to pinpoint the reason for their high death rate.

What is clear is that ESRD patients commonly experience an acceleration of many disease processes found in the general population. If ESRD is added to the diabetic milieu, the diabetic patient's life span is even more shortened. Additionally, ESRD patients most often die from atherosclerosis and MI, which are present at a several fold higher rate of occurrence in patients with ESRD than in the age-matched non-ESRD population (Sarnak & Levey, 2000). The problem is illustrated by an early paper on the incidence of atherosclerotic cardiovascular disease (ASCVD) in dialysis patients. On postmortem examination of 106 consecutive dialysis patients, 86% had some degree of evidence of ASCVD regardless of age, 36% had acute cardiovascular events of some type as cause of death, with 15% dying of MI (Anasari, Kampke, Miller, & Barbari, 1993).

Other reasons exist as well for low survival rates in ESRD. It is well documented that patients on dialysis are immune-suppressed and therefore more prone to serious infection (Hauser et al., 2008), develop genitourinary tumors at a disproportionate rate (Mandayam & Shahinian, 2008), and are considered to be in a constant prothrombotic/proinflammatory state (Henrich, 2009). ESRD patients also develop bone disease and complications such as calciphylaxis due to disorders in calcium, phosphorous, and parathyroid hormone (PTH) levels, which result in disability and premature death. These are only a few examples of why the lives of patients with ESRD are shortened and wrought with disability.

If you are an ESRD provider, disability and death are seen as frequent and expected occurrences. Although a grim fact, this knowledge can serve the useful purpose of guiding the health care team and



patients to make more appropriate therapy decisions that prioritize the desire to preserve QOL and not simply extend life. In fact, the poor prognostic picture associated with ESRD adds to the justification for a conservative treatment approach for many patients. Excluding those patients who have the option of a living donor kidney transplant, the most realistic way for clinicians to think about ESRD is as a chronic disabling, if not terminal, disease for which PC may often be the most effective form of therapy. A PC approach places appropriate emphasis on symptom management and preservation of QOL, as well as quality of the dying process. This, however, should not preclude an aggressive treatment approach when it is warranted. Because ESRD is a chronic disease characterized by early disability and death, it is appropriate to describe the dying trajectory as well.

### Dying Trajectory

As expected, the dying trajectory for ESRD patients is characterized by symptoms of uremia, a term that literally means urine in the blood. Toxins that the kidney normally eliminates, such as urea, excess phosphorus, potassium, acids, hormonal and protein by-products, sodium, and water, begin to accumulate. Symptoms from this abnormal systemic state cause discomfort as fluid and toxins build up. For example, if dying ESRD patients are volume-overloaded, dyspnea is almost certain. Knowing this, PC providers encourage fluid restriction and recommend that fluids be given only to provide comfort from thirst and dry mouth.

Uremic pruritus can become unbearable, and treatment should be performed liberally. (See the PC issues section in this chapter for specific treatment.) Anorexia, nausea, vomiting, and diarrhea are common and should be treated symptomatically as described in other sections of the text. Hyperkalemia commonly occurs and can be the ultimate cause of death. Hyperkalemia first results in hyperreflexia and muscle fasciculation, eventually progressing to muscle weakness, paralysis, cardiotoxicity, and finally death as cells are no longer able to sustain normal electrical activity. One rare but significant symptom that can cause discomfort is hypothermia and should be treated symptomatically with warm blankets and a heating pad (Henrich, 2009).

The final phase of the ESRD dying trajectory is due to the effect of uremic toxins on the brain causing mental and behavioral changes. Memory deficits including amnesia, accompanied by lethargy and drowsiness, are common early symptoms. Gait disturbances, paresthesias, organic psychosis, and finally coma can be seen in the later stages of dying. Families

benefit greatly by being informed prior to the occurrence of these symptoms or their possibility (Henrich, 2009).

### COMMON SIGNS AND SYMPTOMS

Early in the course of CKD, there may be few if any noticeable symptoms of disease, much less evidence of failure. Patients adjust to the gradual onset of symptoms that occur as a result of an underlying chronic disease process, such as diabetes or hypertension, that can ultimately result in ESRD. In fact, progression to ESRD is often so insidious that patients do not realize that they have kidney disease until it is quite advanced. It is commonly revealed for the first time when patients have laboratory work done for other purposes. Even after diagnosis of CKD, the movement to ESRD can be so gradual that patients may be unaware of how badly they feel until they are dialyzed for several weeks and symptoms of uremia subside. Symptoms increase in severity as renal function (GFR) decreases. Different patients develop symptoms at varying GFRs. Amazingly, many patients do not develop life-limiting symptoms of CKD until their GFR is around 10 mL/min or the point at which they have lost 90% of their kidney function. Patients who are Stage 5 CKD with uremic symptoms, or who are underdialyzed or who opted to stop dialysis, will develop the manifestations of uremia found in the second list below. Signs and symptoms include the following:

#### *Early Signs and Symptoms:*

- Hyperparathyroidism
- Anemia
- Hypertension
- Leg cramps, joint pain, gout, arthritis, muscular pains, muscle weakness
- Pitting edema
- Gains in weight with fluid retention
- Weakness and fatigue

#### *Late Signs and Symptoms (Uremic Indicators):*

- Dry scaly skin and pruritus
- Frequent headaches
- Heat or cold intolerance
- Ammonia or urine smell to breath
- Metallic taste in mouth causing food to taste different
- Poor healing of cuts, abrasions
- Chest pain or palpitations
- Dyspnea, orthopnea, paroxysmal nocturnal dyspnea
- Pericardial friction rub
- Easy bruising, purpura, or bleeding
- Anorexia
- Weight loss or gain in weight

- Nausea and vomiting
- Fainting or seizures
- Peripheral neuropathy
- Decreased concentration and memory
- Mood swings and depression
- Grayish-bronze skin color with underlying pallor
- Uremic frost, coma, death (Henrich, 2009)

## ■ COMORBIDITIES AND COMPLICATIONS

This section combines comorbidities and complications of ESRD, as they are intimately connected. Proper management of both determines life expectancy and QOL for ESRD patients. Comorbidities and complications associated with ESRD develop, and because the kidneys are no longer able to fulfill their function, the problems become compounded. Treatments of ESRD (including dialysis) are simply imperfect replacements for the kidneys, a point that is difficult for patients to grasp. Patients often think that dialysis can replace all of the kidney's function.

Most of the comorbidities of ESRD are present for years before the kidneys fail completely. This is important because early identification and treatment of comorbid conditions by a nephrology team can often delay ESRD and, when dialysis is required, help the patient arrive at that point in reasonably good health. Early referral to nephrology can save kidneys and prolong lives as well as ward off or delay debilitating complications. Only 25% of adults and 40% of pediatric ESRD patients receive pre-ESRD care by a nephrologist (USRDS, 2012). This is important because aggressive treatment of hyperglycemia, hypertension, anemia, bone disease, and lipid disorders prior to the onset of ESRD improves survival statistics and nephrologists are aware of this and motivated to act accordingly.

The greater the number and severity of the comorbidities, the lower the survival rate. For example, diabetes mellitus effectively ages a dialysis patient by a decade (Henrich, 2009). Consider that an adult with CKD alone has an increased relative risk of dying as compared to an adult with CKD, diabetes, and congestive heart failure (CHF), who has a relative risk of dying with a greater than twofold higher probability (USRDS, 2012).

The age of the patient also plays a role in the type of complications and their outcomes. Both children and older patients with ESRD present special challenges because of the unique comorbid conditions and ESRD-related complications that are superimposed upon the normal anatomic and physiologic changes associated with those age groups. For example,

pediatric patients with ESRD almost universally have growth failure, often necessitating the use of growth hormone, which has complications associated with it. Disease management for pediatric ESRD patients is also so specialized that adult nephrologists are often ill prepared to care for this age group; therefore, to improve outcomes, a distinct subspecialty has emerged. Elders also often have age-related complications in addition to their ESRD complications as well. For example, they may have age-related osteoporosis as well as bone disease associated with ESRD or cognitive effects of aging that make following treatment regimens even more challenging than they already are.

Finally, one of the most controllable causes of complications in ESRD is adequacy of dialysis treatment. The care team typically has the capability to increase the quality of dialysis for almost every patient. Research has shown that dialysis adequacy can be estimated using a formula based on pre- and posttreatment BUN levels and that there is an optimal level of dialysis that should be achieved. If patients have inadequate dialysis, they are more prone to develop many of the complications associated with uremia such as infection, anemia, and overall poor QOL. Dialysis adequacy is improved when patients have functional dialysis vascular access, receive their full treatment as scheduled, and are dialyzed with the correct size artificial kidney for the correct amount of time, just to name a few of the variables that need to be considered.

A brief review of the major comorbidities and complications associated with ESRD and their palliative treatment options follows. Treatment of these problems would be appropriate for patients who are continuing dialysis. If a decision is made to withhold or withdraw dialysis, then it would not be reasonable to treat most of the conditions discussed in this section unless there is some residual renal function. Without residual renal function, treatment would move into a hospice mode using appropriate palliative options to promote a compassionate death. If there is a small degree of residual kidney function, it might be appropriate to treat the complications of renal failure actively to promote QOL up to the point of death. This is referred to as the conservative or nondialysis option and is discussed in a later section.

## Disorders of Calcium, Phosphorus, and Bone

The calcium-phosphorus imbalance associated with ESRD is responsible for many of the most discouraging and disabling complications that these patients face. The most common calcium-phosphorus disorder is a type of bone disease referred to as renal



osteodystrophy (RO). RO is the result of the effects of secondary hyperparathyroidism or hyperparathyroidism that arises initially not from pathology of the glands themselves but as a result of another disease process. Hyperparathyroidism often begins to develop when the GFR is 50 to 70 mL/min, which is very early in the course of renal failure. Certain factors increase the secretion of PTH, which maintains serum calcium levels. The factors that cause this upregulation of the parathyroid glands in ESRD include hypocalcemia, diminished circulating levels of activated vitamin D (calcitriol), and phosphate retention.

Why does this triad of events occur? First, serum calcium levels fall as pathologic changes associated with kidney failure cause retention of phosphorus. The high levels of serum phosphorus cause calcium to couple with phosphorus and become less available to the cells. This upregulates the parathyroid glands to secrete PTH, which stimulates calcium retention and normal reabsorption by the kidney. However, the diseased kidney cannot retain calcium, so the feedback system fails to accomplish the goal of raising serum calcium levels.

Another major cause of secondary hyperparathyroidism is that calcitriol or activated vitamin D decreases. Calcitriol is synthesized in the kidney and acts on cells in the parathyroid gland to reduce PTH synthesis when there is adequate calcium absorption. So the normal response to low serum calcium is to upregulate calcitriol. Unfortunately, in uremia, calcitriol is less available (cannot be synthesized) and the calcitriol receptors in the parathyroid glands become reduced in number and less sensitive to calcitriol. The combination of low calcium levels and insufficient calcitriol then cause the parathyroids to produce more PTH.

Further, hyperphosphatemia, which occurs in late-stage CKD and ESRD, directly stimulates PTH secretion. Without medical and dietary intervention, these events cause the glands to enlarge and continue to increase the production of PTH. The constant, high levels of phosphorus and PTH and low levels of serum calcium cause calcium to be leached from the bone, thereby causing the unique form of bone thinning and weakening seen in ESRD (Henrich, 2009). It is a complex cycle that requires aggressive intervention, or QOL becomes drastically reduced as bone pain, fractures, and decreased mobility occur.

One of the most devastating complications of the calcium-phosphorus imbalance associated with ESRD is metastatic calcification or calciphylaxis. Prolonged elevation of PTH, as well as calcium-phosphorus complexing, leads to calcium-phosphorus being deposited in blood vessels, tissues, organs, and joints. In severe cases, the calcium deposits inflame the conjunctiva and produce palpable deposits under the

skin that can become infected and cause tissue breakdown. This can be extraordinarily painful and is difficult to treat. The best treatment for calciphylaxis is prevention, which involves maintaining calcium and phosphorus balance through diet and the use of phosphate binders, such as the over-the-counter medication of Tums and Renvela that are taken with food. Foods high in phosphorus include dairy products, meats, legumes, nuts, whole-grain breads and cereals, and many soft drinks. Parathyroid levels can also be maintained in goal ranges with the use of prescription synthetic activated vitamin D (calcitriol). In severe cases, when the glands are hypertrophied from continued stimulation due to serum phosphorus levels and have become desensitized to synthetic calcitriol, a parathyroidectomy becomes the treatment of choice. However, this is a last resort because postoperative complication of parathyroidectomy, such as hypocalcemia, can be life threatening and create a treatment challenge for months after surgery (Henrich, 2009).

## Anemia of Chronic Renal Disease

Insufficient production of the hormone erythropoietin by the kidneys is the most common cause of anemia in patients with renal disease. Without treatment, the hematocrit will often range from 18% to 24%. Before the advent of commercially manufactured erythropoietin, dialysis patients were frequently transfused with blood products, exposing them to blood-borne diseases, transfusion reactions, viral infections, iron overload, and immune sensitization. The development of injectable erythropoietin was obviously a tremendous breakthrough in the treatment of anemia of renal disease.

Treatment of anemia with erythropoietin should begin as soon as it is diagnosed, and almost all ESRD patients require it to maintain their hematocrit and to avoid complications associated with anemia. For example, adequate anemia management can help prevent left ventricular hypertrophy (LVH), the development of which increases morbidity and mortality for all patients. When the hemoglobin (hgb) concentration drops below 10 g/dL, patients are particularly prone to develop LVH as well as CHF. So vigilance in diagnosing and aggressively treating anemia may be life preserving. Anemia may be present a year or more before dialysis is indicated and may not be reliably associated with creatinine levels (Parfrey, Lauve, Latremouille-Viau, & Lefebvre, 2009).

Erythropoietin therapy is started in the predialysis period and continued once patients start dialysis. Interestingly, the recommended optimal hgb per hematocrit level for a dialysis patient has recently changed as studies have shown that normal hgb levels may

predispose ESRD patients to worse outcomes than low hgb levels. Recent guidelines from the Kidney Disease Improving Global Outcomes (KDIGO) initiative recommend a target hgb range of 10 to 11.5 g/dL, which is well below the normal adult range. The reason for this is evidence of increased thromboembolic events when the effort is made to normalize the hgb. Erythropoietin can be given subcutaneously or intravenously (IV), and side effects include worsening of hypertension, seizures, thromboemboli, and dialysis graft clotting. It should not be used to treat patients with a known cancer diagnosis.

Additionally, there are complicating factors associated with anemia of renal disease. One is that HD patients lose blood with each dialysis treatment. This necessitates careful monitoring of the hgb. Patients with advanced kidney disease and on dialysis also generally have low iron stores necessitating iron replacement IV, as oral iron is not absorbed well from the gastric mucosa. Finally, any inflammatory process, such as infection or cancer, creates erythropoietin resistance and impairs release of iron from storage sites. Hyperparathyroidism can also cause erythropoietin resistance, which is another reason to actively control this disorder.

### Cardiovascular Disease

As previously mentioned, cardiac complications are the leading cause of death in the ESRD population, as the prevalence of cardiovascular disease is elevated in this group because of their increased risk of atherosclerosis. Risk factors for atherosclerosis include diabetes mellitus, hypertension, and factors associated with uremia such as hypertriglyceridemia, hyperparathyroidism, vascular calcification, abnormal calcium and phosphorus metabolism, and elevated levels of inflammatory mediators. As mentioned, LVH is also common in the dialysis population and is a strong risk factor for cardiovascular mortality.

Because the morbidity of cardiovascular disease influences the quality and ultimately the length of life in ESRD, prevention and treatment are crucial. Treatment includes screening for LVH and coronary artery disease (CAD); treating hypertension and hyperlipidemia using goals for patients who have preexisting CAD; low-sodium and low-fat diets; fluid restrictions; maintaining a calcium/phosphorus product below 55, which is obtained by multiplying the serum calcium number by the serum phosphorus number; as well as counseling for smoking cessation, exercise, and aggressive treatment of diabetes mellitus. For patients with CAD, attention to maintaining the hematocrit above 30 can help alleviate anginal symptoms in some cases. Dialysis patients also have

increased risks for endocarditis, pericarditis, and arrhythmias, especially if they are inadequately dialyzed. Sudden death risk is increased and has been linked to hyperkalemia, usually related to dietary intake (Henrich, 2009).

### Dialysis Access Problems

Dialysis access procedures and complications of dialysis access are major causes of morbidity, hospitalization, and cost for dialysis patients. Access problems can significantly affect QOL. Dialysis access is defined as the vascular entry point by which HD is accomplished or the abdominal catheter used for peritoneal dialysis (PD). There are three types of access used for HD. They are, in order of preference, (a) fistula, in which a native artery and vein are joined together to produce one large vessel; (b) graft, in which a synthetic material is used to create a large conduit between an artery and vein; and finally (c) catheter, in which a double lumen catheter is placed in a vein, usually the subclavian. In the case of PD, a catheter is placed through the abdominal wall into the peritoneal space and dialysis fluid is infused into the peritoneal space and drained out through the catheter after an exchange of electrolytes and systemic toxins.

Arteriovenous fistulas are least likely to have complications associated with them. They are the safest type of access and have the lowest infection rate as compared to dialysis catheters or grafts. They are also less likely to cause arterial steal syndromes in which blood supply is routed away from the hand of the access arm, causing ischemic pain. Infection rates are highest in patients who have dialysis catheters, but can also occur with grafts. Graft infections can be superficial or, worse, they may be deep-seated. Both catheter and graft infections can lead to sepsis and require surgical removal or, worse, death from profound infection (Ahmad, 2009).

In the case of both the old and the young, successful access placement and maintenance for dialysis can be complicated by anatomy and physiology. Older patients frequently have peripheral vascular calcification or narrowing caused by diabetes, hyperlipidemia, high phosphorus levels, or hypertension. Placement of vascular access in calcified vessels increases the rate of ischemia and thrombosis. In children, blood vessels are often too small, necessitating the use of the PD modality.

### Intradialytic Hypotension

A combination of factors, associated with the older, sick ESRD population, may cause hypotension during dialysis. Factors such as low cardiac reserve and



autonomic neuropathy can make removing fluid during the dialysis process difficult and uncomfortable for patients. If fluid is removed from the intravascular space too rapidly, it can exceed the plasma filling capacity. When combined with an inability to increase peripheral vascular resistance and the host of drugs that dialysis patients are prescribed, abrupt hypotension can occur. Postprandial hypotension is also common and occurs because of increased blood flow to the stomach and gut to digest food when patients eat during treatment. Dialysis often interferes with meal-times for many patients and they must skip meals to avoid hypotension. As a result, many dialysis units prohibit eating and drinking during dialysis treatment because of this. Complications of intradialytic hypotension include seizures; thrombotic events, such as cerebrovascular accidents, myocardial ischemia, and infarction; and thrombosis of the dialysis access (Henrich, 2009).

Treatment involves careful monitoring of patient's weight and fluid intake between dialysis sessions to prevent the need to take off too much fluid during one dialysis session. Patient education can be useful, but is an area for further research. Immediate treatment for intradialytic hypotension consists of volume replacement with normal saline and placing the patient in a recumbent position. Vigilance by the dialysis staff during treatment is required to identify hypotension as soon as there are detectable signs and to then treat it quickly. Older patients typically cannot tolerate as much fluid removal as younger patients. Ideally, no more than 500 to 1,000 mL of fluid is removed per hour in older patients. Hypotensive episodes are avoided, if at all possible, due to reasons cited previously and because they can leave patients weak, contribute to falls, cause cramping during and after treatment, and decrease QOL (Henrich, 2009).

Some patients cannot take any antihypertensive medication before dialysis, even if their blood pressures are elevated, or they will have severe hypotension during treatment. Using shorter-acting medications in the evening prior to dialysis can help the patient arrive at treatment with a more acceptable blood pressure without the risk of intradialytic hypotension (Schena, 2001).

## Severe Hyperkalemia

The development of severe hyperkalemia by ESRD patients results from reduced or absent renal excretion of potassium in combination with normal or increased intake of potassium in the diet. ESRD patients may have no signs or symptoms of hyperkalemia, or they may have signs as severe as flaccid paralysis. ESRD patients tend to tolerate much higher

serum potassium levels than the population at large, but even they have an upper limit beyond which symptoms and death occur. EKG changes parallel the degree of hyperkalemia. There can be initial tenting of the T wave, then P-wave flattening, widening of the QRS complex, and development of a deep S wave. Ventricular fibrillation is usually the cause of death when hyperkalemia is severe (Schena, 2001).

Emergency dialysis is the treatment of choice for hyperkalemic patients who are already established on dialysis. IV calcium and insulin are also commonly used as mechanisms to drive potassium from the serum into the cell where the effects are neutralized. The use of kayexalate is common for dialysis patients who routinely do not follow a low potassium diet.

## Peritonitis

Peritonitis is a leading complication associated with PD. It is best avoided by emphasizing to patients the need to use aseptic technique when they are working with the dialysis catheter connections. Patients who perform PD are taught to visualize the fluid in each dialysate bag at exchanges for turbidity because it can be an indication of peritonitis. Other symptoms include abdominal pain, fever, or vomiting. The diagnosis is confirmed by the presence of 100 white blood cells/mL of dialysate and later by peritoneal fluid cultures. Catheter removal may be necessary if the infection cannot be cleared with it in place and the patient is then dialyzed using the HD modality. In an effort to prevent catheter site infection, in some facilities mupirocin is routinely applied to the nares of patients several times a week to avoid nose-to-catheter cross-contamination with gram-positive organisms.

Early diagnosis and treatment with antibiotics provide the best chance for cure and preserving the access. Repeated infections can cause scarring of the peritoneum, which may cause failure of this dialysis method and lead to a rare complication, known as sclerosing encapsulating peritonitis. In this disorder, the abdominal organs become wrapped in a fibrous cocoon, causing excruciating pain. Surgery is often required to release the bands and the disorder is often fatal.

Internal and external PD fluid leaks can occur at any time. Common signs of internal leaks are edema of the labia, scrotum, penis, or the soft tissue planes of the catheter insertion site, or a preexisting hernia. Hydrothorax is a rare and life-threatening complication that can occur. External leaks are detected when fluid drains out around the catheter. In either case, PD should be stopped and a workup begun by the nephrology team. Prophylactic antibiotics, such as cephalexin, are commonly prescribed. Temporary HD may be necessary if the workup or treatment is prolonged.

## ■ GENERAL MANAGEMENT—TREATMENT OPTIONS

The following section will address a general care management philosophy and broad treatment options for ESRD, as specific management strategies have been outlined in the preceding section. Adherence to this sound general management approach is the best way to palliate the disturbing symptoms of ESRD. At the end of the section, there is a discussion of the non-treatment option, also known as the nondialysis option, which includes conservative management, or withholding or withdrawing of dialysis.

Care management should be designed to give ESRD patients the best possible medical, psychological, and social outcomes by using a shared decision-making approach as recommended by the American Society of Nephrology and the Renal Physicians Association (Renal Physicians Association/American Society Nephrology [RPA/ASN, 2000]). This approach is compatible with a PC philosophy that effectively utilizes all members of the health care team to achieve treatment goals. The main emphasis is on the alleviation of disabling symptoms and prevention of complications that affect longevity and QOL. Ideally, with shared decision making, patients and providers mutually understand diagnosis and prognosis, and develop treatment goals. Providers are also aware of personal data such as medical and social history and patient preferences including advance directive preferences. The intent of shared decision making is to integrate the patient's and provider's goals into a seamless treatment plan to accomplish desirable endpoints through mutual understanding. This is true whether the treatment goals are designed to preserve life or to allow it to end with care and dignity. The ASA/RPA group established a 10-step process for shared decision making to be used with ESRD patients during the initial discussion of treatment options for ESRD; it focuses primarily on candid communication regarding diagnosis and prognosis and culminates in encouraging patients to explore EOL planning with family and friends (RPA/ASN, 2000).

Included in general palliative treatment strategies are the different dialysis modalities. How renal failure is treated is a significant factor in relief of symptoms and QOL. As previously mentioned, treatment options for ESRD include PD, HD, kidney transplant, or only supportive care. The form of treatment or RRT to be used should be a major focus and lends itself particularly well to the shared decision-making approach. The type of RRT should be decided well in advance of the need for dialysis. In this chapter, transplantation will not be discussed in any depth, as it is a highly specialized field and transplant patients

have very specific PC issues that overlap the discussion of ESRD only if the transplant fails. Once this occurs, then the PC needs are the same as those of ESRD patients.

When should dialysis begin? This is a common question asked by patients and their family. The most appropriate answer is that the presence of uremic symptoms is the best indication for initiation of dialysis. Symptoms that indicate the need to begin dialysis in all age groups include confusion and lethargy (which may indicate uremic encephalopathy), pericarditis, gastritis as manifested by nausea and vomiting, fatigue, accumulation of fluid and dyspnea, anorexia, severe anemia, or hyperkalemia. Patients without symptoms are usually started at a GFR of 10 mL/min or 15 mL/min if they are diabetic (Henrich, 2009).

Indications for choosing one dialysis modality (HD vs. PD) over another include lifestyle choice by the patient, physician preferences, distance to the nearest dialysis center, and concurrent illnesses and their symptoms. Comorbidities, such as CHF or hypertension; contraindications to a specific dialysis modality; financial allocation of scarce resources; vascular access limitations; and provider and patient bias are also considerations. Either type of dialysis can generally be used; however, in the United States, HD is the most frequent form of RRT for adults. PD is the most common modality used in pediatrics due to limited vascular access. Internationally, HD and PD are used in equal proportions (Henrich, 2009). All treatment options are replete with complications, especially for older and younger patients.

Older patients have more complications with HD than with PD. They include arrhythmias, hypotension, vascular-access-related infections, and gastrointestinal bleeding. Both older peritoneal and HD patients often have poor nutrition for a variety of reasons including low income, missing teeth, malabsorption, and impaired gastric motility. PD becomes ineffective more frequently in older patients and they then require backup HD more often than younger patients. Older patients predictably are also hospitalized more frequently than younger patients (Berns, 2012). Because older patients have high complication rates on dialysis, a group of Italian nephrologists explored the role of conservative medical and dietary management of ESRD instead of dialysis in older patients with advanced-stage kidney disease with surprisingly positive morbidity and mortality outcomes (Brunori et al., 2007). The nondialysis option is now recognized as a legitimate treatment option for certain patients as evidence is beginning to accumulate that under the right circumstances outcomes are more or less equivalent between the dialysis and nondialysis cohorts. In renal PC guidelines issued by the



Australian nephrology community, Crail, Walker, and Brown (2013) write,

Not surprisingly nephrologist, dialysis nurses and allied staff, along with patients and families are becoming less certain that dialysis will be the right choice for patients with multiple comorbidities, poor quality of life, nutrition or functional status...Many nephrologist have already made it part of their usual practice to offer a non-dialysis pathway to selected patients....(p. 1)

In all age groups, as patients' physical and emotional health declines, or when patients decide or circumstances dictate that dialysis is not desirable, aggressive palliative and hospice care become crucial in order to preserve QOL, manage symptoms, and promote comfort until death. This may be when patients decline dialysis altogether from the beginning, provider and patient agree that dialysis is not the right option, or dialysis is withdrawn after a trial or at any time if it becomes overly burdensome to the patient. These are all morally valid options, especially for patients with a high symptom burden. Health care practitioners should be prepared to offer a nondialysis option and accept a negotiated decision as long as the patient has the mental capacity to make a decision of this magnitude, the decision maker is clearly making the decision in the patient's best interest, and the decision is not the result of a patient's overwhelming clinical depression.

If there is uncertainty about the best option, a "trial" of dialysis can be suggested with clear stopping points established with the patient, such as time to feel well or finish family or personal business (Robert Wood Johnson [RWJ] Foundation, 2002; RPA/ASN, 2000). The patient who is not mentally competent places the provider in a more difficult situation. Finding the appropriate decision maker and involving the patient in a reasonable way is most important. Often the social worker and the ethics consult team can be helpful in wading through the legal and ethical implications of deciding for or against dialysis for patients who lack mental capacity. The primary question to ask is how would the patient decide if he or she were ever competent or if never competent, and how would a reasonable person decide given the same circumstances.

The health care team should view as ethically equivalent the stopping of dialysis for patients when it is overly burdensome or never starting dialysis when the risk or burden outweighs the benefit. Withdrawal from dialysis cannot be equated with killing the patient. In fact, if there is any difference, it is that a trial of dialysis is in many ways a more life-honoring approach when it is appropriately utilized. According

to government data, withdrawal of dialysis is actively utilized in approximately 20% of cases. In the older dialysis population, withdrawal is the second most common reason for death. In the younger dialysis population, death is usually caused by a secondary disease process (USRDS, 2012).

Interestingly, African American patients are 50% to 66% less likely to stop dialysis than White patients (Oreopoulos, Hazzard, & Luke, 2000). It is not known why there is such a discrepancy associated with race. The most likely patients to withdraw from dialysis are White female nursing home residents older than 65 years of age. Further, they are more likely to have other chronic diseases, such as dementia or malignancy. Patients who perform their own HD at home are more likely to withdraw from dialysis when compared to patients that have in-center HD. Patients elect withdrawal from dialysis most commonly in their third month of treatment (Leggat, Bloembergen, Levine, Hulbert-Shearon, & Port, 1997). Implications for caregivers and management of patients who opt to not start or to withdraw from dialysis are discussed in the next section.

## ■ PALLIATIVE CARE ISSUES

Modern PC has benefited from the efforts of professional groups that have promoted the establishment of clinical practice guidelines (CPGs) that are both general and specific to particular patient populations like ESRD. General PC guidelines include American Association of Colleges of Nursing Guidelines for End-of-Life Care; Hospice and Palliative Care Nursing Competencies; National Quality Forum Guidelines and Preferred Practice for Quality Palliative Care; and Liverpool Care Pathway for the Dying Patient. Guidelines specific to care of ESRD patients include those from the American Society of Nephrology entitled "Shared Decision Making in the Appropriate Initiation and Withdrawal from Dialysis" (RPA/ASN, 2000). This guideline was designed to help nephrology professionals decide who will truly benefit from dialysis. A second guideline is the "End-Stage Renal Disease Workgroup—Recommendations to the Field," which was developed in affiliation with the RWJ Foundation's national program of Promoting Excellence in End-of-Life Care (RWJ Foundation, 2002).

The RWJ workgroup in particular has been instrumental in moving forward the effort to improve PC services for those with ESRD. This group identified the gaps, the lack of consensus, and the absence of available research specific to ESRD PC and made recommendations to address these needs to all involved parties. Based on these recommendations,

a demonstration project, the Renal Palliative Care Initiative (RPCI), was developed by eight dialysis clinics and Baystate Medical Center in Springfield, Massachusetts, with the cooperation of a large nephrology practice. Physicians, nurses, and social workers established a group that became educated in techniques of PC, developed programs to implement PC, and introduced them to the routines of dialysis patient care in the hospital and dialysis units. They also established survey instruments to ask family and patients about the quality of dying (Dialysis Quality of Dying Apgar [DQODA]; Cohen, Poppel, Cohn, & Reiter, 2001) and programs to support bereaved families.

The RPCI developed initiatives to holistically address the needs of patients, families, and the care team as they grappled with the challenges of renal disease, dialysis, and transplantation. They incorporated strategies to help with confronting the inevitability of eventual early death in the ESRD population even while continuing with renal replacement therapies. The group found that the initiatives' measures enabled providers to become more likely to address palliative needs of ESRD patients and they became more proficient in doing so (Poppel, Cohen, & Germain, 2003). Gaps still exist but the RWJ ESRD workgroup provided a well-thought-out plan to improve the QOL and dying for ESRD patients. It is a process that is still in infancy but is slowly changing the lives of ESRD patients for the better.

### Never Starting or Withdrawing Dialysis

Although previously discussed under general PC options, the nontreatment option is reexamined here in more detail to reiterate the need to consider it carefully when treatment possibilities are being developed. As previously stated, the Renal Physicians Association and the American Society of Nephrology (RPA/ASN, 2000) responded to a request by the Institute of Medicine to issue guidelines for evaluating patients for whom the burdens of RRT may substantially outweigh benefits. The report is intended to provide direction to providers who frequently find themselves confronting EOL issues in the ESRD population (Levine, 2001). At the core of the report is the belief that initiation of and withdrawal from dialysis should be a decision that the informed patient actively participates in (RPA/ASN, 2000). The discussion has to be broached in the context of shared decision making, or an interactive mutual relationship between patient and provider.

When discussing the option of never starting or stopping dialysis with patients and families, candor is a most prized professional trait. Candor associated with death is regrettably somewhat rare institutionally

and culturally in the United States. This is partially because American patients and families have an idealized view of the capabilities of medicine. As ethicist Daniel Callahan writes,

We expect medicine to devise ever more ingenious ways to save our lives. That is why the NIH budget has always risen, budget crisis or not....Why should anyone be astonished...that the other message many are trying to deliver—the need to stop treatment—has such a hard time getting through? (Callahan, 1987)

If the illusion is allowed to remain that medicine has an unlimited ability to preserve life, patients suffer as inappropriate care is opted for. Candor regarding QOL, prognosis, and life expectancy is crucial to patients who are considering either withdrawal of dialysis or not starting treatment in the first place.

Openness with patients and families who are considering the nontreatment option is a deeply important part of the holistic care and shared decision making that enables the best, most well-informed decisions to be made by chronically ill ESRD patients. When the limits of medicine and technology are reached, patients are best served when they are accurately informed and all who are significant to them work toward agreement on a plan of care. This means that the team begins the important work of care and comfort both for the dying and for those who remain after the patient's death. The ability to adjust thinking from preservation of life to care of the dying is crucial for the provision of full spectrum therapy, especially when working with a high-risk population, such as ESRD patients. Any lag time in this transition of thought and deed can create both psychological and physical suffering for all involved. When patients indicate a readiness to think of and speak about their death, the proper approach at that point is discussion of hospice care when indicated, available general support, and recognition of the importance of therapeutic presence.

As previously noted, recent evidence also suggests that in some cases QOL and life expectancy for ESRD patients is equivalent whether dialysis is utilized or not (Brunori et al., 2007). There are clearly patients for whom dialysis provides no survival benefit and even if a survival benefit exists it may be tempered by comorbidities such as heart disease and poor QOL (Davison, 2012; Murtagh et al., 2007; Schell, Da Silva-Gane, & Germain, 2013). Included in this group are those patients with poor functional status and high levels of comorbidity. One possible reason for this finding is that there have been improvements in the area of renal supportive care (an emerging term used to describe the care of patients who have opted not to start or have decided to stop dialysis treatment)



and there are now sound resources available to guide clinicians in their care of this patient population if the nondialysis option is chosen (Chambers & Brown, 2010). It is important to note that this term is associated with, but not limited to, EOL care as patients may survive for months with adequate supportive care, which includes excellent symptom management. The focus of this care is on preserving what limited renal function there is, actively managing symptoms, and effective use of advanced care planning (Davison, 2012).

### **Renal Supportive Care: Symptom Management**

Patients with ESRD have unique PC needs often years before death (Davison, 2012). Over 90,000 patients, or 24% of the total dialysis population, died in 2009 (USRDS, 2012) and statistics suggest that less than 22% of ESRD patients are enrolled in hospice or PC programs when dialysis is discontinued (Holley, 2013). Once dialysis is stopped, death usually occurs in 6 to 8 days but can range over weeks to months if there is residual kidney function (Holley, 2008). The work groups and organizations trying to address this gap in the use of PC and hospice services and the need for both for ESRD patients all agree that a good QOL until death is a priority. The only way this can be accomplished is through the provision of excellent PC. It has been shown that PC can provide acceptable QOL. Cohen et al. (2001) surveyed ESRD patients and families who discontinued dialysis and asked what a good death would consist of for them. Their findings were that patients and families defined a good death as one that was pain-free, peaceful, and brief. The researchers developed a tool to evaluate the quality of dying in the ESRD group known as the Dialysis Discontinuation Quality of Dying (DDQOD) tool as well as a second tool, the DQODA, which measures the quality of dying of ESRD patients who did not discontinue dialysis (Cohen et al., 2001). As is the case with other dying patients, families believed that the most distressing symptoms at the EOL were pain, weakness, and dyspnea (Cohen, Germain, Woods, Mirot, & Burleson, 2005). To underscore the importance of adequate symptom management, evidence exists that patients dying from uremia have a symptom burden equivalent to that of patients dying from cancer or heart failure (Murtagh et al., 2007). Several EOL symptoms and their treatment will be reviewed below.

### **Nausea and Vomiting**

If dialysis is withdrawn, or never begun, or it becomes difficult to dialyze patients adequately for any reason,

patients eventually revert to a uremic state where uremic toxins accumulate and can cause chemically induced nausea and vomiting. These two symptoms are reported as highly distressing by sufferers (Neely & Roxe, 2000). The mechanism of nausea associated with uremia is stimulation of the central nervous system (CNS) center referred to as the chemoreceptor trigger zone (CTZ). Blocking receptors in this zone, located in the fourth ventricle of the brain, seems to be the most effective pharmacologic therapy for treatment of metabolically induced nausea and vomiting (Mannix, 2010). The tool recommended by the ESRD workgroup for assessment of the symptom of nausea is the Edmonton Symptom Assessment Scale (Bruera, Kuehn, Miller, Selmsler, & Macmillan, 1991).

Haloperidol and prochlorperazine are two agents that effectively block the CTZ. Haloperidol, which can also treat the confusion that may be present if the patient is close to EOL, is given at 1.5 to 5 mg daily by mouth or subcutaneously but may cause extrapyramidal side effects such as dystonia, dyskinesia, and akathisia at higher doses. Promotility agents such as metoclopramide may be used with caution or serotonergic antagonists like ondansetron may be useful to treat the nausea of uremia as well (Mannix, 2010). Even though treatment is available, further research is still needed to assess and treat uremic nausea and vomiting effectively, as the current treatments have side effects that make them less than desirable.

### **Pain**

Pain can occur from any of several comorbidities of ESRD patients. Cancer and peripheral vascular disease are common causes of pain in this patient population and should be aggressively treated prior to but especially at the EOL. Pain is the symptom most frequently reported by dying ESRD patients (Cohen, Germain, Poppel, Woods, & Kjellstrand, 2000). It is more common when patients die in institutions versus at home and is viewed as being unnecessary and highly treatable.

There are a few important points to be made in the case of pain palliation in ESRD. For hospice patients, analgesics should be used on a regular schedule using the World Health Organization (WHO) analgesic ladder as guidance for the management of pain in ESRD. Even so, there are some drugs that should not be used, and there are some drugs for which dosing should be monitored because their metabolites can accumulate in renal failure and cause unwanted side effects. Opioids are generally metabolized in the liver but some accumulate. For example, demerol should not be used for pain control in ESRD because the metabolite normeperidine accumulates and leads to seizures and neuro-excitation. Propoxyphene is another

opioid narcotic that should not be used because of the accumulation of metabolites. Morphine has a distinct place in ESRD pain management and EOL care for short-term use because of the analgesic effect and the positive effect on dyspnea, but it can accumulate; therefore, side effects such as myoclonus should be carefully monitored (Cohen, Moss, Weisbord, & Germain, 2006). If myoclonus occurs, it can be treated with benzodiazepines such as clonazepam, which may help anxiety as well (Holley, 2008). There is anecdotal evidence that alternative strong opioids (hydromorphone, methadone, and fentanyl) are better tolerated but there is inadequate research to support this presently (Davison, 2007).

## Dyspnea

With the addition of complicating illnesses, respiratory symptoms are not uncommon, and as generalized systemic failure occurs at the EOL, they become more prevalent. Dyspnea, tachypnea, cough, and breathlessness may be common EOL symptoms experienced by patients with ESRD. These are typically the result of hypervolemia, CHF, and pleural effusion or pulmonary edema. Relief of these symptoms is crucial to providing comfort and palliation, especially at the EOL. Prevention is highly desirable and is best accomplished by limiting fluid intake; yet, providing mouth care and even over-the-counter saliva substitutes such as Biotene or Oral Balance to prevent thirst and dry mouth are recommended.

One of the most potent causes of dyspnea is pleural effusion. It may be necessary to remove fluid from the chest by pleural aspiration to relieve air hunger and promote comfort regardless of the phase of the dying trajectory. This procedure can effectively improve symptoms and lessen air hunger, even if death is imminent.

## Pruritus

Pruritus is one of the most bothersome symptoms of ESRD. It is a prominent symptom of uremia and is difficult if not impossible to control for some. One estimate is that 60% of ESRD patients experience it. Multiple reasons are proposed, including hyperphosphatemia, hyperparathyroidism, calcium-phosphorus deposition in the skin, inadequate dialysis, anemia, allergy to the dialyzer materials, and chronic xerosis (Cohen et al., 2006). Palliative treatment should be both preventive and symptomatic. Prevention includes adequate dialysis and lowering of the traditionally high phosphorous and parathyroid levels through a well-controlled diet. When necessary, phosphate binders such as calcium carbonate and Renvela are added at meal times and activated

vitamin D is used to control PTH levels. When prevention fails, symptomatic management with antihistamines such as hydroxyzine or loratadine may be useful. If the drowsiness that often accompanies these preparations is undesirable, oatmeal baths and urea-based topical creams are frequently used.

Since itching from renal failure is thought to be the result of uremic toxin accumulation, it makes sense that in the face of dialysis withdrawal, uremia increases and itching may worsen. Logically, in the hospice setting, continuing to give phosphate-binding drugs, such as calcium carbonate, may be useful to control this uncomfortable symptom; however, these drugs are notorious for their gastrointestinal side effects such as bloating and nausea and so may not be useful in many hospice cases. Other interventions include a 0.5% to 2% phenol solution, Sarna, or other menthol phenol creams and pramoxine topically, as well as systemic therapies such as antihistamines, antidepressants such as paroxetine and mirtazapine, thalidomide, and oral corticosteroids. Prevention of skin dryness is crucial, so avoidance of soap unless necessary is common sense. It is imperative to find at least one intervention that will be effective because pruritus is described as one of the more miserable symptoms to endure (Oreopoulos et al., 2000; Seccareccia & Gebara, 2011).

## Pediatric End-Stage Renal Disease

In the United States, over 40,000 children die from trauma, lethal congenital conditions, or acquired illnesses every year. ESRD falls mostly into the latter category. Pediatric ESRD is devastating but rare. In 2004 the incidence rate was 14 cases per million population with a prevalence of 80 cases per million. In 2011, the incidence was the same but the prevalence was 86 per million (USRDS, 2012).

The cause of ESRD and the primary cause of mortality in pediatrics differ from those of adults. Cystic, hereditary, and congenital diseases account for 32% of all cases of pediatric ESRD and glomerular diseases are responsible for 26% of cases. Polycystic kidney disease and two congenital abnormalities, posterior urethral valves (PUVs) and hypoplastic/dysplastic kidneys, as well as GN of different types are the primary causes of long-term kidney failure in children. According to recent data, congenital abnormalities are increasing and ESRD due to glomerular disease is decreasing (USRDS, 2012). Mortality rates for children are significantly lower than for adults, specifically 41 per 1,000 patient years for patients 19 and younger as compared to 148 per 1,000 patient years for adults. As in adults, cardiovascular disease is still the most common cause of death in pediatric ESRD patients, with infection being the second most common cause of death in pediatric ESRD (USRDS, 2012).



Children account for only a fraction of the total dialysis patients in the United States. Children who develop ESRD have a much greater likelihood (at least 30 times higher) of dying than the general pediatric population. Until recently, there were no gains in pediatric ESRD mortality rates. Current assessment, however, of the USRDS database has shown for the first time that there has been a substantial decrease in the mortality rate among children and adolescents treated with dialysis between 1990 and 2010. Their 5-year survival rate is now around 80%—much better than in the adult ESRD population (Mitsnefes, Laskin, Dahhou, Zhang, & Foster, 2013). Even so, PC is still an important intervention for children with ESRD, but as in the case of adult ESRD it is underutilized.

The issue of PC as it relates to children with ESRD is similar to the issue of PC in adult ESRD in that both children and adults with ESRD may need PC not only as treatment to promote a good death but also to alleviate symptoms during life—or while a cure (transplantation) is being pursued. The American Academy of Pediatrics (AAP, 2000) supports PC throughout the course of a wide range of illnesses, and due to the high symptom burden in ESRD, believes it to be appropriate whether cure is possible or not (AAP, 2000; Himelstein, Hilden, Boldt, & Weissman, 2004). Both curative treatments, which seek to reverse the illness, and palliative treatments that are focused on relieving symptoms, have a place in the care of pediatric ESRD patients. According to the AAP, pediatric ESRD falls into a category of conditions for which PC is appropriate and requires intensive long-term treatment aimed at maintaining QOL (Himelstein et al., 2004). Unfortunately, there is little research available on the quality-of-life (QOL) outcomes of PC in this age group.

### Pediatric Palliative Care Issues

The use of PC and hospice services are relatively low in ESRD in general, but especially so in children. The younger the patient, the less likely is referral for palliation and hospice care. The presumed reason is that attempted curative care is ongoing in the case of pediatric patients, and providers and parents are less willing to move in the direction of stopping treatment or withdrawing dialysis. These two goals do not have to be at odds. The AAP has a helpful position on this dilemma. They recommend the availability of

PC to children with a broad range of illnesses even when cure remains a possibility. The components of PC should be offered at diagnosis and continued throughout the course of illness, whether the outcome ends in cure or death. Himelstein et al. (2004) writes that “Pediatric PC should...intersect with the aims of curing and healing...improving the quality of life...maintaining dignity and ameliorating the suffering of seriously ill or dying children...” (p. 1752). The main issue associated with pediatric PC is helping the patient and family confront the reality of the illness with compassion and hope so that the treatment approach is appropriately (not overly) aggressive. With this approach, the topic of palliation and hospice can be introduced.

### ■ CONCLUSION

ESRD is a chronic disease that is characterized by steady functional decline, a 20% yearly mortality rate, and early death for most patients. It is increasing in incidence and prevalence in all age groups in the United States and globally but to the greatest extent in the 75 and older age group. It is a disease with a high symptom burden that takes a toll on patients and families alike and for which PC is crucial to foster QOL and death.

A shared decision-making model facilitates preservation of patient values and preferences and effective care management across the life span for the patient and his or her family. It is important to note that recent evidence suggests that for patients with multiple comorbidities, advanced age, and limited functional ability, conservative management may be as efficacious as RRT; this should be considered when options are discussed with patients. In all cases, full integration of PC principles and standards provides support for ESRD patients to make the difficult decisions as to whether to start dialysis or to withdraw dialysis once it has been started. PC can offer guidance during the process of living fully until the EOL and who are seeking a good death. As nurses, we are often unable to deliver patients from illness and death for very long, but we can always stand with them in their struggle and ease their suffering by promoting and utilizing effective PC interventions.

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### DISCUSSION QUESTIONS

**How can PC improve QOL for the ESRD patient?**

ESRD is a chronic illness with a high symptom burden and the potential to greatly diminish QOL. This is true whether patients are undergoing dialysis, have chosen a

conservative nondialysis option, or have decided to withdraw from treatment. QOL in all of these circumstances can be poor. It is becoming increasingly clear that palliative treatment strategies are beneficial to ESRD patients as they emphasize informed, holistic, and collaborative decision making, advanced care planning, assessment of adequate treatment of symptoms, and appropriate comfort care of the dying. Given the reduced life expectancy of those with ESRD, early referral to PC is a reasonable treatment option.

#### **What makes ESRD unique regarding withdrawal of treatment and PC?**

When a patient reaches the ESRD level of CKD, the decision not to select a form of RRT most often means that death is inevitable sooner rather than later. The exception to this would be some patients who can be managed for a while using conservative treatment strategies because they have a small amount of remaining renal function. Otherwise, if QOL is unacceptable, stopping or not starting dialysis will result in death in a relatively short period of time. Patients are often alert and awake when they make this decision and they are actively choosing death rather than extending life, which is possible. It is important for health care providers to support this decision as a legitimate option for patients who have the cognitive capacity to make this high-level decision. This can be exceedingly difficult for the family and the health care staff; the support of the PC and hospice team is instrumental in adhering to and honoring the patient's wishes.

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#### **CASE STUDY Conclusion**

Gene's turnaround continued for approximately 3 months, until after Christmas when he began to experience nosebleeds from the Coumadin, deterioration in the perfusion to his legs as the Coumadin dose was reduced, and a resumption of pain.

Gene told his family that he was ready to stop dialysis; he was unwilling to tolerate the current symptoms, but the pain and disability were just too great. He wanted to die at home and his family was committed to granting this last request.

The PC team engaged home hospice services to provide comfort and supportive care. The dialysis team agreed to provide dialysis for fluid removal and comfort on an as-needed basis. This provision proved unnecessary because he never returned to the dialysis center. Those who had cared for him over the years stayed in touch with his wife during the 10-day process of his death. Some nurses visited the home to say good-bye.

He remained committed to not having any more invasive therapy and never wavered from this final decision. Gene spent his last days with his family, his friends and pastors from his church, and the health care professionals who knew him best. As symptoms of uremia emerged, the hospice team treated them. His family faithfully followed directions to not overload him with fluids, as this would almost certainly add to his discomfort.

In the end, he died quietly in the night with his wife of almost 40 years at his side. He had assured her that day that he was ready to die, reliant to the last on his faith. He whispered to her that he would see her again. His loss was difficult for the family, but Gene's faith and conviction eased the pain. The dialysis staff loved him. He was a quiet, respectful man with a smile that illuminated the room. His family was devoted to him as he was to them. He was 72 when he died. The funeral was a tribute to a life well lived. As providers, we gathered with family and friends in the church one last time on his behalf.

Gene's case is paradigmatically significant because of not only what happened and how events occurred but also what did not happen as well. Gene did not die in a hospital cared for by strangers; there were no IV drips, tube feedings, and futile attempts to preserve life when the body was clearly unable to sustain life. All talked, agreed, and were sad but comfortable with the decision. Essentially, this is an example of the beneficial



effect of open dialogue and shared decision making around emotionally difficult topics such as death. Desirable outcomes occur when all involved are willing to speak candidly about prognosis and death with patients and their families and think about death as a part of the care continuum and not as failed therapy.

## Evidence-Based Practice

Murtagh, F. E., Addington-Hall, J., Edmonds, P., Donohoe, P., Carey, I., Jenkins, K., & Higginson, I. J. (2010). Symptoms in the month before death for Stage 5 chronic kidney disease patients managed without dialysis. *Journal of Pain and Symptom Management*, 40(3), 342–352.

### Research Question

What were the most prevalent and severe symptoms of ESRD patients who chose the nondialysis option 1 month prior to their death and which PC interventions are most needed for this population? This research is significant as there is little available information on symptom burden in this patient population.

### Methodology

Longitudinal symptom survey in three United Kingdom dialysis units, using the patient-completed Memorial Symptom Assessment Scale-Short Form (MSAS-SF).

### Findings

Seventy-four patients (mean age: 81 years) were recruited with a response rate of 73%; 49 (66%) patients died during follow-up with a mean age of 81 years. Symptom data were available for 43 (88%) of the 49 participants who died. Median time of data collection was 18 days from death.

The most common symptoms were lack of energy (86%), itch (84%), drowsiness (82%), dyspnea (80%), poor concentration (76%), pain (73%), anorexia (71%), edema of extremities (71%), and dry mouth (71%).

### Conclusion and Implications

Symptoms are numerous and concerning in the patients studied and who were near death, who were conservatively managed, or had Stage 5 CKD. There is considerable need for proactive assessment and management of symptoms at the EOL. The most common symptoms reported also affect QOL until death. It is necessary to better manage symptoms to reduce distress. Regular symptom assessment, as offered by the PC team, is one component of care needed by these patients. However, it is not yet standard practice in nephrology care. Additionally, further research is needed to test interventions to better treat the most common symptoms. Lastly, there is need to develop models of care for these patients as the numbers of Stage 5 CKD patients steadily increase and the conservative management pathway itself becomes more common.

## Evidence-Based Practice

Brunori, G., Viola, B. F., Parrinello, G., De Biase, V., Como, G., Franco, V., ... Cancarini, G. C. (2007). Efficacy and safety of a very-low-protein diet when postponing dialysis in the elderly: A prospective randomized multicenter controlled study. *American Journal of Kidney Diseases*, 49(5), 569–580.

### Research Question

Is it possible to effectively delay the initiation of dialysis in an older (greater than 70 years) ESRD patient population using a supplemental very-low-protein diet (sVLPD)? Are the mortality and hospitalization rates and metabolic markers equivalent over the 1-year course of the study?

### Methodology

Prospective, multicenter randomized controlled study designed to evaluate the non-inferiority of diet vs. dialysis on 1-year mortality assessed by using intention-to-treat and per-protocol analysis. Italian uremic patients without diabetes, who were older than 70 years of age, with GFR of 5 to 7 mL/min (0.08–0.12 mL/s) were randomized to a sVLPD (diet group) or dialysis. The sVLPD is a vegan diet (35 kcal; protein [0.3 g/kg body weight daily] supplemented with keto-analogues, amino acids, and vitamins. Patients following a sVLPD started dialysis therapy in the case of malnutrition, intractable fluid overload, hyperkalemia, or appearance of uremic symptoms. Fifty-six patients were randomly assigned to each group. The median follow-up was 26.5 months, and patients in the diet group spent a median of 10.7 months following an sVLPD. Forty patients in the diet group started dialysis treatment because of either fluid overload or hyperkalemia.

### Findings

A sVLPD seems to be safe when postponing dialysis therapy. There were 31 deaths (55%) in the dialysis group and 28 deaths (50%) in the diet group. One-year observed survival rates at intention to treat were 83.7% (95% confidence interval [CI], [74.5, 94.0]) in the dialysis group vs. 87.3% (95% CI [78.9, 96.5]) in the diet group (log-rank test for noninferiority,  $p < .001$ ; for superiority,  $p = .6$ ): the difference in survival was –3.6% (95% CI [–17, +10];  $p = .002$ ). The hazard ratio for hospitalization was 1.50 for the dialysis group (95% CI [1.11, 2.01];  $p < .01$ ).

### Conclusion and Implications

An sVLPD was effective and safe when postponing dialysis treatment in elderly patients without diabetes. This type of research confirms that for some patients conservative management may be the best option and that dialysis may not automatically be the best treatment given the age of patients and their symptom burden. It is contingent upon the provider team to make sure that patients selected for the nondialysis option are adequately followed for symptom management using evidence-based PC treatment guidelines. From an ethical perspective, dialysis is always appropriate when symptom management is not possible otherwise and the patient requests it. Investigators should honor patients' and families' decisions.



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# End-Stage Liver Disease

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## CHAPTER

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## KEY POINTS

- Liver disease is the fourth leading cause of death in individuals aged 45 to 54 years.
  - Chronic liver disease is the 12th leading cause of death in the United States.
  - Hepatitis C has replaced alcohol cirrhosis as the leading cause for liver transplantation.
  - Given trends in obesity, fatty liver disease may soon become the leading cause of liver failure.
  - The only effective treatment for end-stage liver disease (ESLD) is liver transplantation.
  - Nurses should have a proactive role in educating individuals about the prevention of liver disease.
  - Nurses need to be aware of the pathophysiology and etiologies of liver disease.
  - Patients with ESLD present with malnutrition, muscle wasting, hyperlipidemia, electrolyte imbalances, fatigue, and jaundice.
  - Patients with liver disease benefit from the physical, emotional, social, and spiritual interventions offered through palliative care.
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## CASE STUDY

Ann is a 75-year-old woman with a known history of hypertension and hyperlipidemia. She had recently started insulin for her long-standing diabetes when her oral medications no longer adequately controlled her glucose and she began developing symptoms of retinopathy and peripheral neuropathy. Ann presented to her nurse practitioner with more fatigue than usual, fullness in her abdomen, drowsiness, and severe stomach pain after eating pizza. The ultrasound of her abdomen as a part of a workup for gallstones revealed a large liver and ascites. Biopsy afterwards showed hepatic steatosis or “fatty liver disease.” Lab work showed elevated liver function and anemia. Ann’s evaluation for a liver transplant revealed cardiac and peripheral vascular disease that made her a high-risk candidate for the surgery. Recurring ascites caused shortness of breath and required periodic drainage. After a few months, Ann’s fatigue worsened to the point that she needed assistance with most activities of daily living and she decided to utilize hospice.

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## ■ INCIDENCE AND PREVALENCE

In the United States, 31,903 people died in 2010 from chronic liver disease and cirrhosis, a 3.3% increase from the year before. Death rates from chronic liver disease and cirrhosis are highest among Native-Americans, which is more than double that of Whites and African Americans. The rate among women of all ethnicities is half that of males (Murphy, Xu, & Kochanek, 2013). By the end of 2014, 33,190 men and women will be diagnosed with cancer of the liver and intrahepatic bile duct, and 23,000 will die (Surveillance and Epidemiology and End Results, 2013). The incidence of liver cancer has increased for both men and women from 2000 to 2009. While death rates for lung, colorectal, leukemia, and many other cancers have trended downward during this period, deaths from liver cancer has been increasing for both women and men of all ethnicities with the exception of Asians and Pacific Islanders. This increase has been attributed, in part, to excess body weight (Eheman et al., 2012).

Viral hepatitis is also a leading cause of liver failure in the United States and throughout the world. Vaccinations have led to a sharp decline in incidences of hepatitis A (HAV) and B, but no vaccination or treatment for HCV has yet been developed. As a result, HCV is now the leading cause of chronic liver disease affecting approximately 4.1 million people in the United States and is the primary cause of liver transplantation. IV drug use, high-risk sexual behavior, administration of blood products, tattooing, hemodialysis, and needle stick injuries are some of the key methods of transmission for HCV.

Hepatic toxicity is another cause of liver failure. Ingestion of acetaminophen resulted in 168,093 calls to the American Association of Poison Control Center's National Poison Data System in 2006 alone (Nourjah, Ahmad, Karwoski, & Willy, 2006). This has provoked a nationwide public education program warning that overuse or chronic use of APAP can result in irreversible liver damage. The Food and Drug Administration (FDA) has led a campaign to reduce the amount of acetaminophen in prescription and nonprescription compounds, such as Vicodin and many cold medications. This is critical information for people who ingest two or more ounces of alcohol or its equivalent per day, people who use other medications metabolized by the liver, or parents who administer acetaminophen to their children for pain and fever.

Perhaps the most disturbing, but heretofore under-reported, trend in hepatic disease is the rise in hepatic steatosis or "fatty liver" disease. Fatty liver disease is most often found in patients with type 2 diabetes. Health officials are using the term *epidemic*

to describe the escalation in the prevalence of obesity in the United States. With the rise in obesity has come an increase in the frequency of a constellation of diabetes-associated comorbidities often referred to as "metabolic syndrome." These include the following:

- Abdominal obesity (excessive fat tissue in and around the abdomen)
- Atherogenic dyslipidemia (blood fat disorders—high triglycerides, low high-density lipoprotein [HDL] cholesterol, and high low-density lipoprotein [LDL] cholesterol—that foster plaque build-ups in artery walls)
- Elevated blood pressure
- Insulin resistance or glucose intolerance (the body cannot properly use insulin or blood sugar)
- Prothrombotic state (e.g., high fibrinogen or plasminogen activator inhibitor-1 in the blood)
- Proinflammatory state (e.g., elevated C-reactive protein in the blood)

While estimates of the prevalence of metabolic syndrome vary widely, a study by Kuk and Ardern (2010) estimated that 26% of those 65 years old and younger meet the criteria for metabolic syndrome and the prevalence in those older than 65 years is 55%. It is projected that by the year 2020, fatty liver disease will surpass hepatitis as the primary cause of liver transplantation in the United States (American Liver Foundation, 2008).

## ■ PHYSIOLOGY AND PHYSICAL ASSESSMENT

To understand liver disease, we must first review salient points related to anatomy and physiology. The liver is the largest solid organ in the body and has two primary functions. First, the liver is an essential organ of digestion-producing chemicals that break down food. Second, as the primary organ for the recycling of red blood cells, the liver receives approximately 20% of its oxygen-rich blood flow from the hepatic artery. Critical to understanding end-stage liver disease (ESLD) is knowing that the remaining 80% of the flow is nutrient-rich blood from the stomach, intestines, and spleen via the portal vein (Braun & Anderson, 2010).

The liver is responsible for (Nair & Peate, 2012):

- Synthesis of most serum proteins (albumin, carrier proteins, coagulation factors, many hormonal and growth factors)
- Production of bile and its carriers (bile acids, cholesterol, lecithin, phospholipids)
- Regulation of nutrients (glucose, glycogen, lipids, cholesterol, amino acids)



- Metabolism and conjugation of bilirubin, cations, as well as medications and excretion of these compounds into the bile or urine

The assessment of the liver begins with a history that includes the past and present use of alcohol, IV drug use, acetaminophen, herbs, and prescription drugs, as well as over-the-counter medications. Immunizations against HAV and HBV, tattooing, and sexual history are important to note. Blood work needs to include a comprehensive liver function panel, comprehensive metabolic panel with close attention paid to glucose metabolism, and a hepatitis panel if indicated. Jaundiced skin tone is usually a late sign of liver failure, but a careful examination of the patient's sclera may reveal early evidence of discoloration. Sometimes skin ulceration on skin surfaces that have sun exposure can indicate liver disease.

The liver is the largest organ in the body and is located in the upper right quadrant of the abdomen with a portion of the inferior aspect often palpable just under the rib cage. Since it is solid, when percussed the sound is a flat or dull tone in comparison to the bowel, which is more tympanic. The healthy liver is smooth and nontender to palpation. Evaluating the size of a patient's liver via percussion is imprecise, but should generally be about 6 to 12 cm vertically at the right nipple or midclavicular line. Ascites can be crudely distinguished from adipose tissue by assessing a wave action to a patient's abdominal girth. To do this the patient or a helper firmly places the ulnar side of the hand along the umbilical line of the patient. This stabilizes adipose tissue and internal organs. The examiner then quickly presses and retracts finger tips on one side of the patient's abdomen while feeling for a fluid wave on the opposite side of the abdomen with the palm of the other hand. Having the patient lay on the side and percussing laterally across the abdomen can reveal dullness in the dependent areas where the fluid collects (Jarvis, 2011). Abdominal ultrasound is a more precise assessment technique for determining liver size and the presence of ascites and is relatively inexpensive as well as being minimally invasive.

## ■ COMORBIDITY AND COMPLICATIONS

The liver is a resilient solid organ and withstands 80% to 90% loss in function before symptoms occur (McGrew, 2001). Liver disease is usually divided into obstructive and hepatocellular. Obstructive liver disease is most often caused by stones blocking the bile duct. This is an acute problem corrected surgically. The causes of ESLD are hepatocellular and can be divided into (a) infectious, (b) chemical, (c) metabolic,

and (d) neoplastic. The various forms of viral hepatitis are the primary infectious agents. Alcohol is the primary cause of chemical damage to the liver, followed by medications like acetaminophen and industrial chemicals such as acetone. The metabolic category includes relatively rare complications of cystic fibrosis and Wilson's disease, but its most common form is nonalcoholic fatty liver disease (NAFLD; Masuoka & Chalasani, 2013). The neoplastic category is noted by malignant tumors of the liver, which are often sites of metastases. Liver cancer can result from any of these other causes of liver failure or can occur without the other's presence.

## Infectious Liver Disease

The primary infectious agents of the liver are an expanding cluster of viral hepatitis agents. Hepatitis can be subdivided into acute and chronic diseases. HAV is the most common acute form of hepatitis and has no chronic state. It is passed through the feco-oral route and normally produces flu-like symptoms among a nonimmune compromised population. In the older adult, and subsequently immune compromised, population, HAV can be deadly as it stresses the already damaged liver.

Hepatitis B (HBV), HCV, and others in this expanding list have both acute and chronic stages. The major sources of chronic hepatitis are blood, blood products, tattoos with contaminated tools, IV drug use, and unprotected sexual activity. A review of transfusions and other medical procedures should therefore be a part of medical history. HBV infects over 1.25 million Americans and is presently the leading cause of hepatitis mortality. Infection is not restricted to the young or middle aged. As the overall American population ages, the rate of all hepatitis infections also increases.

Never assume that an older patient is not sexually active. While the number of sexual partners and frequency of coitus may decrease with age, elderly does not mean abstinent. Older women are at greater risk of sexually acquired hepatitis, HIV, and other sexually transmitted diseases (STDs) than might be expected. Older women may not see themselves as vulnerable due to their age and in comparison to younger women, having quantifiably diminished sexual activity (Davis, Duncan, Turner, & Young, 2001). Up until the mid-1980s, condoms were primarily used as a birth control device. The postmenopausal woman may not view condoms as an integral part of the sex act. In addition, the aging tissue of the genitalia is more susceptible to microscopic tears during coitus.

Screening for the increasing variety of hepatitises will be a challenge for medical and laboratory science.

When writing this chapter, the alphabet variations of hepatitis was passing the letter “E” and rising. Due to lack of long-term experience, the natural disease history of HCV and beyond is unknown, but appears deadly and increasingly widespread. Interferon alpha-2b and lamivudine (Epivir®) are the treatments recommended for HBV at the present time (Malik & Lee, 2000).

### Chemical and Alcoholic Cirrhosis

Many prescribed, herbal, and over-the-counter medications stress the aging liver. Acetaminophen, once considered a benign pain killer outside the medical community, can, if used in combination with prescription drugs, assimilate in the liver and thus be a deadly combination, especially with older people taking multiple medications. Presently, acetaminophen overdose is the leading cause of acute liver failure in the United States, and its increasing incidence has been attributed to (a) intentional suicide gestures; (b) a shift away from the use of aspirin as an analgesic and antipyretic; as well as (c) the use of APAP in more and more over-the-counter and prescription combination products (Fontana, 2008; Johnson, 2008; McKay, 2011).

In a 4-year study in the metropolitan Atlanta region, Bower, Johns, Margolis, Williams, and Bell (2007) found that acetaminophen poisoning was the leading cause of admissions to local ICUs for acute liver failure. Of those admissions, 48% of adults and 25% of children were affected due to acetaminophen, with “undetermined etiology” being the next most prevalent cause listed. In this study, there was a 40% mortality rate, a 42% rate of survival with supportive care, and a 12% rate of liver transplant. In a similar study, Gyamlani and Parikh (2002) reported that 86% of acetaminophen poisons in the Denver, Colorado, area were suicide attempts and the remainder were accidental overdoses.

At least 70% of adults in the United States drink alcohol to some degree, but consumption of more than two drinks per day (22–30 g) in women and three drinks (33–45 g) in men increases the risk for liver disease. Most patients with alcoholic cirrhosis have a much higher daily intake and have drunk excessively for 10 years or more before onset of liver disease. Alcoholism is often intertwined with depression and may be described by the patient as “the blues,” fatigue, social isolation, and decreased interest in social as well as physical activities. Alcohol is the leading cause of chemical cirrhosis in the United States and alcohol-induced cirrhosis is the primary cause of portal hypertension in the portal venous system or vena cava. This pressure increase eventually will cause an expansion of the

veins surrounding the esophagus, creating hemorrhoid-like sacks that are susceptible to sudden rupture. Without intervention early in the development of esophageal varices, the rupture of varices is a life-threatening emergency. Intervention must include abstinence from alcohol and may include sclerosis of the varices.

Increased pressure in the mesenteric arms to the portal vein causes fluid to leak into the peritoneal cavity, causing ascites. Likewise, because blood is not circulated completely through the liver, toxins build up causing encephalopathy. Ammonia is produced by the breakdown of protein during metabolism or by the breakdown of protein by bacteria in the gut. Since one of the functions of the liver is the conversion of ammonia to urea before excretion, ammonia can accumulate along with other toxins and eventually affect cognition.

As encephalopathy develops and progresses, the patient’s ability to make informed decisions about interventions diminishes and the burden of that responsibility falls onto family members who may not be prepared. A frank discussion of the patient’s wishes for interventions and end-of-life (EOL) care needs to be initiated early and be made clear to the patient’s circle of caregivers. Lack of preparation may be due to communication problems among the family members, a family member’s beliefs being at odds with those of the patient, guilt, or other factors (Larson & Curtis, 2006).

Alcohol consumption patterns should be a part of the physical assessment. Less than 50% of primary care physicians include the diagnosis of alcohol dependence for patients who consumed four or more drinks per day, and less than a third of health care professionals can effectively identify patients with substance abuse patterns. Exacerbating the lack of consistent assessment is the reluctance of many individuals to openly discuss how much they drink. To decrease the likelihood of conflict, several questionnaires are available for patients to answer while filling out their health history. The most commonly used questionnaire is “CAGE,” which asks, “Have you ever . . .”

- Tried to Cut down on your drinking?
- Been Annoyed by anybody criticizing your drinking?
- Felt Guilty about your drinking?
- Had an “Eye opener” (drink) in the morning?

A “yes” answer to two or more of these questions indicates alcohol dependence. The CAGE tool may not be as valid in older adults who are retired or living alone (Fingerhood, 2000; Rigler, 2000).

Developed by the World Health Organization (WHO), the Alcohol Use Disorders Identification Test



(AUDIT) in Exhibit 17.1 provides more detail than the CAGE questionnaire. A score of 8 or more indicates alcohol dependence. High scores on the first three items and lower scores on Items 4 through 10 suggest hazardous alcohol use. Higher scores on questions 4, 5, and 6 point to the presence or emergence of alcohol dependence. High scores on questions 7 through 10 suggest harmful alcohol use (Trotto, 2000).

## Metabolic and Other Causes of Liver Disease

Hepatic steatosis and NAFLD or nonalcoholic steatohepatitis is the gradual metamorphosis from a normal cell structure to one of fatty tissue. NAFLD is more common in obese diabetic patients with hyperlipidemia (Marchesini et al., 2001) or those on long-term parenteral nutrition. Patients with fatty liver disease may show few signs of disease other than mild to moderate tenderness over the upper right abdominal quadrant. Without control of their diabetes and

lipids, as well as alcohol abstinence, these patients may progress to acute liver failure.

In a study by Ford, Giles, and Dietz (2002), slightly less than 7% of the sample younger than 30 years met the criteria for metabolic syndrome; however, approximately 43% of those older than 60 years did. As obesity continues on its trend to become more prevalent among children and adolescents, so too is the incidence of developing type 2 diabetes and metabolic syndrome at increasingly younger ages. Duncan, Li, and Zhou (2004) found that the prevalence of metabolic syndrome among children and adolescents has increased from 4.2%, between 1988 and 1994, to 6.4%, from 1999 through 2000. With this comes increased incidences of chronic liver and renal end-organ damage in these age groups (Ford, Li, Cook, & Choi, 2007).

## Liver Cancer

Primary liver cancer is significantly lower in the United States than in foreign countries, especially those in

### Exhibit 17.1

#### Alcohol Use Disorders Identification Test (AUDIT)

1. How often do you have a drink containing alcohol?  
(0) Never (1) Monthly or less (2) Two to four times a month (3) Two to three times a week (4) Four or more times a week
2. How many drinks do you have in a typical day when you are drinking?  
(0) 1 or 2 (1) 3 to 4 (2) 5 to 6 (3) 7 to 9 (4) 10 or more
3. How often do you have six or more drinks on one occasion?  
(0) Never (1) Less than monthly (2) Monthly (3) Weekly (4) Daily or almost daily
4. How often during the last year have you found that you were unable to stop drinking once you had started?  
(0) Never (1) Less than monthly (2) Monthly (3) Weekly (4) Daily or almost daily
5. How often during the last year have you failed to do what was normally expected from you because of drinking?  
(0) Never (1) Less than monthly (2) Monthly (3) Weekly (4) Daily or almost daily
6. How often within the last year have you needed a drink first thing in the morning to get yourself going after a heavy drinking session the night before?  
(0) Never (1) Less than monthly (2) Monthly (3) Weekly (4) Daily or almost daily
7. How often in the past year have you felt guilty or remorse after drinking?  
(0) Never (1) Less than monthly (2) Monthly (3) Weekly (4) Daily or almost daily
8. How often during the last year have you been unable to remember what happened the night before because you had been drinking?  
(0) Never (1) Less than monthly (2) Monthly (3) Weekly (4) Daily or almost daily
9. Have you, or has someone else, been injured as a result of your drinking?  
(0) No (1) Yes, but not within the last year (2) Yes, during the last year
10. Has a relative, friend, doctor, or other health care worker been concerned about your drinking or suggested that you cut down?  
(0) No (1) Yes, but not within the last year (2) Yes, during the last year

Source: World Health Organization (1992).

Africa and Asia. In those regions, the primary cause of liver cancer is chronic viral hepatitis infections. The rate of liver cancer is declining in developing countries and increasing in developed nations. This trend is due to an increase in HCV among developed countries and an increasing use of HBV vaccines in underdeveloped areas. As the incidence of viral hepatitis increases in the United States, it is also likely that liver cancer due to this etiology will increase. However, for now, like so many other diseases of the liver, risk of hepatic carcinoma in America increases proportionally with alcohol consumption (el-Serag, 2001; McGlynn, Tsao, Hsing, Devesa, & Fraumeni, 2001). Some of the increase in the incidence of liver cancer in the United States is due to an overall aging of our population. Primary cancer of the liver is often in an advanced state before symptoms appear. The first symptom is usually liver pain. The patient is usually tender over the liver and a mass may be palpable. A friction rub or bruit may be heard when the abdomen is auscultated. Alkaline phosphatase and alpha-fetoprotein (AFT) may be elevated; however, AFT is not elevated in 20% to 30% of liver cancers (Stuart, Anand, & Jenkins, 1996). Although survival rates for liver and bile duct cancers has doubled over the past two decades, less than 11% of liver cancer patients will be alive 5 years after diagnosis. The most likely long-term survivor of primary hepatic carcinoma is someone whose cancer is detected early enough for surgical resection. If the older patient presents symptomatically, the prognosis is poor with the average survival between 3 and 6 months. As a solid organ, which is rich in blood, the liver's structure and function make it unsuitable for radiation therapy. If the tumor is caught early, surgery is the only definitive treatment. Surgical debulking of the tumor and chemotherapy at this time are only palliative (Lau, 2000). Because the liver filters blood, many of the cancers that affect the liver have their origin somewhere else in the body. The liver is therefore second only to lymph nodes as the most common site of metastasis. Metastatic cancer in the liver is over 20 times more prevalent than primary liver carcinoma.

### ■ DYING TRAJECTORY

The life expectancy of a person with ESLD is difficult to predict. Fox et al. (1999) followed over 2,600 patients who had been diagnosed with the advanced stages of either chronic obstructive pulmonary disease (COPD), congestive heart failure (CHF), or ESLD. Fox et al. defined ESLD as patients with a diagnosis of cirrhosis and at least two of the following:

- Serum albumin of 30 g/L or less
- Cachexia
- A serum bilirubin level of 51 mol/L (30 mg/dL) or more
- Uncontrolled ascites
- Hepatic encephalopathy
- Massive gastrointestinal bleed requiring two or more units of blood transfused within a 24-hour period
- Hematemesis or gross blood on endoscopic examination or nasogastric tube aspiration

Of those meeting these criteria and predicted to die within 6 months by their physician, over 50% were still alive 6 months later. Roth, Lynn, Zhong, Borum, and Dawson (2000) likewise found the 6-month projection of death in liver failure to be tenuous but very predictable only in the last 2 weeks when symptoms such as significant jaundice developed.

The average size of esophageal varices increase 5% each year the alcoholic continues to drink. If varices hemorrhage, 20% to 30% of these patients die. If left untreated, 70% of patients with varices will die within a year (Hegab & Luketic, 2001). Over 50% of patients will die within 2 years of their diagnosis of ascites (Garcia & Sanyal, 2001).

One tool in assessing the severity of liver failure and estimating survival is the "Model of End-Stage Liver Disease" (MELD) introduced by Kamath et al. (2001). In a large prospective and retrospective study of the variables that predicted the survival of ESLD patients, these researchers found a formula that assessed international normalized ratio (INR) for prothrombin time (INR), serum bilirubin, and serum creatinine:

$$\begin{aligned} \text{MELD} = & 3.8 (\log_e \text{ serum bilirubin [mg/dL]}) \\ & + 11.2 (\log_e \text{ INR}) \\ & + 9.6 (\log_e \text{ serum creatinine [mg/dL]}) \\ & + 6.4 \end{aligned}$$

This formula (which can be found in Mayo Clinic, 2013) produces a score that is inversely related to the patient's likelihood of survival over time. MELD scores are used to rank patients awaiting liver transplantation with a higher score indicating worse liver failure. Several studies of the MELD formula over the intervening years have supported this tool's predictive value and validity. Some of these studies have attempted to determine if other variables should be included in the MELD formula. Dunn et al. (2005) tested MELD to determine if the presence of ascites or encephalopathy should be included as predictive variables but found that MELD was able to stand alone as the best predictor.

In cases of encephalopathy, the palliative care (PC) nurse is a vital link in shaping the environment for the liver failure patient. O'Neal, Olds, and Webster (2006) developed and described a protocol for the administration of mannitol when acute liver failure



**Exhibit 17.2**  
**Encephalopathy and Ascites as Predictors of 90-Day Mortality**

Encephalopathy	Ascites	90-Day Mortality	Mean $\pm$ SD
		Total # (%)	
Yes	Yes	7/9 (78)	29 $\pm$ 9 (17–38)
No	Yes	7/33 (21)	17 $\pm$ 8 (6–36)
Yes	No	2/8 (25)	21 $\pm$ 8 (7–33)
No	No	0/23 (0)	10 $\pm$ (0–18)

Source: Dunn et al. (2005).

patients in an ICU develop signs of encephalopathy. Their protocol incorporate evidence-based practice interventions, a criteria for patient assessment, and a collaborative model of nursing and medicine.

The Child-Pugh-Turcotte (CPT) classification is also utilized to categorize the severity of liver failure. It uses five variables: (a) ascites; (b) encephalopathy; (c) bilirubin; (d) albumin; and (e) prothrombin time. Level of liver failure is then ranked by the CPT system into Class A through Class C. One year median survival is less than 50% in the more severe Class C. Today, organ transplant centers, however, use the MELD system for their ranking (Hansen, Sasaki, & Zucker, 2010). An online calculator for the CPT scale can be found at [prodruginfo.com/formulary/child-pugh\\_score\\_calculator.htm](http://prodruginfo.com/formulary/child-pugh_score_calculator.htm) (Pierce, 2013).

## Emergency Situations

Emergencies in ESLD can result from one, but more likely a combination, of factors, specifically (a) bleeding; (b) mental status changes; (c) electrolyte imbalance; or (d) infections. The goal of PC is to have a plan in place that addresses what actions to take if a crisis occurs. This plan is a joint undertaking by the patient and his or her circle of caregivers. Nurses, family members, and other medical personnel must be willing to respect the wishes of the patient. What has changed in the medical community is the willingness to accept exacerbations or collateral diseases as a part of a natural process. Although health care professionals have the capability to intervene and stop the course of a collateral disease process, such as pneumonia, the question is should we? This section will address the key emergency conditions that will likely result in the death of patients with ESLD. The interventions outlined range from the aggressive to comfort care only.

The most immediate life-threatening emergency in liver failure is hemorrhage from esophageal varices. A gradual decline in hemoglobin level or changes in stool toward a dark or tarry consistency heralds a slow low-grade hemorrhage. The differential diagnosis of these changes may be ulcerative or cancerous lesions in the upper gastrointestinal (GI) tract. A careful history that includes a thorough assessment of alcohol use focuses the clinician to evaluate the liver and esophagus.

An alcoholic vomiting bright red blood is always an emergency. Even when this occurs in a hospital emergency department, the bleeding may be so severe and the patient so debilitated by the disease that survival is doubtful. Aggressive intervention in hemorrhage includes intubation to protect the airway, the careful infusion of blood products and crystalloid, and then endoscopy to sclerose the varices. Endoscopic sclerotherapy or banding is more effective than balloon tamponade and pharmacological treatment to increase survival in patients with varices. The primary surgical intervention used in patient rescue at this time is a transjugular intrahepatic portosystemic shunt (TIPS) in which a metal tube is placed connecting the portal and hepatic veins, reducing portal hypertension (Hegab & Luketic, 2001). Like many of the treatments for varices, TIPS does not improve survival rates.

Although ESLD-induced dementia is usually a gradual process, dramatic changes are possible. Rapid behavioral changes can be due to (a) resumption of heavy drinking; (b) ingestion of other hepatotoxic chemicals such as acetaminophen; (c) cerebral-vascular disease, (d) electrolyte imbalance; or (e) infection. Stopping the alcohol or other drugs is the first step and may return the patient's mental status back near baseline. If the change is due to acetaminophen overdose, the antidote, *N*-acetylcysteine, must be given within 10 hours if it is to be effective.

Cerebral-vascular accident (CVA), stroke, or brain attack can result in the abrupt onset of dementia in ESLD patients. Family members will report that these changes occurred “overnight” or within a matter of hours. On examination, the patient may not show unilateral weakness or hemiparalysis. Unless it is a hemorrhagic stroke, CT of the head has little diagnostic utility. Care of the stroke patient is dealt with elsewhere in this book and comorbid ESLD does not significantly change those interventions. The patient with slow-progressing liver disease, however, may be more malnourished than the healthy stroke patient.

Infections and electrolyte changes can also lead to a more gradual change in patient’s behavior rather than the more abrupt changes caused by a stroke. Because the patient may not be able to reliably relate pain or other symptoms, aggressive assessment of the patient includes (a) complete blood count with differential; (b) blood cultures; (c) urine analysis; (d) blood chemistries; and (e) chest x-ray. Chemical imbalances in ESLD often result from low serum albumin levels due to malnutrition or fluid shifts. Aggressive intervention for electrolyte imbalances includes parenteral nutrition and hydration.

For patients with ESLD, the site of the infection is commonly in the lungs, bladder, or perineum. Risk of peritonitis associated with ascites is the only infection that separates the ESLD patient from any other older person. Spontaneous bacterial peritonitis (SBP) is common in patients with ascites and presents with fever, chills, and generalized abdominal pain (rarely rebound tenderness). However, symptoms may be vague in the confused and debilitated patient. IV cefotaxime coupled with an aminoglycoside are initiated while waiting for the results of the ascites culture. Left untreated, the patient with SBP will quickly slip into septic shock (Garcia & Sanyal, 2001).

### Common Symptoms—Early to Late

Fatigue is often the first sign of a failing liver’s inability to process toxins and other waste products from the body. During the “compensated” period of chronic liver failure, symptoms may wax and wane for years. The “uncompensated” phase is heralded by the development of one or more of the following symptoms (Hansen et al., 2010):

- Ascites
- Urticaria
- Jaundice
- Malnutrition
- Poor wound healing
- Lethargy
- Pain

Fatigue, itching, decreased appetite, and abdominal bloating singly or in combination may be the presenting symptoms of a patient with ESLD. The patient will usually complain of fatigue with activity or lack of stamina. They will feel best early in the morning and later need periods of rest between activities of daily living. Chronic nausea may be accompanied by alterations in taste and aversion to food and food preparation smells.

The itch of liver failure is not localized and is not associated with a rash. In some instances, the patient may have open superficial wounds on the sun-exposed areas of the skin that recur and are slow to heal. The patient may report increasing right upper quadrant abdominal pain as the sack enclosing the liver expands as the size of the liver increases.

Darkening of the urine as bilirubin is excreted occurs before the development of jaundice. Jaundice, or the accumulation of bilirubin in the skin, is usually a sign of advanced disease and may only present as death approaches. The development of jaundice may be so slow that family members do not recognize the change.

Ascites may be distinguished from gas by having the patient lie flat. The abdomen is round or distended and is dull to percussion. Gas bloating has a tympanic sound to percussion and the abdomen may not be uniform in its contour. With ascites, a fluid wave motion can be assessed by placing your hands on both sides of the patient’s abdomen and pushing one side in quickly. A ripple of abdominal fluid will roll across to the other hand.

Because of the resilient nature of the liver, blood tests may be normal despite advanced disease. Likewise, measurements of liver function may be elevated for problems that do not have their origin in this organ. Laboratory testing is fivefold. First is to assess if the liver is damaged through liver function tests (LFTs). Second, blood work is used to determine if the patient is malnourished and the degree of malnutrition. Albumin of less than 4 g/L of blood is considered malnourished. If the albumin drops below 2.1, the patient is extremely malnourished. Next, complete blood chemistry is used to determine the fluid and electrolyte balance of the patient. High mineral concentration indicates dehydration. Approximately half of the patients with chronic liver disease have macrocytosis and thrombocytopenia but many will have no significant change to their complete blood count (CBC).

Drawing an ammonia level requires special handling and is best drawn at the lab running the test. In the hospital, check the protocol for drawing this test. An elevated ammonia level indicates portal-systemic encephalopathy (PSE). Lastly, a hepatitis panel is used to identify if there is an infectious cause to the liver disease. Muscle wasting can also result in an elevated



serum ammonia level and cannot be taken alone as a measure of PSE.

All LFTs are measurements of serum bilirubin, albumin, and prothrombin time. The serum bilirubin level is a measure of hepatic conjugation and excretion, and the serum albumin level and prothrombin time are measures of protein synthesis. Abnormalities of bilirubin, albumin, and prothrombin time are typical of hepatic dysfunction. Decreased intake and absorption of vitamin K is common in alcohol cirrhosis and prolonged bleeding times can make the rupture of varices deadly. Bilirubin found in the urine is conjugated bilirubin and its presence implies liver disease. A urine dipstick test can give the same information as the serum bilirubin and is almost 100% accurate. While a thorough history, physical examination, and testing just described will provide enough information to make a diagnosis, liver biopsy is the “gold standard” for grading and staging of the disease.

## Complications of End-Stage Liver Disease

The onset of refractory ascites or esophageal varices coupled with low albumin or any gastrointestinal bleeding are thought to be sentinel events in the decision to initiate PC in advanced liver disease (McGrew, 2001). Essential to any treatment is abstinence from alcohol.

■ **Ascites.** The patient, family, and even the clinician may misidentify ascites as the bloating of simple fluid retention or weight gain. This may be attributed to excess sodium in the diet or CHF. Without a thorough physical examination, the first reaction to a patient presenting with fluid “bloating” is to prescribe a diuretic. Diuretics can cause hypovolemia, therefore concentrating ammonia. This patient may quickly become disoriented, demented, and then comatose. Other causes of ascites besides liver failure include cancer, tuberculosis, renal failure, and pancreatic disease (Riley & Bhatti, 2001).

Progressive ascites pushes up on the diaphragm, making it difficult for patients to take a deep breath, exert themselves, or sleep lying down. As the degree of ascites increases, the patient will feel increasing shortness of breath. All these factors raise the risk of pneumonia. With increased abdominal girth is a shift in the patient’s center of gravity and this affects ability to walk. Ascites also increases the risk of peritonitis and other infections associated with a high volume of fluid in the abdomen.

Bed rest is the first nonaggressive treatment for ascites. Keeping the patient reclined for a few days reduces the activation of the renin–angiotension system. However, this is impractical for long-term treatment. Dietary sodium restriction is the mainstay of ascites

treatment. The addition of the diuretic spironolactone (Aldactone) that reduces aldosterone-dependent sodium reabsorption is very effective in reducing ascites if used in conjunction with dietary sodium restriction. A daily dose of 100 mg spironolactone and/or furosemide (Lasix) is given. Rapid diuresis can result in hyponatremia, azotemia, potassium imbalance, and onset of or increase in encephalopathy.

If sodium restriction and diuresis do not reduce ascites, the next treatment is paracentesis, which is the drainage of excess fluid in the abdominal cavity. The primary purpose of paracentesis is decompression of the chest and abdominal cavity’s organs. The patient will be able to breathe with less strain and he or she will feel less bloated and therefore able to eat. However, paracentesis is not without risk of secondary infection and potential puncture of an abdominal organ. Overly aggressive paracentesis can result in extracellular fluid shifts and orthostatic hypotension. First, a sample of the fluid is examined for infection, blood, and tumor. One kilogram of fluid can be removed in an outpatient setting if the ascites is coupled with peripheral edema. More aggressive or “large-volume” paracentesis of up to 5 L of fluid requires hospitalization and parenteral albumin supplementation (Garcia & Sanyal, 2001). Fifty percent of patients with either ascites or encephalopathy will die within 2 years of onset (Sanchez & Talwalkar, 2006).

■ **Portal-Systemic Encephalopathy (PSE).** Hepatic encephalopathy is a continuum of cognitive symptoms caused by the presence and accumulation of toxins in the brain. Early signs commonly are lethargy and somnolence. Untreated, this progresses to confusion and then psychosis. Near the end, patients become obtunded and eventually comatose. Ammonia is a by-product of protein metabolism and until recently has been considered the primary cause of the encephalopathy common to end-stage liver failure. Now, ammonia is considered only one toxin among many that lead to confusion, lethargy, and eventually coma as the liver completely fails. Restricting protein in the diet, once thought to be the mainstay of treatment, can cause further fatigue, malnutrition, and skin breakdown (Rhee & Broadbent, 2007). To reduce the accumulation of toxins in the gut, lactulose is considered the first treatment to employ. Its mechanism of action is to increase bowel motility and thereby decrease the likelihood that toxins will be absorbed. Use of the nonabsorbed rifampin analogue rifaximin to control the proliferation of gut bacteria is off-label, but is considered useful in the reduction of toxins that are the waste products of bacteria in the intestine (Sanchez & Talwalkar, 2006). At the present time, severe protein restriction is not recommended as doing so increases the likelihood of malnutrition and skin breakdown.

**Exhibit 17.3**  
**Grading of Portal-Systemic Encephalopathy (PSE) and Characteristic Signs**

Stage of PSE	Cognitive Signs	Neuromuscular Signs
Subclinical	Abnormal psychometric test scores	None
Grade 1	Abnormal sleep patterns, shortened attention span, irritability, apathy	Tremor, incoordination
Grade 2	Personality changes, time disorientation, memory loss	Asterixis, dysarthria, abnormal muscle tone
Grade 3	Confusion, drowsiness, sleeplessness, paranoia, anger, stupor	Hyperactive reflexes, muscle rigidity
Grade 4	Coma	

Source: Butterworth (1995).

Vitamin and mineral supplementation is a special need of patients with alcoholic cirrhosis. Dietary restriction of sodium to no more than 800 mg or 2 g of salt per day may be helpful in reducing fluid retention. Diet in ESLD should employ a team approach consisting of the patient, family, health care provider, and dietician.

■ **Esophageal Varices.** Treatment of esophageal varices is limited because surgical interventions are invasive and have not been shown to improve the overall survival rate. A noninvasive approach is to reduce portal hypertension using nonselective beta-blockers, such as propranolol (Inderal) or nadolol (Corgard). Higher doses that are normally used to treat hypertension will be required and dosage is adjusted upward until the resting heart rate is reduced by 25%, but not below 55 beats/min. The advantage of nadolol is that it can be given in a single daily dose of 40 to 320 mg. Propranolol at a dose between 10 and 480 mg may be divided over the course of the day. Use of beta-blockers has been shown to reduce the risk of bleeding by 45% and bleeding-related death by 50%. Surgical intervention using a laser to cauterize the varices is a recent innovation, but can result in fatal hemorrhage. Endoscopic sclerotherapy and banding have been used in the past for treatment of bleeding varices (Hegab & Luketic, 2001). Today, TIPS between the hepatic vein and the intrahepatic segment of the portal vein is used to reduce refractory ascites as well as reduce the pressure causing varices.

■ **Pain Management and Urticaria.** Pain control is a high priority for patients and families. Urticaria or

itching that is often associated with high bilirubin levels is often irritating for patients and is often difficult to control. Pain in the later stages of ESLD can be equivalent to that of late-stage lung or colon cancer (Roth et al., 2000). Despite its hepatotoxicity in high dosage, low dose acetaminophen (no more than 1 g/day) is the first-line treatment for pain associated with ESLD. Later, as pain increases, morphine in lower dosages is the drug of choice (Cox-North, Doorenbos, Shannon, Scott, & Curtis, 2013). As the patient has difficulty swallowing or retaining oral medications, the use of transdermal fentanyl or a morphine pump may be used. Family members will likely be concerned that their loved one will become “addicted” to these pain medications or become “doped-up.” The patient and family need to be repeatedly reassured that comfort is the priority and that addiction is extremely rare.

Diphenhydramine (Benadryl), hydroxyzine (Vistaril), or promethazine (Phenergan) often act synergistically with pain medications in addition to reducing nausea and decreasing the severity of itching skin, but their primary benefits for the ESLD patient are these medications’ sedative properties (Larson & Curtis, 2006). The treatment of urticaria in ESLD lacks research. Anecdotal reports suggest trials of gabapentin starting at 100 mg three times a day, selective serotonin reuptake inhibitors (SSRIs), opiate antagonists, and other medications in the treatment of itching (Bergasa, 2006).

Often with progressing ascites and shortness of breath, the patient becomes increasingly restless and anxious even though pain is adequately controlled. Family members may become frightened with a loved



one who is struggling to breathe or who is confused. In these cases, they are more likely to call paramedics or take the patient to the emergency department. Antianxiety agents such as lorazepam (Ativan) or alprazolam (Xanax) are essential in reducing these symptoms. While finding the appropriate combination of medications to control pain, anxiety, urticaria, and nausea may require some trial and error, no patient should suffer in pain (Tremblay & Breitbart, 2001).

Hospice can be an effective source for information, family counseling, and pain control, if this resource is initiated early in ESLD. As mentioned before in this chapter, prediction of life expectancy is problematic and clinicians often wait until death is certain and imminent before involving hospice. Effective pain control is, therefore, inconsistent and pain appraisal is made difficult as the patient's level of consciousness diminishes. If hospice is not involved, problems with pain control are confounded by withdrawal of contact with the health care community as the patient deteriorates. In a study of people who died at home, Desbiens and Wu (2000) found that half were conscious in the last 3 days of life and of the conscious patients, 40% reported severe uncontrolled pain.

## ■ CONCERNS AND IMPLICATIONS FOR NURSING PRACTICE

Nurses should have a proactive role in the prevention of liver disease. This includes the following:

- Early immunizations against hepatitis
- Alcohol moderation
- Acetaminophen safety
- Weight management
- Exercise
- Safer sex practices
- Dangers of needle contamination (tattooing and IV drug use)
- Regular primary care evaluation including glucose monitoring and LFT

Patients with ESLD may first seek care due to increasing fatigue. This sense of fatigue will increase as the disease progresses. Community health nurses need to assess the patient's capabilities and the home environment to determine what support resources are needed. The patient must learn to self-pace activities, take frequent breaks, and build naps into his or her day. The goals of professional nursing care for the ESLD patient are the following:

- Maintain activities of daily living
- Prepare the family and circle of caregivers for their roles

- Help the patient avoid alcohol and other hepatotoxic chemicals
- Maintain nutrition and hydration
- Management of symptoms such as pain and itching (Larson & Curtis, 2006)

Nurses are in key position to assess the family for their capacity to give care (Groen, 1999). There may be unresolved issues of guilt and recrimination surrounding the patient's alcohol abuse. Spouse and children may need counseling to deal with these issues. The circle of caregivers must be willing to help the patient avoid alcohol. Likewise, the family needs to be informed of the natural course of the disease process and what changes should be expected. There should be a written plan of the steps to be taken in the event of an emergency or rapid deterioration so that the patient's wishes are addressed. At a minimum, every family member should read and discuss a patient's advanced directive.

Early referral to PC is important for patients with life-threatening illness (Medici et al., 2008). Because the only effective treatment for ESLD is liver transplantation, these patients can be on a transplant registry and receive hospice care at the same time. Unfortunately, many of those awaiting transplant will die. The PC's role is to control symptoms as they occur and promote physical, emotional, and spiritual support to the patient and family.

The first step to alcohol abstinence may be detoxification in a specialized facility. With advanced disease, the patient may be hemodynamically unstable with severe nutritional and mineral deficits. These will need to be stabilized before the patient can return to family or long-term care. Most detoxification facilities interface with alcoholics anonymous (AA) and arrangements for follow-up with AA should be established before the patient is discharged. Older patients may have more severe alcohol withdrawal symptoms with increased hallucinations, sleep disturbance, and confusion.

Older alcoholics are often malnourished because alcohol has been a significant source of calories. A dietician is an essential part member of the health care team, especially if the decision is made to restrict protein. "Meals On Wheels" can deliver food that provides a specialized diet to home-bound patients. Vitamin and mineral supplementation is specialized to avoid chemicals that are hepatotoxic. Extra vitamin K may be needed to correct bleeding irregularities. Aspirin should be avoided and salt intake reduced.

Elderly alcoholic patients are at increased risk of falls. Due to increased prothrombin time, bleeding precautions such as the use of soft toothbrushes is a part of the lifestyle change. The patient needs to be weighed daily on the same scale and report any

sudden gain of over 2 kg in a day. The patient needs to be assessed daily for pain, itching, fever, edema, increased shortness of breath, and mental status changes (Martin, 1992). Emphasis should be given to patients and family members discussing and planning for care in the event the patient loses the cognitive ability to direct his or her own care.

### Family Concerns and Considerations— Caregiver Fears

The progression to death from liver disease is often a slow and difficult process. Roth et al. (2000) studied 575 patients with ESLD. Two thirds of these patients died within 2 years. Eighty-nine percent of the patients rated their quality of life (QOL) as fair to poor with the inability to perform activities of daily living as the major source of dissatisfaction. Eighty-eight percent of the study's patients had a family caregiver in the home and two thirds required professional home-health services. One third of the family's savings were devastated by the costs of health care for the dying patient.

The circle of caregivers needs to be supported by health professionals. Support of the family members is extremely important, particularly in certain cultures. Pain control and comfort measures are, however, universal goals. African Americans, Hispanics, and recent immigrants are less likely to utilize advance directives (Huff & Kline, 1999; Waters, 2001). This is primarily due to distrust or lack of familiarity with the medical system in the United States. In a study of PC choices, Phillips et al. (2000) found no difference, based on race, with regard to decisions to withdraw or withhold life support for dying patients. Clergy should also be included as a part of the caregiving circle early in the disease process, while the patient is oriented and can have meaningful interaction. In many ethnic, national, and religious groups, clergy can act as a bridge between the family and health care providers.

Alcohol cirrhosis and hepatitis from drug use or sexual contact will likely create issues of guilt and blame that will be difficult to resolve as the patient's condition deteriorates rapidly. While alcoholic cirrhosis is still seen as the more common origin of ESLD today, hepatitis and fatty liver disease will be the causes of most liver failure in the future. The caring circle, to include health professionals and family, needs to rally around the patient's present rather than dwelling on his or her past actions.

Children of a dying alcoholic parent will likely harbor memories of neglect or even abuse. Spouses may also be the victims of neglect or abuse. The

codependent model may be exceedingly difficult to maintain if the other partner is frail and unable to provide the increasingly demanding day-to-day care of his or her spouse. Family members need to be informed of the mental status changes that take place when death is imminent. In Roth's et al. (2000) study, less than 10% of the patients showed confusion 6 months before death; however, within the last month of life one third displayed serious mental status changes.

### ■ CONCLUSION

Today, end-stage liver failure carries with it the stigma of alcohol cirrhosis and the risk-taking behavior associated with HCV. With a growing number of children and older people suffering the effects of fatty liver disease, they will likely be associated with the "shame" of obesity and the social perception that a person's lifestyle or lack of healthy behaviors lead to his or her disease state. No matter what the cause of the liver failure, the treatment of the patient and family remains the same—reduction in the symptoms of the disease process and emotional support. Family members will likely feel guilty or want to assign blame as they consider themselves or others as enablers who sat by while their loved one drank or become obese.

The only effective treatment for liver failure, regardless of the cause, is transplantation. Unfortunately, as in the case of Ann, the need for donor livers will increase dramatically over the next 20 years, while the supply has remained relatively consistent. Over the next decade, it is hoped that the artificial or bioartificial liver-support systems that are being tested will allow ESLD patients a means of survival until transplantation (Fontana, 2008; Kjaergard, Liu, Als-Nielsen, & Gluud, 2003; O'Grady, 2007). These devices would also have benefit for patients with acute liver failure as a bridge until some degree of spontaneous recovery of liver function occurs.

There is a changing face to ESLD as we progress through the first quarter of the 21st century. HCV has now surpassed alcoholic cirrhosis as the leading reason for liver transplantation. As the epidemic of obesity spreads through the United States, by 2020, fatty liver disease will demand more transplantable livers than any other cause. The cost and public health burden is difficult to predict. As nurses, we should be proactive in encouraging the public health initiatives of improving young people's diet and their access to exercise. Otherwise, as PC nurses, we will have to address the health outcomes.



## CASE STUDY Conclusion

The story of Ann will be more common as the general population of the United States ages and the percentage of obese Americans increases. Over time “metabolic syndrome” will likely warrant a close monitoring of liver function. With metabolic syndrome comes a wide range of comorbidities that increase a person’s surgical risk.

## Evidence-Based Practice

Hofer, S., Oberholzer, C., Beck, S., Looser, C., & Ludwig C. (2008). Ultrasound-guided radiofrequency ablation (RFA) for inoperable gastrointestinal liver metastases. *Ultraschall in der Medizin*, 29(4), 388–392.

### Background

Surgery is the most effective treatment for liver metastases. Some patients, however, cannot tolerate this procedure due to comorbidity, advanced age, site of the lesion, or previous liver surgery. At our institution, we now have increasing experience with radio frequency ablation (RFA), a thermo-ablative modality. We compare the outcome and survival results to those who receive standard treatment for liver metastases.

### Methods

From April 2000 to June 2005, 30 consecutive patients with liver metastases from gastrointestinal primaries were treated with ultrasound-guided RFA for their liver metastases (patients’ mean age: 63.5 years, range: 37–80; size of lesions, range: 0.4–6 cm). Main indications were nonoperable lesions due to the site of the lesion or comorbidity. RFA was also applied as an additive to liver surgery and as a repetitive palliative treatment. Fifteen patients underwent one RFA-intervention, eight patients two interventions, three patients three, one patient four, two patients five, and one patient six. RFA-interventions ( $n = 60$ ) were performed either percutaneously (71.5%), in an open approach without liver surgery (22%), or in addition to liver surgery (6.5%).

### Results

Mean observation time after first RFA was 23.5 months (range: 3–63). Median survival in the patient cohort was 34 months, which compares favorably with results obtained by hepatic resection, which is the standard of care for liver metastases. Complication rate, attributed to the RFA procedure, was small (5.5%) with one pleural effusion and one abscess formation in the ablated lesion due to underlying bacteraemia.

### Conclusion

RFA is an effective and low risk treatment modality in patients with liver metastases. The procedure is safe (complication rate less than 6%) with low morbidity. RFA can be performed repeatedly on an outpatient basis with good palliative effects. Of note, surgery remains the treatment of choice in resectable liver metastases of colorectal origin.

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# Palliative Care in HIV/AIDS

## CHAPTER

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**KEY POINTS**

- In countries with advanced health care, HIV/AIDS is managed as a chronic illness, while in underdeveloped countries individuals without access to care are continuing to die from AIDS.
  - HIV and AIDS are not synonymous terms but, rather, refer to the natural history or progression of the infection, ranging from asymptomatic infection to life-threatening illness.
  - The components of high-quality HIV/AIDS palliative care include competent, skilled practitioners; confidential, nondiscriminatory, culturally sensitive care; flexible and responsive care; collaborative and coordinated care; and fair access to care.
  - The control of pain and symptoms associated with HIV/AIDS enables the patient and family to expend their energies on spiritual and emotional healing, and the possibility for personal growth and transcendence even as death approaches.
  - Knowledge regarding HIV disease enables nurses to offer effective and compassionate care to patients and families at all stages of HIV disease.
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**CASE STUDY**

Miriam, a 36-year-old woman with *Mycobacterium avium intracellulare* (MAC), began to have daily episodes of diarrhea. She was admitted to the hospital with fever, fatigue, anorexia, nausea and vomiting, and weight loss of 15 lbs over the last 3 weeks. Her significant other was diagnosed with HIV 8 years ago. She was offered antiretroviral therapy (ART) but was noncompliant due to active substance use and is currently not on therapy. She also reported having unprotected sex on several occasions to support her drug habit. Miriam's CD4 count was 60 cells/mm<sup>3</sup> with a viral load (VL) of 130,000 copies/mL. Her laboratory work indicated anemia and an elevated alkaline phosphatase. MAC was confirmed by biopsy with acid fast bacterial (AFB) stain. On physical examination, she had an enlarged spleen, and lymph nodes are palpable in her inguinal area. The diagnosis was advanced-stage AIDS. Miriam was begun on an antiretroviral regimen consisting of a protease inhibitor (PI) plus two nonnucleoside reverse transcriptase inhibitors (nNRTIs). She was also treated for MAC with azithromycin and rifabutin. Miriam's mother and sister, although close by, have a poor relationship with her. Miriam has a 5-year-old son from a previous relationship; her mother is the legal guardian of her son.

Miriam responded well following MAC treatment and her diarrhea improved. However, she still remained weak and found it difficult to climb the stairs of her four-story walk-up apartment. Although Miriam is Catholic, she finds little comfort in her faith, believing that her illness is a punishment from God for an abortion she had 2 years ago. Miriam is becoming increasingly depressed. The home health aide, which assisted her in the first few weeks after discharge, was no longer available. It became clear to Miriam that her life was threatened by the disease and she may never see her child grow up.

Despite being on ART, there was little improvement in her CD4 counts or in the lowering of her VL. Miriam began to stay in bed for long periods of time during the day. She feared that she was never going to recover and worried about who would care for her son. After some additional testing, the infectious disease physician, who she saw at the AIDS clinic, changed her initial regimen. Miriam was also treated with an antidepressant and within weeks her mood, as well as her appetite, improved.

Within 3 months, Miriam's quality of life (QOL) improved because she was free of opportunistic infections. Although unemployed, she kept busy with household activities and the care of her son. Even though Miriam has two friends, who live in her building, they have their own personal and health-related issues. Miriam understands the fragility of her condition and this time is adherent to her medication regimen. She needs ongoing management of symptoms related to the disease and its treatment, as well as emotional and spiritual support, as she faces her own mortality.

It has been more than 30 years since the beginning of the HIV/AIDS epidemic, yet there remains no cure for this disease that has affected global health. In countries with advanced health care, the development and accessibility of ART has significantly reduced the mortality from HIV and has transformed AIDS into a manageable chronic illness. The global expansion of access to HIV treatment ranks among the great recent achievements in public health. At the end of 2011, an estimated 8 million people in low- and middle-income countries are receiving ART, which is a 25-fold increase since 2002 (World Health Organization [WHO], 2012). About 54% of the people eligible for ART are receiving it. Several countries, those with limited resources, have reached or are close to achieving "universal access" to ART. HIV incidence and mortality rates are falling in many countries. In 2011, there were 1.7 million AIDS-related deaths, lower than the 2.5 million deaths in 2005 (UNAIDS, 2012).

In clinical practice, care for people with HIV/AIDS has changed dramatically in the past decade. As care has changed, so has the trajectory of HIV/AIDS, shifting to a disease less like cancer and more like chronic diseases such as diabetes or heart disease. Palliative care (PC) for patients with HIV/AIDS is an approach to care not only in the advanced stage of the illness but also as an aspect of care that begins in the early stage of illness and continues as the disease progresses (Dahlin, 2013). PC offers physical, emotional, social, and spiritual support to promote the QOL of patients and their families. Patients with AIDS continue to experience a high burden of pain and other chronic symptoms, over a longer period of time, with

a disease course marked by more cumulative exacerbations and remissions than when AIDS was a stereotypic, rapidly fatal illness (Selwyn & Rivard, 2003). Contrary to popular perceptions, palliative nursing continues to have much to offer patients in the chronic disease era of HIV/AIDS for whom treatment outcomes will only benefit from greater integration of disease-specific and palliative interventions (Selwyn, 2003).

## ■ INCIDENCE AND PREVALENCE

AIDS has been characterized as a volatile and dynamic epidemic, which has spread globally. This epidemic is complex due to the virus's ability to mutate and cross all socioeconomic, cultural, political, and geographic boundaries. As a worldwide epidemic, HIV/AIDS has affected more than 34 million people. In 2011, an estimated 2.5 million acquired HIV, with an estimated 1.7 million people dying from AIDS (UNAIDS, 2012; WHO, 2012). In the United States, an estimated 1.1 million people are living with HIV infection (CDC, 2013). HIV incidence has remained relatively stable in the United States at about 50,000 infections per year since the mid-1990s. Certain groups, including African Americans, Latinos, and gay and bisexual men of all races/ethnicities, still continue to be disproportionately affected (CDC, 2013).

Perinatal transmission of HIV has seen a dramatic decline in the United States. This is largely due to a highly effective public health initiative focusing on prevention and early intervention for mothers with



HIV. Prior to effective and timely treatment, more than 2,000 HIV-infected infants were born each year; today, that number is approximately 300 infants annually (CDC, 2013).

## ■ PATHOGENESIS OF HIV

The HIV virus survives by reproducing itself in a host cell, replacing the genetic machinery of that cell, and eventually destroying the cell. The HIV is a retrovirus whose life cycle consists of (a) attachment of the virus to the cell, which is affected by cofactors that influence the virus's ability to enter the host cell; (b) uncoating of the virus; (c) reverse transcription by an enzyme called reverse transcriptase, which converts two strands of viral RNA to DNA; (d) integration of newly synthesized proviral DNA into the cell nucleus, assisted by the viral enzyme integrase, which becomes the template for new viral components; (e) transcription of proviral DNA into messenger RNA; (f) movement of messenger RNA outside the cell nucleus, where it is translated into viral proteins and enzymes; and (g) assembly and release of mature virus particles out of the host cell (Fan, Conner, & Villarreal, 2011).

These newly formed viruses have an affinity for any cell that has the CD4 molecule on its surface, such as T lymphocytes and macrophages, and become major viral targets. Because CD4 cells are the master coordinators of the immune-system response, chronic destruction of these cells severely compromises individuals' immune status, leaving the host susceptible to opportunistic infections and eventual progression to AIDS.

Since the identification of the first case of HIV in 1981, there has been significant scientific advancements made in the diagnosis and treatment of the disease, specifically, the virus has been identified; screening for HIV infection has been implemented; biological and behavioral cofactors have been identified related to infection and disease progression; prophylactic treatments are available to prevent opportunistic infections; HIV-RNA quantitative assays have been developed to measure VL; combination ARTs are available to treat the infection; and vaccines are being tested (Fan et al., 2011).

## ■ DISEASE TRAJECTORY

HIV and AIDS are not synonymous terms but, rather, refer to the natural history or progression of the infection, ranging from asymptomatic infection to life-threatening illness characterized by opportunistic infections and cancers. Without treatment, this continuum of illness is associated with progressive immune-

system dysfunction (as evidenced by a decrease in CD4 cell count) and persistent viral replication (as evidenced by a rise in plasma HIV-RNA levels).

The natural history of HIV infection begins with acute HIV infection in which the virus enters the body and replicates in large numbers in the host cell. As a result, there is a rapid depletion in the number of CD4 cells and a significant rise in viral replication (as measured by the VL) during the first 2 weeks of the infection. Within 5 to 30 days of infection, 70% of individuals experience flu-like symptoms, such as fever, sore throat, skin rash, lymphadenopathy, and myalgia. Other symptoms of primary HIV infection include fatigue, splenomegaly, anorexia, nausea and vomiting, meningitis, retro-orbital pain, neuropathy, and mucocutaneous ulceration (Pilcher, Eron, Galvin, Gay, & Cohen, 2004). Within 6 to 12 weeks of the initial infection, the production of HIV antibodies results in seroconversion. If tested at this time, the patient will be diagnosed as HIV positive.

Clinical latency refers to the chronic, clinically asymptomatic state in which there is a decreased VL and resolution of symptoms of acute infection. At this point, there is continuous viral replication in the lymph nodes with more than 10 billion copies of the virus being made every day.

After years of HIV infection, the individual enters a stage that is apparent by conditions indicative primarily of defects in cell-mediated immunity. Symptomatic infection generally occurs when CD4 counts fall below 500 cells/mm<sup>3</sup> and indicates the progression of HIV disease. Symptoms of advancing HIV infection include oral candidiasis and hairy leukoplakia as well as ulcerative lesions of the mucosa. Gynecological infections are common in women with HIV disease as well as dermatological manifestations, which include bacterial, fungal, viral, neoplastic, and other conditions such as exacerbation of psoriasis, severe pruritus, or the development of recurrent pruritic papules (CDC, 2013; Lazenby, 2012; Oramasionwu et al., 2012).

When the CD4 count drops below 200 cells/mm<sup>3</sup>, HIV infection now meets one of the Centers for Disease Control and Prevention's definitions of AIDS (CDC, 2013). With AIDS, patients often experience several opportunistic infections or cancers (see the following discussion). When the CD4 cell count drops below 50 cells/mm<sup>3</sup>, the immune system is so impaired that both HIV and non-HIV-related infections become commonplace. With advanced disease, individuals may experience symptomatic health problems such as shortness of breath from pneumonia, difficulty swallowing from oral candidiasis, depression, dementia, skin infections, anxiety, incontinence, fatigue, isolation, bed dependency, wasting syndrome, and significant pain.

## AIDS-Related Opportunistic Infections and Comorbidities

Opportunistic infections are the greatest cause of morbidity and mortality in individuals with HIV disease. Given the compromised immune system of HIV-infected individuals, there is a wide spectrum of pathogens that can produce primary, life-threatening infections, particularly when the CD4 cell counts fall below 200 cells/mm<sup>3</sup>.

Given the weakened immune systems of HIV-infected persons, even previously acquired infections can be reactivated. Most of these opportunistic infections are incurable and can at best be palliated to control the acute stage of infection and prevent recurrence through long-term suppressive therapy. In addition, patients with HIV/AIDS often experience concurrent or consecutive opportunistic infections that are severe and cause a great number of symptoms. In addition to opportunistic infections, individuals may be diagnosed with other comorbidities such as hepatitis B or C and various malignancies that increase symptomatology and mortality rates (Selwyn & Rivard, 2003). Based on patients ( $n = 230$ ) in a large urban New York Medical Center, who had been referred to the HIV PC team, close to half of all deaths for these patients were attributable to non-AIDS-specific causes, including cancer and end-organ failure (Shen, Blank, & Selwyn, 2005). The overall proportion of deaths that were attributed to non-AIDS diseases increased significantly as opposed to death due to AIDS-related diseases and included hepatic, cardiovascular, and pulmonary diseases as well as non-AIDS malignancies (Palella et al., 2006).

By 2015, at least half of those living with HIV in the United States will be 50 years of age or older (Effros et al., 2008). Increasing age, comorbid conditions, and markers of functional status are more predictive of mortality than traditional HIV-prognostic variables (Justice, 2010; Piggott et al., 2013). AIDS involves multiple symptoms not only from the disease processes but also from the side effects of medications and other therapies. Patients with AIDS present with complex care issues because they experience bouts of severe illness and debilitation alternating with periods of symptom stabilization.

## ■ HIV/AIDS AND PALLIATIVE CARE

PC is the comprehensive management of the physical, psychological, social, spiritual, and existential needs of patients with incurable progressive illness (Dahlin, 2013). PC has become an increasingly important component of AIDS care from diagnosis to death, involving ongoing prevention, health promotion, and health maintenance to promote the patient's QOL

throughout the illness trajectory. The components of high-quality HIV/AIDS PC, as identified by health care providers, include competent, skilled practitioners; confidential, nondiscriminatory, culturally sensitive care; flexible and responsive care; collaborative and coordinated care; and fair access to care. Resources aimed at prevention, health promotion and maintenance, symptom surveillance, and end-of-life (EOL) care are essential (Gysels et al., 2013). Not only the treatment of chronic debilitating conditions but also the treatment of superimposed acute opportunistic infections and related symptoms is necessary to maintain a good QOL. As one example, health prevention measures, such as ongoing intravenous (IV) therapies to prevent blindness from cytomegalovirus (CMV) retinitis, must be available to patients with AIDS to maintain their QOL.

The precepts of PC include comprehensive care with respect for patient goals, preferences, and choices, and acknowledgment of caregivers' concerns (Dahlin, 2013). These precepts are fundamental in addressing the complex needs of patients and families with HIV/AIDS and require the coordinated care of an inter-professional PC team, involving physicians, advanced practice nurses, staff nurses, social workers, dietitians, physiotherapists, and clergy. The management decisions for patients with advanced AIDS must consider the benefits and burdens of the various diagnostic and treatment modalities, and the patient's expectations and goals as well as anticipated problems (Sherman, 2001). Curtis et al. (2002) suggests that health care personnel taking care of patients with advanced AIDS should, in addition to the medical management and providing adequate relief of pain, maintain hope while helping the patient and his or her family to confront the chronic and terminal nature of the illness. Health care providers and patients must determine the balance between aggressive and supportive efforts, particularly when increasing debility, wasting, and deteriorating cognitive function are evident in the face of advanced disease. As the unit of care is the patient and family, the PC team offers support not only for patients to live as fully as possible until death but also for the family to help them to cope during the patient's illness and in their own bereavement (Dahlin, 2013).

Although the hospice and PC movement developed as a community response to those who were dying, primarily of cancer, the advent of the AIDS epidemic made it necessary for hospices to begin admitting patients with AIDS. This meant applying the old model of cancer care to patients with a new infectious, progressive, and terminal disease. Unlike the course of cancer, which is relatively predictable once the disease progresses beyond cure, AIDS patients experience a series of serious and sometimes



life-threatening opportunistic infection. With appropriate treatment offered, there may be resolution of an AIDS-related illness or chronic therapy may be necessary. Therefore, the underlying goal of AIDS care remains one of palliation.

The predominate thinking is of HIV disease as a chronic illness. Both public and private third-party payers have reimbursed for EOL care when physicians have verified a life expectancy of less than 6 months. However, private third-party payers are not required to provide hospice or PC services. Yet, generally speaking, comprehensive AIDS care is publicly funded. While no studies exist that examine the cost of AIDS-related palliative or hospital care, the cost of care in cities with large HIV populations indicate that as CD4 cells decline, particularly less than 50 cells/mm<sup>3</sup>, annual health care expenditures are 2.6 times greater than expenditures for patients with CD4 greater than 350 cells/mm<sup>3</sup>. The increased expenditures are also related to nonantiretroviral medications and hospitalization (Chen et al., 2006).

An additional barrier to PC is the patients themselves. There is a need to shift the perception of PC as only EOL care and to promote PC as an aggressive approach to enhance QOL throughout the course of the illness. Over the years, there have been public initiatives and media campaigns to improve the care of the seriously ill in the United States and to inform patients and families about the availability of PC across health care settings.

A review of the evidence of barriers and inequality in HIV care by Harding et al. (2005) found that there is increased complexity in the balance of providing concurrent curative and palliative therapies given the prolongation of life span as a result of ART therapy. Harding and colleagues propose the need for multidimensional PC assessment for differing populations; basic PC skills training for all clinical staff in standard assessments; the development of referral criteria and systems for patients with complex PC needs; and the availability of specialist consultation across all settings.

When patients are in the advanced stage of AIDS, Grothe and Brody (1995) suggested that four criteria be considered regarding the admission to hospice: functional ability, statistical prognosis, CD4 count and VL, and history of opportunistic infections. These criteria give a better understanding of the patient's prognosis and needs. Hospices are offering the necessary support to patients with AIDS at the EOL. Different models of PC are being developed including partnerships with community hospitals or agencies.

### Assessment of Patients With HIV/AIDS

Throughout the course of their illness, individuals with HIV disease require primary care services to

identify early signs of opportunistic infections and to minimize related symptoms and complications. This includes a complete health history, physical examination, and laboratory data including determination of immunological and viral status.

■ **Health History.** In the care of patients with HIV/AIDS, the health history should include the following (Sherman, 2006):

- History of present illness, including a review of those factors that led to HIV testing.
- Past medical history, particularly those conditions that may be exacerbated by HIV disease or its treatments, such as diabetes mellitus, hypertriglyceridemia, or chronic or active hepatitis B infection.
- Childhood illnesses and vaccinations for preventing common infections such as polio, DPT, or measles.
- Medication history, including the patient's knowledge of the types of medications, side effects, adverse reactions, drug interactions, and administration recommendations.
- Sexual history, regarding sexual behaviors and preferences and history of sexually transmitted diseases, which can exacerbate HIV disease progression.
- Lifestyle habits, such as the past and present use of recreational drugs, including alcohol, which may accelerate progression of disease; cigarette smoking, which may suppress appetite or be associated with opportunistic infections such as oral candidiasis, hairy leukoplakia, and bacterial pneumonia.
- Dietary habits, including risks related to foodborne illnesses such as hepatitis A.
- Travel history, to countries in Asia, Africa, and South America, where the risk of opportunistic infections increase.
- Complete systems review, to provide indications of clinical manifestations of new opportunistic infections or cancers as well as AIDS-related complications both from the disease and its treatments.

■ **Physical Examination.** A physical examination should begin with a general assessment of vital signs and height and weight as well as overall appearance and mood. A complete head-to-toe assessment is important and may reveal various findings common to individuals with HIV/AIDS such as the following (Sherman, 2006)

- Oral cavity assessment may indicate candida, oral hairy leukoplakia, or Kaposi sarcoma (KS).
- Funduscopic assessment may reveal visual changes associated with CMV retinitis; glaucoma screening annually is also recommended.

- Lymph node assessment may indicate adenopathy detected at any stage of disease.
- Dermatological assessment may indicate various cutaneous manifestations that occur throughout the course of the illness such as HIV exanthema, KS, or infectious complications such as dermatomycosis.
- Neuromuscular assessment may determine various central, peripheral, or autonomic nervous system disorders and signs and symptoms of conditions such as meningitis, encephalitis, dementia, or peripheral neuropathies.
- Cardiovascular assessment may reveal cardiomyopathy.
- Gastrointestinal assessment may indicate organomegaly, specifically splenomegaly or hepatomegaly, particularly in patients with a history of substance abuse as well as signs related to parasitic intestinal infections. Annual stool of guaiac and rectal examination, as well as sigmoidoscopy every 5 years, are also parts of health maintenance.
- Reproductive system assessment may reveal occult sexually transmitted diseases or malignancies, as well as vaginal candidiasis, cervical dysplasia, pelvic inflammatory disease, or rectal lesions in women with HIV/AIDS as well as urethral discharge and rectal lesions or malignancies in HIV-infected men. Health maintenance in individuals with HIV/AIDS also includes annual mammograms in women older than 40 years, as well as testicular examinations in men, and prostate screening examinations as per current recommendations.

■ **Laboratory Data.** Evaluation of these laboratory data is important in assisting the health practitioner in making therapeutic decisions. The following laboratory test performed during initial patient visits can be used to stage HIV disease and in the selection of ART (Department of Health and Human Services [DHHS], 2013):

- HIV antibody testing (if prior documentation is not available or if HIV-RNA is below the assay's limit of detection)
- CD4 T-cell count (CD4 count)
- Plasma HIV-RNA (VL)
- Complete blood count, chemistry profile, transaminase levels, blood urea nitrogen (BUN), and creatinine, urinalysis, and serologies for hepatitis A, B, and C viruses
- Fasting blood glucose and serum lipids
- Genotypic resistance testing at entry into care, regardless of whether ART will be initiated immediately. For patients who have HIV-RNA levels less than 500 to 1,000 copies/mL, viral amplification for resistance testing may not always be successful

The DHHS's (2013) panel on clinical practices for the treatment of HIV recommends that the CD4 count and the VL be measured upon entry into care and every 3 to 6 months subsequently. Immediately before a patient is started on ART, the patient's HIV-RNA (VL) should be measured, and again 2 to 8 weeks after treatment is initiated, to determine the effectiveness of the therapy. With adherence to the medication schedule, it is expected that the HIV-RNA will decrease to undetectable levels (less than 50 copies/mL) in 16 to 24 weeks after the initiation of therapy (DHHS, 2013). If a patient does not significantly respond to therapy, the clinician should evaluate adherence, repeat the test, and rule out malabsorption or drug-drug interactions.

The decision regarding laboratory testing is based on the stage of HIV disease, the medical processes warranting initial assessment or follow-up, and consideration of the patient benefit-to-burden ratio (Sherman, 2006). Complete blood counts are often measured with each VL determination or with a change of ART, particularly with patients on drugs known to cause anemia. Chemistry profiles are done to assess liver function, lipid status, and glycemia every 3 to 6 months or with a change in therapy, and are determined by the patient's ART, baseline determinations, and coinfections. Abnormalities in these profiles may occur as a result of ART. Increasing hepatic dysfunction is evident by elevations in the serum transaminases (aspartate aminotransferase (AST), alanine transaminase (ALT), and bilirubin). Blood work should also include hepatitis C serology (antibody), hepatitis B serology, and *Toxoplasma* immunoglobulin G (IgG) serology (DHHS, 2013).

Urine analysis should be done annually unless the person is on ART, which may require more frequent follow-up to check for toxicity. Syphilis studies should be done annually; however, patients with low positive titers should have follow-up testing at 3, 6, 9, 12, and 24 months. Gonorrhea and chlamydia tests are encouraged every 6 to 12 months if the patient is sexually active. Annual Papanicolaou (Pap) smears are also indicated, with recommendations for Pap smears every 3 to 6 months in HIV-infected women who are symptomatic. In addition, HIV-infected persons should be tested for IgG antibody to *Toxoplasma* soon after the diagnosis of HIV infection to detect latent infection with *Toxoplasma gondii*. *Toxoplasma* seronegative persons who are not taking a PCP prophylactic regimen known to be active against toxoplasma encephalitis (TE) should be retested for IgG antibody to *Toxoplasma* when their CD4<sup>+</sup> counts decline to less than 100 cells/mm<sup>3</sup> to determine whether they have seroconverted and are therefore at risk of TE (CDC, 2013).



Individuals should be tested for latent tuberculosis infection (LTBI) at the time of their HIV diagnosis, regardless of their TB risk category, and then annually if negative. LTBI diagnosis can be achieved with the use of tuberculin skin test (TST) or by interferon gamma release assay (IGRA) using the patient's serum. A TST is considered positive in patients with induration of greater than or equal to 5 mm. An IGRA is reported as positive or negative. Any positive test warrants chest radiograph for active disease and consideration of antituberculosis therapy based on history, laboratory, physical, and radiographic findings.

## Management of HIV/AIDS

With no current cure, the health management of patients with HIV/AIDS is directed toward controlling HIV disease and prolonging survival, while maintaining QOL (Burgoyne & Tan, 2008). QOL is associated with health maintenance for individuals with HIV/AIDS, particularly as it relates to physical and emotional symptoms and functioning in activities of daily living as well as social functioning (Vigneshwaran, Padmanabhareddy, Devanna, & Alvarez-Uria, 2013). QOL is based on the patient's perceptions of his or her ability to control the physical, emotional, social, cognitive, and spiritual aspects of the illness. In a study regarding the functional QOL of 142 men and women with AIDS, Vosvick et al. (2003) concluded that maladaptive coping strategies were associated with lower levels of energy and social functioning and that severe pain interfered with daily living tasks and was associated with lower levels of functional QOL (physical functioning, energy/fatigue, social functioning, and role functioning). Therefore, health promotion interventions should be aimed at developing adaptive coping strategies and improving pain management.

■ **Health Promotion.** In the management of HIV/AIDS, it is important to prevent or decrease the occurrence of opportunistic infections and AIDS-indicator diseases. HIV management therefore involves health promotion and disease prevention. In addition to the treatment of AIDS-related diseases and related symptoms, PC involves prophylactic interventions and the prevention of behaviors that promote disease expression (Bolin, 2006).

Through all stages of HIV disease, health can be promoted and maintained through diet, micronutrients, exercise, reduction of stress and negative emotions, symptom surveillance, and the use of prophylactic therapies to prevent opportunistic infections or AIDS-related complications. A health-promoting diet is essential for optimal functioning of the immune system. Cell-mediated immunity, phagocytic function,

and antibody response are impaired by deficiencies in diet, including low protein intake. Alteration in nutrition leads to secondary infections, disease progression, psychological distress, and fatigue. In patients with AIDS, common nutritional problems are weight loss, vitamin and mineral deficiencies, loss of muscle mass, and loss or redistribution of fat mass. With the administration of ART, there is the possibility of redistribution of fat, characterized by increased abdominal girth, loss of fat from the face, and a "buffalo hump" on the back of the neck (Keithley, Swanson, Murphy, & Levin, 2000). Diseases of the mouth and oropharynx, such as oral candidiasis, annular cheilitis, gingivitis, herpes simplex, and hairy leukoplakia, may limit oral intake. Diseases of the GI tract that can cause malabsorption include CMV, MAC, cryptosporidiosis, and KS. These diseases are experienced in individuals with CD4 counts of 50 or less and may adversely affect their nutritional status (Crum-Cianfione, 2010). Metabolic alterations may be due to HIV infection or secondary infections as well as abnormalities in carbohydrate, fat, and protein metabolism (Vosvick et al., 2003). A good diet is one of the simplest ways to delay HIV progression and will bolster immune-system function and energy levels and help patients live longer and more productive lives (Hussein, 2003). It is recommended to have 2 or 3 servings daily from the protein and dairy groups, 7 to 12 servings from the starch and grain group, 2 servings of fruits and vegetables rich in vitamin C, as well as 3 servings of other fruits and vegetables (Grobler, Siegfried, Visser, Mahlangu, & Volmink, 2012).

Multivitamin supplementation is a good preventive measure (Mehta & Fawzi, 2007). Vitamin B, C, E, and folic acid have been shown to delay the progression of HIV. Supplementation with selenium, *N*-acetyl cysteine, probiotics, and prebiotics has considerable potential, but the evidence needs to be further substantiated. Vitamin A, iron, and zinc have been associated with adverse effects and caution is warranted for their use (Hummelen, Hemsworth, & Reid, 2010).

Exercise is also important to health promotion in patients with HIV/AIDS, as it increases natural killer-cell activity (Freeman & MacIntyre, 1999). However, variable results are reported on the effects of exercise on neutrophil, macrophage, and T- and B-cell function and proliferation (Nieman, 1996). O'Brien, Nixon, Tyan, and Glazier (2010) examined the safety and effectiveness of aerobic exercise interventions on immunologic and virologic, cardiopulmonary, psychologic outcomes, and strength, weight, and body composition in adults living with HIV. Performing constant or interval aerobic exercise, or a combination of constant aerobic exercise and progressive resistive exercise for at least 20 minutes at least three

times per week for at least 5 weeks, appears to be safe and may lead to significant improvements in selected outcomes of cardiopulmonary fitness (maximum oxygen consumption), body composition (leg muscle area, percent body fat), and psychological status (depression–dejection symptoms).

Summarizing the importance of exercise in HIV disease, Hand, Lyster, Jagers, and Dudgeon (2009) concluded that moderate- to high-intensity aerobic exercise combined with a resistance exercise regimen is safe and favorable and results in changes in body composition, muscular strength, improved depression and anxiety, and improving QOL.

Stress and negative emotions are also associated with immune-suppression and increases an individual's vulnerability to infections. For patients living with HIV/AIDS, there is stress related to the uncertainty regarding illness progression and prognosis, stigmatization, discrimination, financial concerns, and increased disability as the disease progresses. Individuals with AIDS frequently cite the avoidance of stress as a way of maintaining a sense of well-being (Antoni, 2003). Based on a study of 96 HIV-infected homosexual men without symptoms or antiretroviral medication use, Leserman et al. (2002) reported that higher cumulative average stressful life events, higher anger scores, lower cumulative average social support, and depressive symptoms predicted a faster progression to both the CDC AIDS classification and a clinical AIDS condition. In a study of QOL of women with AIDS, cognitive-behavioral interventions have been shown to improve cognitive functioning, health distress, and overall health perceptions, yet there were no changes in energy/fatigue, pain, or social functioning (Lechner et al., 2003). There is some evidence to support the use of massage therapy to improve QOL for people living with HIV/AIDS, particularly in combination with other stress-management modalities, and that massage therapy may have a positive effect on immunological function (Hiller, Louw, Morris, Uwimana, & Statham, 2010). A further consideration is the use of recreational drugs such as alcohol, chemical stimulants, tobacco, and marijuana, which increases physical and emotional stress. In patients with HIV/AIDS, physical and emotional stress is associated with these agents, as they have an immunosuppressant effect and may interfere with health-promoting behaviors. Substance use may also have a negative effect on interpersonal relationships and are associated with a relapse to unsafe sexual practices (Lambert et al., 2011). Patients who have substance abuse problems are encouraged to participate in self-health groups and harm-reduction programs to promote their health and QOL.

Research further suggests that the promotion of health involves positive emotional coping. In a study by Remien, Rabkin, and Williams (1992), patients

diagnosed with AIDS demonstrated that long-term survivors used numerous strategies to support their health. These included a strong will to live, positive attitudes, feeling in charge, a strong sense of self, expressing their needs, and a sense of humor. Based on a sample of 103 HIV/AIDS patients (Cohen, 2001), the relationship between the use of humor to cope with stress (coping humor) and perceived social support, depression, anxiety, self-esteem, and stress was examined. Although patients who used more coping humor were less depressed, expressed higher self-esteem, and perceived greater support from friends, humor did not buffer stress, anxiety, or immune-system functioning. Other health-promotion strategies frequently used by these patients included remaining active, seeking medical information, talking to others, socializing and pursuing pleasurable activities, good medical care, and counseling. It is recognized that stress can also be associated with the financial issues experienced by patients with HIV/AIDS. Financial planning, identification of financial resources available through the community, and public assistance offered through Medicaid were important in reducing stress.

In addition, health promotion for patients with HIV/AIDS includes avoidance of exposure to organisms in the environment and thereby prevention of the development of opportunistic infections. The immune system can be supported and maintained through the administration of prophylactic and/or suppressive therapies, which decrease the frequency or severity of opportunistic infections (Panel on Opportunistic Infections in HIV-Infected Adults and Adolescents (n.d.)). The administration of a pharmacological agent to prevent initial infection is known as primary prophylaxis, while the administration of a pharmacological agent to prevent future occurrences of infection is referred to as secondary prophylaxis (Panel on Opportunistic Infections in HIV-Infected Adults and Adolescents (n.d.)). There has been a significant decrease in the incidence of opportunistic infections due to the effectiveness of ART. Prophylaxis for life for HIV-related coinfections is no longer necessary in many cases. With restoration of immune-system function, as evident by a rise in CD4 counts, clinicians may consider discontinuation of primary prophylaxis under defined conditions (CDC, 2013). Ending preventive prophylaxis for opportunistic infections in selected patients may result in a decrease in drug interactions and toxicities, lower cost of care, and greater adherence to highly active antiretroviral therapy (HAART) regimens. However, prophylaxis remains important to protect against opportunistic infections in the late symptomatic and advanced stages of HIV disease, when CD4 counts are low. Therefore, throughout the illness trajectory, and even in hospice settings, patients may be taking prophylactic medications, requiring sophisticated planning



and monitoring. The recommendation is that prophylaxis and suppressive therapy continues in hospice care/PC if the patient is clinically stable and wants to continue prophylaxis drug therapy (Alexander, 2011). However, if side effects occur, and the patient continues to be otherwise stable, alternative regimens should be considered. Furthermore, if the patient is intolerant of prophylaxis and/or the regimens are burdensome, medications should be discontinued. In addition, HIV-infected individuals are at risk of severe diseases such as hepatitis B, tetanus, influenza, pneumococcal disease and measles, rubella, and mumps. Therefore, it is important to offer such vaccinations as a component of health promotion and disease prevention.

## The Use of Antiretroviral Therapy

The goal of ART is to slow disease progression and limit the occurrence of opportunistic infections. ART is administered to maximize long-term suppression of HIV-RNA and restore or preserve immune-system function, thereby reducing morbidity and mortality and promoting QOL (DHHS, 2013). Historically, assessment of the CD4 cell count was used to determine the initiation of ART with ART primarily reserved for CD4 counts below 350 cells/mm<sup>3</sup>. Currently, HIV therapy is recommended for all HIV patients regardless of CD4 cell count (DHHS, 2013). When initiating therapy, consideration must be given to toxicities associated with certain antiretroviral medications, such as elevations in serum levels of triglycerides and cholesterol, alterations in fat distribution, or insulin resistance and diabetes mellitus. However, the benefits of early therapy include earlier suppression of viral replication, preservation of the immune-system functioning, prolongation of disease-free survival, and a decrease in the risk of HIV transmission (DHHS, 2013).

## Classifications of Antiretroviral Therapies and Recommendations

Antiretroviral drugs are broadly classified by the phase of the retrovirus life cycle that the drug inhibits. Specifically, they act in the following ways:

- NRTIs interfere with the action of an HIV protein called reverse transcriptase, which the virus needs to make new copies of itself.
- nNRTIs inhibit reverse transcriptase directly by binding to the enzyme and interfering with its function.
- PIs target viral assembly by inhibiting the activity of protease, which is an enzyme used by HIV to cleave nascent proteins for final assembly of new virions.

- Integrase inhibitors inhibit the enzyme integrase, which is responsible for integration of viral DNA into the DNA of the infected cell.
- Entry inhibitors (fusion inhibitors and CCR5 antagonists) interfere with binding, fusion, and entry of HIV-1 to the host cell by blocking one of several targets. Maraviroc and enfuvirtide are the two currently available agents in this class.

When patients are naïve to ART, it is recommended that they begin a combination antiretroviral regimen. Preferred regimens are either nNRTI based, PI based, or integrase inhibitor based. The exact combinations recommended changes based on the emergence of high-quality evidence that supports its use. The reader should refer to the DHHS website to obtain the latest recommendations ([aidsinfo.nih.gov/guidelines](http://aidsinfo.nih.gov/guidelines)). The goal of therapy is maximal VL suppression.

If there is insufficient viral suppression, which is evidenced by an increase in VL, inadequate increase in CD4 cell counts, evidence of disease progression, adverse clinical effects of therapy, or compromised adherence caused by the inconvenience of difficult regimens, it is appropriate to consider a change of the medication regimen. The decision to change therapy involves consideration of whether other drug choices are available, the results of baseline resistance assays, and the patient's commitment to adhere to therapy.

The criteria for considering changing a patient's antiretroviral regimen include the following (DHHS, 2013):

- When there is virologic or incomplete failure; when the HIV VL fails to fall to a level less than 200 copies/mL or less than 50 copies/mL by 48 weeks after starting therapy; virologic rebound when there is HIV-RNA greater than 200 copies after complete suppression
- When there is immunologic failure; persistent decline in CD4 cell or failure to achieve an adequate CD4 response despite virologic suppression
- The occurrence or recurrence of HIV-related events after at least 3 months on an antiretroviral regimen (excluding immune reconstitution syndrome)

A change in an antiretroviral regimen can also be guided by drug-resistance tests, such as genotyping and phenotyping assays. Consultation with an HIV specialist is often of value.

## Considerations Relevant to Antiretroviral Therapy in Palliative Care

Clinicians must consider possible drug interactions with the administration of drugs in the treatment of HIV/AIDS and relief of symptoms. Pharmacokinetic

interactions occur when administration of one agent changes the plasma concentration of another agent. Pharmacodynamic interactions also occur when a drug interacts with the biologically active sites and changes the pharmacological effect of the drug without altering the plasma concentration. In PC, drug interactions have been reported for patients who are receiving methadone for pain management and who begin therapy with an nNRTI, nevirapine. These individuals have reported symptoms of opioid withdrawal within 4 to 8 days of beginning nevirapine due to its effect on the cytochrome P-450 (CYP) metabolic enzyme CYP3A4 and its induction of methadone metabolism (DHHS, 2013).

Furthermore, patients and health care providers should discuss the continuation of ART in hospice or palliative settings. Such decisions are often contingent on the feelings of patients regarding the therapy. Patients may be asked such questions as “How do you feel when you take your antiretroviral medications?” Patients who enter hospice may have a greater acceptance of their mortality and may wish to stop antiretrovirals because of the side effects. However, patients may wish to continue ART because of its symptom relief and the prevention of future symptoms related to opportunistic infections. Alexander (2011) has recommended that antiretrovirals be discontinued if the drugs cause burdensome symptoms or the patient no longer wants to use the drug. However, if the patient is asymptomatic and wishes to continue with ART, medications should be continued with close clinical assessment. Facilitating discussion of benefits and burdens of ART is an important aspect of PC and the decision to discontinue ART for hospice patients with AIDS should be a part of comprehensive PC.

In the hospice and PC settings, it is important for clinicians to discuss with patients and families their goals of care to make important decisions regarding the appropriateness of curative, palliative, or both types of interventions. More specifically, examples of clinical decisions about palliative or disease-specific care include use of blood transfusions, psychostimulants, or corticosteroids to treat fatigue in patients with late-stage AIDS; aggressive antiemetic therapy for PI-induced nausea and vomiting; discontinuation of ARTs that give severe side effects; continued suppressive therapy, for example, for CMV retinitis to prevent blindness; use of potent and potentially toxic anti-infectives, for example, amphotericin B for azole-resistant candidiasis; use of prophylactic medications in dying patients; withdrawal of therapies to prevent opportunistic infections in patients who are expected to die soon; the continuation or withdrawal of ART; as well as decisions to initiate ART in newly diagnosed late-stage patients (Selwyn & Rivard, 2003).

## Symptom Management in HIV Disease

Patients with HIV/AIDS require symptom management not only for chronic debilitating opportunistic infections and malignancies but also for the side effects of treatments and other therapies. Personal characteristics that interact with both HIV diagnosis and its medical management can influence symptom experience. The most prevalent symptoms in the AIDS population are fatigue (54–85%), pain (63–80%), nausea (43–49%), and constipation (34–35%); other symptoms include depression, breathlessness, insomnia, diarrhea, anorexia, and anxiety (Solano, Gomes & Higginson, 2006). In a prospective longitudinal study, 317 men and women living with HIV/AIDS in the San Francisco Bay Area completed the Memorial Symptom Assessment Scale, which is designed to estimate prevalence, severity, and distress of each symptom and global symptom burden. The median number of symptoms was nine, and symptoms experienced by more than half the sample population included lack of energy (65%), drowsiness (57%), difficulty sleeping (56%), and pain (55%). Global symptom burden was unrelated to age or CD4 cell count. Those with an AIDS diagnosis had significantly higher symptom burden scores as did those currently receiving ART. According to Lee et al. (2009), African Americans reported fewer symptoms than Whites or mixed/other race, and women reported more symptom burden after controlling for AIDS diagnosis and race.

Symptom and comfort measures at the EOL for HIV-infected patients share many of the features seen in non-HIV-infected patients at the EOL because a large percentage of late-stage AIDS patients are now dying of non-AIDS-defining illnesses. Therefore, translation of basic principles in pain and symptom management should be used for HIV-infected patients at the EOL (Fausto & Selwyn, 2011).

The five broad principles fundamental to successful symptom management are (a) taking the symptoms seriously, (b) assessment, (c) diagnosis, (d) treatment, and (e) ongoing evaluation (Newshan & Sherman, 1999). Patient’s self-report of symptoms should be taken seriously by the practitioner and acknowledged as a real experience of the patient. An important rule in symptom management is to anticipate the symptom and attempt to prevent it. Assessment and diagnosis of signs and symptoms of disease and treatment of side effects require a thorough history and physical examination. Questions as to when the symptom began and its location, duration, severity, and quality, as well as factors that exacerbate or alleviate the symptom, are important to ask. Patients can also be asked to rate the severity of a symptom by using a numerical scale from 0 to 10, with 0 being *no*



*symptom* to 10 being *extremely severe*. Such scales can also be used to rate how much a symptom interferes with activities of daily life, with 0 meaning *no interference* and 10 meaning *extreme interference*. One of the most frequently used tools to assess symptoms is the Edmonton Symptom Assessment Scale (ESAS), which is a valid and reliable instrument to assist in the assessment of nine common symptoms: pain, tiredness, drowsiness, nausea, appetite, shortness of breath, depression, anxiety, and well-being. When using this tool, patients who score greater than 7 have a self-defined symptom burden, meaning that their symptoms significantly impact their physical, emotional, and social functioning. Use of this tool is a simple and effective method of assessing the impact of select symptoms on individual QOL (Selby et al., 2011). When a patient seeks medical care for a specific symptom, the clinician should conduct a focused history including any past medical illnesses that may exacerbate HIV disease, a comprehensive physical examination, and judicious diagnostic testing. Assessment of current medications and complementary therapies, including vitamin therapy and the administration regimen of chemotherapy and radiation therapy, should also be ascertained to determine the effects of treatment, side effects, adverse effects, and drug interactions. In the case of extremely advanced disease, practitioners must reevaluate the benefits versus burden of diagnostic testing and treatments, particularly the need for daily blood draws or more invasive and uncomfortable procedures. When the decision of the practitioners, patient, and family is that all testing and aggressive treatments are futile, their discontinuation is warranted. Ongoing evaluation is key to symptom management and to determining the effectiveness of traditional, experimental, and complementary therapies. Changes in therapies are often necessary because concurrent or sequential illness or conditions occur (Newshan & Sherman, 1999).

In an article regarding the symptom experience of patients with HIV/AIDS, Holzemer (2002) emphasized a number of key tenets; specifically, (a) the patient is the gold standard for understanding the symptom experience; (b) patients should not be labeled *asymptomatic* early in the course of the infection because they often experience symptoms of anxiety, fear, and depression; (c) nurses are not necessarily good judges of patients' symptoms, as they frequently underestimate the frequency and intensity of HIV signs and symptoms; however, following assessment, they can answer specific questions about a symptom, such as location, intensity, duration, and so forth; (d) nonadherence to treatment regimens is associated with greater frequency and intensity of symptoms; (e) greater frequency and intensity of

symptoms leads to lower QOL; (f) symptoms may or may not correspond with physiological markers; and (g) patients use few self-care symptom management strategies other than medication.

## Pain in HIV/AIDS

Pain syndromes in patients with AIDS are diverse in nature and etiology. For patients with AIDS, pain can occur in more than one site, such as pain in the extremities (peripheral neuropathy), which may be associated with ARTs, particularly those administered early in the AIDS epidemic, or from nerves directly damaged by HIV itself as well as pain in the abdomen, oral cavity, esophagus, skin, perirectal area, chest, joints, muscles, and headache. In a study to identify the most common sites of pain in patients with advanced AIDS, Norval (2004) reported that lower limb pain was the most prevalent (66%), followed by mouth pain (51%), headache (42%), throat pain (40%), and chest pain (18%). Pain is also related to HIV/AIDS therapies such as antibacterials (e.g., isoniazid, ethambutol), chemotherapy such as vincristine, radiation, surgery, and procedures (Lorenz, Cunningham, Spritzer, & Hays, 2006). Patients may be suffering from inflammatory or infiltrative processes and somatic and visceral pain. Neuropathic pain is commonly a result of the disease process or the side effect of medications. The survival rate of patients without pain was significantly higher than those who report pain (Frich & Borgbjerg, 2000).

Following a complete assessment, including a history and physical examination, an individualized pain management plan should be developed to treat the underlying cause of the pain, often arising from underlying infections associated with HIV disease. The principles of pain management in the PC of patients with AIDS are the same as for patients with cancer and include regularity of dosing, individualization of dosing, and the use of combinations of medications. The three-step guidelines for pain management as outlined by WHO should be used for patients with HIV disease. This approach advocates for the selection of analgesics based on the severity of pain. For mild-to-moderate pain, anti-inflammatory drugs such as nonsteroidal anti-inflammatory drugs (NSAIDs) or acetaminophen are recommended. However, the use of NSAIDs in patients with AIDS requires awareness of toxicity and adverse reactions because they are highly protein-bound, and the free fraction available is increased in AIDS patients who are cachectic or wasted. For moderate to severe pain that is persistent, opioids of increasing potency are recommended, beginning with opioids such as codeine, hydrocodone, or oxycodone, each available

with or without aspirin or acetaminophen, and advancing to more potent opioids such as morphine, hydromorphone (Dilaudid), methadone (Dolophine), or fentanyl either intravenously or transdermally. In conjunction with NSAIDs and opioids, adjuvant therapies are also recommended (Trescot et al., 2008), such as the following:

- Tricyclic antidepressants, heterocyclic and noncyclic antidepressants, and serotonin reuptake inhibitors for neuropathic pain
- Psychostimulants to improve opioid analgesia and decrease sedation
- Phenothiazine to relieve associated anxiety or agitation
- Butyrophenones to relieve anxiety and delirium
- Antihistamines to improve opioid analgesia and relieve anxiety, insomnia, and nausea
- Corticosteroids to decrease pain associated with an inflammatory component or with bone pain
- Benzodiazepines for neuropathic pain, anxiety, and insomnia

Caution is noted, however, with use of PIs because they may interact with some analgesics. For example, Ritonavir has been associated with potentially lethal interactions with meperidine, propoxyphene, piroxicam, codeine, hydrocodone, oxycodone, and methadone increasing their levels, resulting in drug toxicity. Furthermore, for patients with HIV disease who have high fever, the increase in body temperature may lead to increased absorption of transdermally administered fentanyl, leading to toxic levels of drug.

To ensure appropriate dosing when changing the route of administration of opioids, or changing from one opioid to another, the use of an equianalgesic conversion chart is suggested (see Table 19.7). As with all patients, oral medications should be used, if possible, with round-the-clock (ATC) dosing at regular intervals, and the use of rescue doses for breakthrough pain. Often, controlled-release morphine or oxycodone are effective drugs for patients with chronic pain from HIV/AIDS. Taking under consideration that patients with HIV infection take several medications per day, minimizing the number of medications is the best option. Sustained-release opioids can provide 8 to 12 hours of analgesia, where transdermal opioids do not require taking the pills at all. In the case of neuropathic pain, often experienced with HIV/AIDS, tricyclic antidepressants such as amitriptyline, or anti-convulsants such as Neurontin, can be very effective (Trescot et al., 2008). However, the use of neuroleptics must be weighed against an increased sensitivity of AIDS patients to the extrapyramidal side effects of these drugs. A recent randomized placebo-controlled

trial demonstrates that, in addition to the above-mentioned pharmacological interventions, smoked cannabis effectively relieves chronic neuropathy associated with HIV (Abrams et al., 2007).

If the cause of pain is increasing tumor size, radiation therapy can also be very effective in pain management by reducing tumor size as well as the perception of pain. In cases of refractory pain, nerve blocks are available through neurosurgical procedures for pain management. Increasingly, epidural analgesia is an additional option that provides continuous pain relief.

In addition to pharmacologic management of pain and other symptoms, clinicians may consider the value of nonpharmacological interventions such as bed rest, simple exercise, heat or cold packs to affected sites, massage, transcutaneous electrical stimulation (TENS), and acupuncture. Psychological interventions to reduce pain perception and interpretation include hypnosis, relaxation, imagery, biofeedback, distraction, art therapy, and patient education.

Patients with HIV disease seek complementary therapies to treat symptoms, slow the progression of the disease, and enhance their general well-being. Milan et al. (2008) found that more than 90% of inner-city, middle-aged, heterosexual women and men ( $n = 93$ ) who were at risk for or who had HIV infection reported the use of complementary and alternative therapies in the prior 6 months. The 10 most commonly used complementary therapies and activities reported by 1,106 participants in the Alternative Medical Care Outcomes in AIDS study were aerobic exercise (64%), prayer (56%), massage (54%), needle acupuncture (48%), meditation (46%), support groups (42%), visualization and imagery (34%), breathing exercises (33%), spiritual activities (33%), and other exercises (33%; Milan et al., 2008). Nurses' knowledge, evaluation, and recommendations regarding complementary therapies are important aspects of holistic care.

### ■ PSYCHOSOCIAL ISSUES FOR PATIENTS WITH HIV/AIDS AND THEIR FAMILIES

Many practitioners focus on patient's physical functioning and performance status as the main indicators of QOL, rather than on the symptoms of psychological distress such as anxiety and depression. Based on a sample of 203 patients with HIV/AIDS, Farber, Mirsalimi, Williams, and McDaniel (2003) reported that positive meaning of the illness was associated with a higher level of psychological well-being and lower depressed mood, and contributed more than problem-focused coping and social support to predicting both psychological well-being and depressed



mood. Sherman et al. (2006), in a 2-year longitudinal pilot study regarding QOL for patients with advanced cancer and AIDS, found that while patients with advanced AIDS ( $n = 63$ ) reported a total lower QOL as compared to patients with advanced cancer ( $n = 38$ ), AIDS caregivers ( $n = 43$ ) reported greater overall QOL, psychological well-being, and spiritual well-being than did cancer caregivers ( $n = 38$ ). Sherman et al. posited that even as death approaches, health professionals can identify changes in QOL and appropriate interventions to improve QOL outcomes for HIV/AIDS patients.

Uncertainty is also a source of psychological distress for persons living with HIV disease, particularly as it relates to ambiguous symptom patterns, exacerbation and remissions of symptoms, selection of optimal treatment regimens, the complexity of treatments, and the fear of stigma and ostracism. Uncertainty is linked with negative perceptions of QOL and poor psychological adjustment (Brashers, Neidig, Reynolds, & Haas, 1998). Slater et al. (2013) identified the determinants of QOL in a sample of 60 older gay individuals with HIV/AIDS. Age, social support, and problem-focused coping were significantly and positively correlated with QOL, while medical comorbidities, social stigma, and emotion-focused coping were all significantly and negatively associated with QOL ( $p < .01$ ). In stepwise linear regression analysis, emotional/informational support remained as a significant positive predictor, and medical comorbidities, HIV stigma, and emotion-focused coping remained as significant negative predictors, accounting for 64% of the variance in QOL. The prevalence of major depression disorder (MDD) in patients diagnosed with HIV/AIDS has been estimated at 36%, 27% with dysthymic disorder, and 21% with both MDD and dysthymic disorder and is characterized by depressed mood, low energy, sleep disturbance, anhedonia, inability to concentrate, loss of libido, weight changes, and possible menstrual irregularities (Bing et al., 2001). In patients experiencing depression, clinicians also should assess their use of alcohol, drugs, and opioids.

The psychosocial issues experienced by patients with HIV/AIDS include multiple losses, complicated grief, substance abuse, stigmatization, and homophobia, which contribute to patients' sense of alienation, isolation, hopelessness, loneliness, and depression (Sherman, 2006). Such emotional distress often extends to the patient's family caregivers as they attempt to provide support and lessen the patient's suffering, yet experience suffering themselves.

Psychosocial assessment of patients with HIV disease is important throughout the illness trajectory, particularly as the disease progresses and there is increased vulnerability to psychological distress.

Psychosocial assessment includes the following (Sherman, 2006):

- Past social, behavioral, and psychiatric history, which includes the history of interpersonal relationships, education, job stability, career plans, substance use, preexisting mental illness, and individual identity
- Crisis points related to the course of the disease as anxiety, fear, and depression intensify, creating a risk of suicide
- Life-cycle phase of individuals and families, which influences goals, financial resources, skills, social roles, and the ability to confront personal mortality
- Influence of culture and ethnicity, including knowledge and beliefs associated with health, illness, dying, and death, as well as attitudes and values toward sexual behaviors, substance use, health promotion and maintenance, and health care decision making
- Past and present patterns of coping, including problem-focused and/or emotion-focused coping
- Social support, including sources of support, types of supports perceived as needed by the patient/family, and perceived benefits and burdens of support
- Financial resources, including health care benefits, disability allowances, and the eligibility for Medicaid/Medicare

Patients diagnosed with depression should be treated with antidepressants to control their symptoms (Repetto & Petitto, 2008). Selective serotonin reuptake inhibitors (SSRIs) are as effective as tricyclic antidepressants but are better tolerated because of their more benign side-effect profile. SSRIs may interact with such antiretroviral medications as PIs and nNRTIs; therefore, initial SSRI dosage should be lowered with careful upward titration and close monitoring for toxic reactions (Repetto & Petitto, 2008). Serotonin and norepinephrine reuptake inhibitors (SNRIs), such as venlafaxine and duloxetine, are newer antidepressants that also are useful in treating chronic pain. Tricyclic antidepressants are indicated for treating depression only in patients who do not respond to newer medications. It is noted that monoamine oxidase inhibitors (MAOIs) may interact with multiple medications used to treat HIV disease and, therefore, should be avoided. Medication interaction and liver function profiles should be considered before antidepressant therapy is initiated.

Another psychological symptom experienced by persons with HIV/AIDS is anxiety. Anxiety may also result from the medications used to treat HIV disease, such as anticonvulsants, sulfonamides, NSAIDs, and corticosteroids. Manifestations of generalized anxiety

disorder include worry, trouble falling asleep, impaired concentration, psychomotor agitation, hypersensitivity, hyperarousal, and fatigue (Arriandel, 2003). The treatment for patients with anxiety is based on the nature and severity of the symptoms and the coexistence of other mood disorders or substance abuse. Short-acting anxiolytics, such as lorazepam (Ativan) and alprazolam (Xanax), are beneficial for intermittent symptoms, while buspirone (BuSpar) and clonazepam (Klonopin) are beneficial for chronic anxiety (Gallego, Barreiro, & López-Ibor, 2012).

Significant stress is also associated with sharing information related to the diagnosis, and particularly when such disclosures occur during the stage of advanced disease. The need for therapeutic communication and support from all health professionals caring for the patient and his or her family exists throughout the illness continuum. For many patients experiencing psychological distress associated with HIV disease, therapeutic interventions such as skills building, support groups, individual counseling, and group interventions using meditation techniques can provide a sense of psychological growth and a meaningful way of living with the disease (Hanrahan et al., 2011). Fear of disclosure of the AIDS diagnosis and stigmatization in the community often raise concern in the family about the diagnosis stated on death certificates. Practitioners may therefore write a nonspecific diagnosis on the main death certificate and sign section B on the reverse side to signify to the registrar general that further information will be provided at a later date.

### Spiritual Issues in HIV/AIDS

Assessment of patients' spiritual needs is an important aspect of holistic care. Nurses must assess patients' spiritual values, needs, and religious perspectives, which are important in understanding their perspectives regarding their illness and their perception and meaning of life. Patients living with and dying from HIV disease have the spiritual needs of meaning, value, hope, purpose, love, acceptance, reconciliation, ritual, and affirmation of a relationship with a higher being (Kylmä, Vehviläinen-Julkunen, & Lähdevirta, 2001). Assisting patients to find meaning and value in their lives, despite adversity, often involves a recognition of past successes and their internal strengths. Encouraging open communication between the patient and family is important to work toward reconciliation and the completion of unfinished business.

As with many life-threatening illnesses, patients with AIDS may express anger with God. Some may view their illness as a punishment or are angry that God is not answering their prayers. Expression of feelings can be a source of spiritual healing. Clergy can also serve as valuable members of the PC team in

offering spiritual support and alleviating spiritual distress. The use of meditation, music, imagery, poetry, and drawing may offer outlets for spiritual expression and promote a sense of harmony and peace.

For all patients with chronic life-threatening illness, hope often shifts from hope that a cure will soon be found to hope for a peaceful death with dignity, including the alleviation of pain and suffering, determining one's own choices, being in the company of family and significant others, and knowing that their EOL wishes will be honored. Often, the greatest spiritual comfort offered by caregivers or family for patients comes from active listening and meaningful presence by sitting and holding their hands and knowing that they are not abandoned and alone.

Spiritual healing may also come from life review, as patients are offered an opportunity to reminisce about their lives, reflect on their accomplishments and misgivings, and forgive themselves and others for their imperfections. Indeed, such spiritual care conveys that even in the shadow of death, there can be discovery, insight, the completion of relationships, the experience of love of self and others, and the transcendence of emotional and spiritual pain. Often, patients with AIDS, by their example, teach nurses, family, and others how to transcend suffering and how to die with grace and dignity.

### Advanced Care Planning

Advanced planning is another important issue related to EOL care for patients with HIV/AIDS. First, the health care provider must assess the patient's competency to participate in his or her own plan of care. In assessing the patient's competency, the health provider must question whether the decision maker knows the nature and effect of the decision to be made and understands the consequences of his or her actions, and determine if the decision is consistent with an individual's life history, lifestyle, previous actions, and best interests. When an individual is competent, and in anticipation of the future loss of competency, he or she may initiate advance directives such as a living will and/or the designation of a health care proxy who will carry out the patient's health care wishes or make health care decisions in the event that the patient becomes incompetent. The patient may also give an individual the power of attorney regarding financial matters and care or treatment issue. Advance directives include the patient's decisions regarding such life-sustaining treatments as cardiopulmonary resuscitation, use of vasoactive drips to sustain blood pressure and heart rate, dialysis, artificial nutrition and hydration, and the initiation or withdrawal of ventilatory support. The signing of advance directives in a form of a health care proxy must be witnessed



by two individuals who are not related to the patient or involved in the patient's treatment. Individuals who are mentally competent can revoke at any time their advance directives. If a patient is deemed mentally incompetent, state statutes may allow the court to designate a surrogate decision maker as the legal guardian to make decisions for the patient.

Up until a few years ago, the majority of patients with AIDS usually had not discussed with their physicians the kind of care they want at the EOL for a variety of reasons, although more gay men have executed an advance directive than injection-drug users or women (J. R. Curtis, Patrick, Caldwell, & Collier, 2000; R. Curtis, Patrick, Caldwell, & Collier, 2000). White patients were more likely to believe that their doctor was an HIV/AIDS expert and good at talking about EOL care, recognize they have been very sick in the past, and that such discussions are important. By contrast, non-White patients with AIDS report that they do not like to talk about the care they would want if they were very sick and are more likely to feel that if they talk about death it will bring death closer (J. R. Curtis et al., 2000; R. Curtis, 2000).

In addition to the discussion of goals of care and the completion of advance directives, health care providers can also assist patients and families by discussing the benefits of social support programs, unemployment insurance, worker's compensation, pension plans, insurance, and union or association benefits. In addition, they may emphasize the importance of organizing information and documents so that they are easily located and accessible, and suggest that financial matters be in order, such as power of attorney or bank accounts, credit cards, property, legal claims, and income tax preparation. Health professionals may also discuss matters related to the chosen setting for dying and the patient's wishes regarding his or her death.

## Care of the Dying

The dying process for patients with advanced AIDS is commonly marked by increasingly severe physical deterioration, with patients becoming dependent on others for their care. Patients often are bedbound and experience wasting as their appetite decreases as well as their energy. At the EOL, common symptoms include pain, dyspnea, and pressure ulcers. Febrile states and changes in mental status often occur as death becomes more imminent. Maintaining the comfort and dignity of the patients becomes a nursing priority. Symptomatic treatments, including pain management, should be continued throughout the dying process since even obtunded patients may feel pain and other symptoms.

Because PC also addresses the needs of family, it is important to consider the vulnerability of family members to patients' health problems at the EOL. As illness

progresses and death approaches, health professionals can encourage patients and family members to express their fears and EOL wishes. Encouraging patients and families to express such feelings as, "I love you," "I forgive you," "Forgive me—I am sorry," "Thank you," and "Good-bye," is important to the completion of relationships (Byock, 1997). Peaceful death can also occur when families give patients permission to die and assure them that they will be remembered.

## Loss, Grief, and Bereavement for Persons With HIV/AIDS and Their Survivors

Patients with HIV disease experience many losses across the illness trajectory including a sense of loss of identity as they assume the identity of a patient with AIDS; loss of control over health and function; loss of roles as the illness progresses; loss of body image due to skin lesions, changes in weight, and wasting; loss of sexual freedom because of the need to change sexual behaviors to maintain health and prevent transmission to others; loss of financial security through possible discrimination and increasing physical disability; and loss of relationships through possible abandonment, self-induced isolation, and the multiple deaths of others from the disease (Sikkema, Kochman, DiFranceisco, Kelly, & Hoffmann, 2003). Each occurrence of illness may pose new losses and heighten the patient's awareness of mortality. Illness experiences are opportunities for health professionals to respond to cues of the patients in addressing their concerns and approaching the subject of loss, dying, and death. Given that grief is the emotional response to loss, patients dying from AIDS may also manifest the signs of grief, which include feelings of sadness, anger, self-reproach, anxiety, loneliness, fatigue, shock, yearning, relief, and numbness; physical sensations such as hollowness in the stomach, tightness in the chest, oversensitivity to noise, dry mouth, muscle weakness, and loss of coordination; cognitions of disbelief and confusion; and behavior disturbances in appetite, sleep, social withdrawal, loss of interest in activities, and restless overactivity (Mallinson, 2013).

The patient's family and significant others enter a state of bereavement upon the death of their loved one. Bereavement is a state of having suffered a loss, which is often a long-term process of adapting to life without the deceased (Mallinson, 2013). Family and significant others may experience signs of grief, including a sense of presence of the deceased, paranormal experiences or hallucinations, dreams of the deceased, a desire to have cherished objects of the deceased, and to visit places frequented by the deceased. Grief work is a dynamic process that is not time-limited and predictable (Mallinson, 2013). Those left behind never "get over" the loss but, rather, find a place for it in

their life and create through memory a new relationship with their loved one.

Families and partners of patients with AIDS may experience disenfranchised grief, defined as the grief that persons experience when they incur a loss that is not openly acknowledged, publicly mourned, or socially supported (Doka, 2002; Mallinson, 2013). Support is not only important in assisting families in the tasks of grieving, but is also important for nurses who have established valued relationships with their patients. Disenfranchised grief may also be experienced by nurses who do not allow themselves to acknowledge their patient's death as a personal loss, or who are not acknowledged by others, such as the patient's family or even professional colleagues, for having suffered a loss.

Worden (2008) has identified the tasks of grieving as accepting the reality of the death; experiencing the pain of grief; adjusting to a changed physical, emotional, and social environment in which the deceased is missing; and finding an appropriate emotional place for the person who died in the emotional life of the bereaved. Mallinson (2013) recommends the following nursing interventions to facilitate grief work:

- Accept the reality of death by speaking of the loss and facilitating emotional expression.
- Work through the pain of grief by exploring the meaning of the grief experience.
- Adjust to the environment without the deceased by acknowledging anniversaries and the experience of loss during holidays and birthdays; help the bereaved to solve problems and recognize their own abilities to conduct their daily lives.
- Emotionally relocate the deceased and move on with life by encouraging socialization through formal and informal avenues.

The complications of AIDS-related grief often come from the secrecy and social stigma associated with the disease. Reluctance to contact family and friends can restrict the normal support systems

available for the bereaved. The death of patients with AIDS may therefore result in complicated grief for the bereaved. Complicated grief may also occur when death occurs after lengthy illness and the relationship has been ambivalent. Culturally sensitive and truthful communication is important as health professionals offer support to families in their grief.

## ■ CONCLUSION

PC offers a comprehensive approach to address the physical, emotional, social, and spiritual needs of individuals with incurable progressive illness throughout the illness trajectory until death. For patients with HIV/AIDS, PC offers a combination of disease-modifying and supportive interventions throughout the disease trajectory to relieve the suffering associated with opportunistic infections and malignancies. Knowledge regarding HIV disease is important so that nurses can offer effective and compassionate care to patients, alleviating physical, emotional, social, and spiritual suffering at all stages of HIV disease. By establishing a partnership with their health care professionals in planning and implementing their health care, patients can maintain a sense of control during the illness experience. Through advanced care planning, patients can ensure that their EOL preferences and wishes are honored. The control of pain and symptoms associated with HIV/AIDS enables the patient and family to expend their energies on spiritual and emotional healing, and the possibility for personal growth and transcendence even as death approaches (Sherman, 2006). PC preserves patients' QOL by protecting their self-integrity, reducing a perceived helplessness, and lessening the threat of exhaustion of coping resources. Through effective and compassionate nursing care, patients with AIDS can achieve a sense of inner well-being even at death, with the potential to make the transition from life as profound, intimate, and precious an experience as their birth (Byock, 1997).

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## CASE STUDY Conclusion

Within 6 months, Miriam experienced night sweats, fever, and diarrhea due to an exacerbation of MAC. This resulted in severe dehydration. The PC team was asked for a consultation by the AIDS specialist. The advanced practice nurse developed a very supportive relationship with Miriam and her significant other. She listened attentively and offered a comforting presence. The PC nurse provided effective symptom management and lessened their anxiety by developing together a plan of care based on Miriam's wishes and preferences. They discussed her relationship with her mother and sister. Miriam decided to reach out and call her sister to tell her about her hospitalization. Her sister came to the hospital to visit. Over the next few weeks, a closeness was reestablished and her sister told her that she would be the guardian of her little boy. This conversation was facilitated by the advanced practice nurse. Miriam was coming to terms with her diagnosis



and confided that she wanted to speak to a priest for confession. An intimate conversation with the nurse was of comfort and a visit by the chaplain was arranged.

Miriam never left the hospital as her fever began to rise and she became delirious. Several tests were conducted to identify other potential sources of the infection and other possible reasons for the delirium. Her symptoms were treated with Haldol and antipyretics. However, within the next day, Miriam slipped into a coma. Her breathing was labored and she was given low doses of morphine to increase her comfort. With support from the advanced practice nurse, Miriam's little boy visited his mother. He kissed her hand and hung a picture he drew from the bedrail. With her mother, sister, and significant other at the bedside, tears flowed. Miriam left a letter to her family in the nightstand. She reminded her son of her strong love for him and promised to watch over him from above. Miriam thanked her mother and sister for their promise to protect and care for her child. To her partner, she expressed a love and wish that things were different. She asked the PC nurse to offer ongoing support to her family and thanked her for her loving and supportive care.

## Evidence-Based Practice

Slater, L., Moneyham, L., Vance, D., Raper, J., Mugavero, M., & Childs, G. (2013). Support, stigma, health, coping and quality of life in older gay men with HIV. *Journal of the Association of Nurses in AIDS Care*, 24(1), 38–49.

### Background

As life expectancy for persons living with HIV has increased due to antiretroviral therapy, quality of life (QOL) has become an emerging issue for older gay men with HIV, who comprise more than 50% of older adults living with HIV in the United States.

### Purpose

The purpose of this study was to determine predictors of QOL in older gay men with HIV.

### Design

Sixty gay men ages 50 to 65 participated in this quantitative research study.

### Results

Age, social support, and problem-focused coping were significantly and positively correlated with QOL, while medical comorbidities, social stigma, and emotion-focused coping were all significantly and negatively associated with QOL ( $p < .01$ ). In stepwise linear regression analysis, emotional/informational support remained as a significant positive predictor, and medical comorbidities, HIV stigma, and emotion-focused coping remained as significant negative predictors, accounting for 64% of the variance in QOL.

### Conclusion

Study findings may help researchers develop interventions aimed at increasing QOL in this population.

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# IV

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## Physical Aspects of Palliative Care: Symptoms

S E C T I O N





# Pain Assessment and Pharmacological/ Nonpharmacological Interventions

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## KEY POINTS

- Poorly controlled pain will be experienced by many patients at the end of life (EOL). This results in unnecessary suffering to both patients and their families.
  - Pain can be chronic or acute and it is the number one reason patients seek visits from health care providers.
  - We have the knowledge and the art to control pain and ameliorate suffering, yet patients continue to die in pain.
  - Pain is multidimensional, multifactorial, and rarely occurs in isolation from other symptoms.
  - Comprehensive assessment of pain is a necessary first step in management.
  - A sound knowledge of clinical pharmacology of analgesic drugs is also essential.
  - Nondrug pain interventions attempt to address aspects of a patient's pain that have not responded to pharmacological interventions. Or, when an individual is experiencing significant side effects from analgesic medications, they may be considered a better option with less likelihood of adverse experiences.
  - Consider whether a particular intervention will need high or low levels of patient or caregiver involvement at a time when both may be unable to participate at the level necessitated for success of the intervention.
  - Evidence for the use of nondrug pain interventions at the EOL is frequently limited because of the lack of large, well-designed, rigorous studies. Evidence-based literature continues to evolve.
  - The nurse is a key figure in bringing a comprehensive pain management approach to the bedside.
  - Ensuring that a dying patient has relief from pain is a moral obligation.
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## CASE STUDY

Mr. J. is a 68-year-old gentleman with non-small cell lung cancer, a widely metastatic disease to the bones. He was diagnosed 6 months earlier after a workup for a persistent cough and low back pain. He is married with two grown sons and has recently retired from his job in a bank. His plans upon retirement are to travel with his wife and to “enjoy life.” He is, however, a pragmatist and usually “takes life as it comes.”

His low back pain was described as dull, aching, persistent, worse with movement and better at rest—5/10 at its worst and 1/10 at its best. He was initially treated with palliative chemotherapy for his underlying disease and radiation therapy for his back for pain control. Residual pain was initially well managed with a combination of oxycodone and acetaminophen. He slept well at night and moved his bowels on a regular basis. However, Mr. J. decided against further chemotherapy.

Over several weeks, his back pain increased in severity, that is, 4/10 at rest and 7/10 on movement. He was using approximately 40 mg of oxycodone and 2,600 mg of acetaminophen a day. Constipation had become a problem but there were no other side effects. He was started on controlled-release oxycodone 30 mg every 12 hours (50% increase in oxycodone) and this was gradually increased to 120 mg every 12 hours. Mr. J. continued on acetaminophen as he found this gave him added pain relief. Rescue dose of oxycodone was 20 mg (approximately 10% of his 24-hour opioid dose) every 3 hours as needed. He was also started on an effective bowel regimen of a laxative and stool softener. His back pain was now under adequate control, with on average 3/10 on movement, and he continued to enjoy life.

Unfortunately, a change in his drug coverage mandated that he be given a trial of morphine therapy and that his controlled release oxycodone would no longer be covered. His medication was rotated to extended-release morphine 100 mg every 12 hours based on his daily oxycodone intake of 300 mg—240 mg around-the-clock + 60 mg as needed (PRN)—the oral equianalgesic dose of morphine = 450 mg. Because his pain control was good and because cross-tolerance is not complete, this dose was decreased by 25%. His final dose of extended-release morphine was 200 mg/day. He was also prescribed immediate-release morphine sulfate 30 mg every 3 hours PRN for breakthrough pain (15% of his 24-hour dose).

Mr. J.'s pain remained well controlled on this regimen although he had some initial nausea after the opioid rotation to morphine and some increased sedation. Around the clock metoclopramide was added for 2 days with the nausea resolving. It was then continued on a PRN basis. His daytime sleepiness had not resolved after a week, so he was started on a psychostimulant, methylphenidate 5 mg, each morning and at 12 noon with good effect. He continued to move his bowels daily.

Mr. J. was well for several months and then had a sudden and severe exacerbation of his back pain, rated 10/10, requiring hospitalization for a pain crisis. He was initially given 10 mg of IV dexamethasone and his oral morphine regimen was switched to the parenteral route for rapid pain control. Using a 3:1 ratio for the change from oral to parenteral route Mr. J.'s 300 mg of oral morphine/24 hours was converted to 100 mg of parenteral morphine per day via patient-controlled analgesia (PCA). This translated to his receiving 4 mg of morphine per hour via PCA with 2 mg IV every 15 minutes as needed for breakthrough pain. Mr. J.'s pain returned to his base line of 3/10 and within 72 hours he was rotated back to his previous oral morphine regimen. He continued on dexamethasone. The cause of his pain exacerbation was identified as tumor impinging on the spinal cord but he decided against further treatment except for continued steroids.



Two weeks later, Mr. J. developed a burning, shooting pain in his right chest wall. Previous imaging studies revealed impingement of the brachial plexus by tumor. Gabapentin (Neurontin) was added to his current regimen with dose titrated up to an effective tolerated dose.

Hospice was consulted and continued to work with this man and his family. His opioids and coanalgesic/adjuvant drugs were adjusted as needed and his pain remained under control. During an exacerbation of his pain, he was admitted to the inpatient unit of hospice. His family was educated on how to insert subcutaneous catheters and he was discharged once again with a PCA pump for pain management. When he was not able to use the delivery system, his family was instructed on use of “PCA by Proxy” to assist management of his pain. He passed away in his home surrounded by his family. His family received bereavement counseling as part of the benefits provided under hospice for the year following his death.

What types of pain was this man experiencing? What principles of opioid and coanalgesic management were demonstrated in this case? What would you add, if anything, to his analgesic regimen?

Few things are of more concern to patients at end of life (EOL) and to their families than that pain will be well controlled (D’Arcy, 2012; Ferrell & Coyle, 2010; Hospice and Palliative Nurses Position Statement, 2011; National Cancer Institute at the National Institute of Health, 2013 c). In the words of one patient, “I can’t emphasize enough that pain blinds you to all that is positive—I mean the real bad pain. It just closes you down.” Unrelieved pain can consume the attention and energy of those who are dying, and create an atmosphere of impotency and despair in their families and caretakers (Hospice and Palliative Nurses Position Statement, 2011). The fear of unrelieved pain expressed by patients and their families is sadly often reflective of what they have or will experience (American Geriatrics Society, 2013; SUPPORT, 1995). With the knowledge and art that is now available, we have the ability to relieve the majority of pain including pain at the EOL (American Nurses Association, 2010).

The intent of this chapter is to provide nurses with a basic overview of the principles of pain assessment and pharmacological management at EOL. The needs of special populations who have been identified as “at risk” for inadequate pain control are highlighted, including those who are elderly, those who are children, those who are communication impaired, and those with a history of substance abuse. These tend to be patients “without a voice” or whose voice is not heard, not respected, or not believed. Sometimes there is a mismatch between the normative values of the patient and the health care provider.

## ■ SECTION 1: PAIN ASSESSMENT AND PHARMACOLOGICAL INTERVENTIONS

The prevalence of pain in those with advanced illness varies by diagnosis and other factors. Pain in the cancer population is highly prevalent, has been widely studied, and is therefore a useful model from which to review pain assessment and management at the EOL (National Cancer Institute at the National Institute of Health, 2013b). The assessment and management of cancer pain will be used as the framework for this chapter. It is recognized that pain associated with a terminal disease may be superimposed on many other chronic pain syndromes, including musculoskeletal pain such as osteoarthritis and low back pain. The principles outlined in this chapter can be applied to any pain situation.

### Barriers to Pain Relief

Numerous clinician-, institutional-, and patient- and family-related barriers have been identified that consistently interfere with adequate pain management even at the EOL. In addition, there is a growing research on the influence of sex and gender on the experience of pain and response to treatment (Hurley & Adams, 2009).

Clinician-related barriers include inadequate knowledge of pain management, incomplete assessment of pain, concern about regulation of controlled substances, fear of causing patient addiction, concern about analgesic side effects, and concern that if strong opioids are used “too early” they will be

ineffective later when the need is greatest. In addition, a failure of clinicians to evaluate or appreciate the severity of the pain problem and to appreciate the impact of pain on the patient's day-to-day existence is likely to be a major predictor of inadequacy of relief (Ferrell & Coyle, 2010; Office of the Army Surgeon General, 2010).

Health care setting-related barriers include lack of visibility of pain, lack of a common language to describe pain, lack of commitment to pain management as a priority, and failure to use validated pain measurement tools in clinical practice. Use of the appropriate tool in the appropriate setting can improve pain and patient outcomes. The health care provider should be knowledgeable to choose the best tool given the patient population. The Critical-Care Observation Tool (CCOT); Faces Legs, Arms, Cry, Consolability (FLACC); Faces, Pain Scale-Revised (FPS-R); Visual Analog Scale (VAS); and Numerical Rating Scale (NRS) are examples of valid and reliable pain assessment tools (Pasero & McCaffery, 2011). Economic factors and drug availability are further impediments to adequate pain treatment, especially in underserved and minority communities and when pain is to be managed in the home (Hazin & Giles, 2011; Voelkner, 2010).

Patient-related barriers have many similarities to clinician-related barriers and include reluctance to report pain, reluctance to follow treatment recommendations, fears of tolerance and addiction, concern about treatment-related side effects, fears regarding disease progression, and belief that pain is an inevitable part of cancer and must be accepted (International Association for the Study of Pain, 2009; McCarberg, 2008).

Family-related barriers to pain management at end-of-life (EOL) are extremely important to understand (National Cancer Institute at the National Institute of Health, 2013 b). Frequently, it is a family member who is the primary care provider in the home and it is a family member who will be assessing pain and administering the pain medications. An early small descriptive study investigated the experience of managing pain at home from the perspectives of the patient, the primary family caregiver, and the home care nurse, and it encapsulated many of the important areas that still affect pain management in the home (Vallerand, Collins-Bohler, Templin, & Hasenau, 2007). Areas of decision making and conflict mainly centered on the use of medications. Patients were preoccupied with decisions about which pain medication to take and how much of it to take. Negative side effects and meaning in regard to these medications contributed to conflicts in the patient's mind as to whether they were doing the "right thing" in taking the pain medication. Nearly all the patients assumed their

pain would increase with impending death. Patient decisions about how to live with and cope with their pain included considerations of how what they did and said affected their health care professionals and family members. Sometimes, these factors continue to lead the patients to deny the pain (National Cancer Institute at the National Institute of Health, 2013 c). Similarly, the decisions and conflicts that arose most frequently for family caregivers also related to pain medication and having to make decisions about which pill to give and when. Compounding these decisions were the concerns related to overdosing, adverse side effects, and addiction.

A variety of approaches and specific programs have been developed to address these barriers; for example, making pain visible within an institution by incorporating a pain measurement tool into institutional daily clinical practice and introducing broad educational efforts to change attitudes, behaviors, and knowledge deficits in patients, clinicians, and institutions (The Joint Commission [TJC], 2012a). TJC standards on pain management have been helpful in making institutions accountable for assessment and management of pain across care settings (TJC, 2012a). In addition, varieties of professional organizations have developed and regularly update clinical practice guidelines for the assessment and management of pain. These organizations include the American Pain Society (APS), the American Society for Pain Management Nursing, the National Comprehensive Cancer Network (NCCN), the American Geriatric Society, and the National Consensus Guidelines for Quality Palliative Care. Clinical practice guidelines, as well as major national professional educational efforts on EOL care (End of Life Nursing Education Consortium [ELNEC] and Education for Physicians on End of Life Care [EPEC]), and Initiative for Pediatric Palliative Care (IPPC) are ongoing efforts to improve care of the dying and address the problem of inadequate control of pain (American Association of Colleges of Nursing, 2013; Education for Physician on End of Life Care, 2012; IPPC, 2003). Since the initiation of these organizations, the field of palliative care (PC) has expanded to include pediatrics, geriatrics, veterans, and critical care areas.

### **Basic Principles of Pain Assessment at the End of Life**

Pain assessment is the underpinning of pain management. The goals of pain assessment are to prevent pain if possible and to identify pain immediately should it occur. This can be facilitated by standardized screening of all patients for pain on a routine basis and across care settings (TJC, 2012 a). Standardized screening for pain can be as simple as asking the patient, "Do



you have pain?” A comprehensive assessment of pain follows if a patient reports pain that is not being addressed or adequately managed. TJC’s *Speak Up* series is a consumer publication urging the patient to take a more active role in pain management (TJC, 2013). Pain is always subjective and is defined by the International Association for the Study of Pain (IASP, 2012) as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage.” This definition clarifies the multidimensionality of pain. McCaffery’s definition of pain, “Whatever the person says it is, existing whenever he or she say it does” (Pasero & McCaffery, 2011), describes the subjectivity of pain. The patient is acknowledged as the expert on the severity of his or her pain and of the adequacy of relief obtained. The interprofessional team’s expertise is in identifying the different etiologies of the pain and arriving at effective management strategies with the patient and/or family. Although verbal report of pain and adequacy of pain relief is considered the gold standard, some individuals at EOL are unable to communicate verbally (Herr, Coyne, McCaffery, Manwarren, & Merkel, 2011). Other behavioral measures for assessing pain are therefore required and the American Society for Pain Management position statement (2011) promotes that in the presence of a pathology that is known to cause pain, a practitioner can “*assume pain is present*” and an analgesic trial is appropriate in this circumstance. For example, patients who are semiconscious or in a coma may moan or cry out or exhibit other signs of distress when moved. Although these behaviors are not necessarily associated with pain, the likelihood of pain should be strongly considered. If the decision is made to medicate the patient for pain, subsequent signs of diminished distress on movement may indicate that pain was present. If such a patient was on an analgesic regimen prior to diminution of consciousness, analgesics should be continued or increased until the patient shows signs of comfort.

Assessment of pain at EOL is often complicated by the presence of multiple other symptoms that are common in the last few days of life, including cognitive impairment (Gao et al., 2013; refer to Table 19.1). In addition, the suffering that patients experience at the EOL is not necessarily related to the severity of the symptom. Mild symptoms may cause considerable distress to the individual sometimes because of the meaning of that symptom to the person and sometimes because the individual has not yet come to terms with dying (National Cancer Institute at the National Institute of Health, 2012). Unrelieved pain and suffering can deprive patients and their families of interaction at the EOL around anything other than pain. A time of potential growth, communication, and

**TABLE 19.1 Challenges When Assessing Pain in the Far-Advanced Cancer Patient**

■ Multiple concurrent medical problems.
■ Multiple symptoms and symptom clusters.
■ Hepatic and renal failure and susceptibility to drug accumulation and adverse side effects.
■ Prevalence of delirium when close to death.
■ Requires more time than patients who are less ill.
■ Patients become easily fatigued and may be short of breath.
■ May be in “too much pain” or bothered by other symptoms to answer questions.
■ Possible tendency of family members to answer questions on patient’s behalf.

reconciliation can be lost. Nurses have an extraordinary responsibility to be patient advocates in the assessment and management of pain throughout the course of a disease process, but especially at the EOL (American Nurses Association, 2010). Because of its complexity, the assessment of pain is enhanced by a multidimensional and interprofessional approach (Institute of Medicine Report, 2011; National Quality Forum, 2006). The tissue damage response leading to the complaint of pain, the suffering component of the pain, and the meaning of the pain to the individuals and their families all need to be addressed. Although this comprehensive pain assessment is usually interprofessional, it is the nurse who brings that assessment and plan to the bedside. The assessment of pain is carried out within the framework of goals of care, patient and family values, knowledge of the disease process, and nearness of the individual to death.

### Types of Pain—Neurophysiological Mechanisms of Pain

Two major types of pain, *nociceptive pain* (which includes somatic and visceral pain) and *neuropathic pain*, have been described in the cancer patient (Pasero & McCaffery, 2011). *Somatic pain* occurs as a result of activating pain sensitive structures, or nociceptors, in the cutaneous and deep musculoskeletal tissues. This pain is typically well localized and may be felt in the superficial cutaneous or deeper musculoskeletal structures. Examples of somatic pain include bone metastases, postsurgical incisional pain, and pain accompanying myofascial or musculoskeletal inflammation or spasm (Pasero & McCaffery, 2011). Somatic pain is responsive to the nonsteroidal

anti-inflammatory drugs (NSAIDs), opioid drugs, and steroids.

*Visceral pain* results from infiltration, compression, distention, or stretching of thoracic or abdominal viscera (e.g., liver metastases or pancreatic cancer). This type of pain is poorly localized, often described as deep, squeezing pressure, and may be associated with nausea, vomiting, and diaphoresis (especially when acute). Visceral pain is often referred to cutaneous sites that may be remote from the site of the lesion; for example, shoulder pain associated with diaphragmatic irritation. Tenderness and pain on touching the referral cutaneous site may occur. Visceral pain is responsive to the NSAIDs, the opioid drugs, and steroids (Pasero & McCaffery, 2011).

*Neuropathic pain* results from injury to the peripheral or central nervous systems (CNS). In the cancer patient, neuropathic pain most commonly occurs as a consequence of the tumor compressing or infiltrating peripheral nerves, nerve roots, or spinal cord. In addition, this type of pain may result from surgical trauma and chemical or radiation-induced injury to peripheral nerves or the spinal cord from cancer therapies. Examples of common neuropathic pain syndromes include metastatic or radiation-induced brachial or lumbosacral plexopathies, epidural spinal cord or cauda-equina compression, postherpetic neuralgia (PHN), diabetic retinopathy, and painful chemotherapy-induced neuropathies. Neuropathic pain is often described as having sharp, shooting, electric shock-like qualities that are unfamiliar to the patient. It can also be described as a constant dull ache, sometimes with a pressure or vise-like quality with episodic paroxysms of burning or electric shock-like sensations. Neuropathic pain is often severe, very distressing to the patient, and sometimes difficult to control. Although partially responsive to the opioid drugs, neuropathic pain is also responsive to adjuvant drugs or coanalgesics such as antidepressants, anticonvulsants, steroids, local anesthetics, and N-methyl-D-aspartate (NMDA) antagonists such as ketamine (Portenoy & Dhingra, 2012).

### Temporal Pattern of Pain

Pain can also be defined on a temporal basis; for example, acute pain and chronic pain. Patients at the EOL frequently have a combination of both acute and chronic pain (Broglio & Portenoy, 2013).

*Acute pain* is characterized by a well-defined pattern of onset. Generally, the cause of the pain can be identified and the pain may be accompanied by physiological signs of hyperactivity of the CNS such as a rapid pulse and elevated blood pressure. Acute pain usually has a precipitating cause; for example,

small bowel obstruction, a painful dressing change, or a pathological fracture. The pain tends to be time-limited and responds to analgesic drug therapy and, where possible, treatment of the precipitating cause. Acute pain can be further subdivided into subacute pain and intermittent or episodic types (Pasero & McCaffery, 2011). Subacute pain describes pain that comes on over several days, often with increasing intensity, and may be associated with a variety of causes such as a progressive pathological process or an analgesic regimen that has not been titrated upward to accommodate for a progressive painful disease process. Episodic pain refers to pain that occurs during defined periods of time on a regular or irregular basis (Pasero & McCaffery, 2011). Intermittent pain is an alternative way to describe episodic pain. Such pain may be associated with movement, dressing changes, or other activities. Because the trigger for intermittent pain often can be identified, the nurse, through appropriate use of analgesics prior to the pain-provoking event, can have a significant impact on decreasing these painful episodes for the patient. The fear of pain associated with these activities is therefore lessened for the patient. Communication among caregivers and disciplines can minimize the fear and anxieties of the patient. Poor communication experiences and processes correlate with emotional distress, moral distress, and work-related stress (Goldsmith, Ferrell, & Wittenberg-Lyles, 2013).

*Chronic pain* differs from acute pain in its presentation. These differences are essential for the nurse to understand because patients with chronic pain are at risk to have their pain unrecognized, untreated, or undertreated. Chronic pain is defined as pain that persists for more than 3 months (Pasero & McCaffery, 2011). Adaptation of the autonomic system occurs and the patient does not exhibit the objective signs of pain found so frequently in those with acute pain (e.g., there is no rapid pulse or elevated blood pressure). Poorly relieved chronic pain at the EOL can contribute to fatigue, depression, insomnia, general despair, withdrawal from interaction with others, and desire for death (National Cancer Institute at the National Institute of Health, 2013c; Pasero & McCaffery, 2011).

*Breakthrough pain* is defined as a transient increase in pain to greater than moderate intensity, occurring on a baseline pain of moderate intensity or less (American Cancer Society, 2010; Pasero, 2012). Breakthrough pain has a diversity of characteristics. In some patients, for example, it is characterized by marked worsening of pain at the end of the dosing interval of regularly scheduled analgesics, known as end-of-dose failure (Hall & O'Lenic, 2012). In other patients, it occurs by the action of the patient or the nurse (e.g., when turning or having a dressing



change), and is referred to as incident pain. Patients frequently have a combination of these different types of pain; noting the patterns of pain in a particular individual is an essential component of pain assessment. Attention to such details is the essence of symptom control at the EOL. A pain diary or log, kept by the patient or family, can help identify the pattern of pain. The log can indicate, over the course of the day, the patient's rating of pain, medication taken, activity level, and any other pain relief measures tried.

## Clinical Assessment of Pain

The previously described mechanisms of pain and types of pain that can be experienced by patients with advanced progressive disease are a useful background from which to start a clinical pain assessment. The clinical assessment is based on a process of both observation and interview. The basic principles of a pain assessment are outlined in Table 19.2. It is based on the premise that the person experiencing the pain is the expert on his or her pain (Herr et al., 2011). The clinician's role is to sort out the etiology

of the pain complaint and arrive at a targeted management approach with the patient and family. If the patient is too ill or cognitively impaired to respond to the questions, a family member or care provider is asked to give the pain history as best he or she can. A variety of validated pain assessment tools are available for use in the hospital or home setting. Ideally, any pain assessment tool includes intensity of pain, relief of pain, psychological distress, and functional impairment. For the patient with severe cognitive impairment, various assessment tools are also available (Pasero & McCaffery, 2011). In the terminally ill patient when multiple symptoms are common, it can be useful to follow the intensity of pain and other symptoms in graph form longitudinally.

*Taking a focused pain history* involves assessing the following parameters:

■ **Onset.** Have the patient describe when the pain first began. Was it associated with a particular activity or known medical event? Did other symptoms accompany the onset of pain such as nausea or vomiting?

**TABLE 19.2 Clinical Assessment of Pain: Basic Principles**

■ Accept the patient's complaint of pain. The patient is the expert on the pain being experienced. The multidisciplinary staff are the experts in determining the etiology of the pain.
■ Take a careful history of the pain complaint and place it within the context of the patient's medical history and goals of care. If the patient is unable to communicate verbally, obtain a history from those most involved in the patient's care, both family and formal health care providers.
■ Observe the patient for nonverbal communication regarding pain; for example, guarding, wincing, and moaning, bracing or crying out when turned or moved.
■ Recognize that the patient near the end of life may have multiple symptoms complicating pain assessment.
■ Assess the characteristics of each pain, including the site, pattern of referral, what makes it better and what makes it worse, and the impact of the pain on the individual's activities of daily living and quality of life; for example, mood, sleep, movement, and interaction with others.
■ Clarify the temporal aspects and pattern of the patient's pain; for example, acute, chronic, baseline, intermittent, breakthrough, or incident.
■ Assess the psychological state of the patient and the meaning of the pain to the patient and his or her family.
■ Examine the site of the pain for presence of pathology.
■ Facilitate an appropriate diagnostic workup, making sure that the patient's pain is adequately managed during the workup.
■ Provide continuity of care for the patient and family during ongoing pain assessment and management.
■ Assess and reassess the effectiveness of the pain management regimen both for baseline pain and breakthrough pain and make adjustment accordingly.
■ Give a time frame where you would expect to see evidence of patient comfort after the start or adjustment of a pain management approach. If this is not evident, reassess the patient. Ongoing reassessment is essential in the setting of a complex patient with multiple symptoms.
■ Assess and reassess for the presence of adverse side effects from the pain management regimen.

■ **Site(s).** Ask the patient to point to the site or sites of pain. Frequently, individuals with pain have multiple sites of pain. Each site needs to be assessed as the management approach may differ depending on the etiology of the pain.

■ **Quality of the Pain.** Have the patient describe the quality of each pain. Word descriptors used by patients to describe their pain help the clinician to arrive at an inferred pain mechanism. This, in turn, influences the choice of pharmacotherapy. For example, sharp, shooting, electric shock–like descriptions of pain, often described by the patient as “unfamiliar,” suggests a neuropathic component to the pain (Pasero & McCaffery, 2011). Such pain may be responsive to coanalgesic/adjuvant drugs as well as to opioid analgesics.

■ **Severity of the Pain.** Have the patient describe the severity of each pain. It is particularly important that the nurse recognize the significance of escalating pain within the context of that particular patient’s disease process, value system, goals of care, and nearness to death. Treatment decisions take all of these factors into account. As previously described, a variety of tools for measuring pain are available for use in the hospital or home setting. Ask the patient the amount of distress caused by each site of pain. In this way each pain can be prioritized.

Although numerical estimates are the most frequently used methods of assessing severity of pain and adequacy of pain relief, some patients cannot use a numerical estimate. In these cases, one of the other tools may be more appropriate. Consistency in using a particular assessment tool with an individual patient is likely to enhance communication among team members regarding the efficacy of a pain management approach. Some patients will underreport their pain. The reasons are varied but include a patient’s appraisal of the consequences of reporting pain (National Cancer Institute at the National Institute of Health, 2012). For example, having an opioid dosage increased may lead to fear of increased constipation. This potential outcome may not be acceptable to the patient and therefore he or she chose not to report the pain. Other patients do not report escalating pain because previous reports of pain have led to ineffective management. In other words, they “give up” trying.

■ **Assess Pain Severity at Times of Different Activity.** Pain intensity should be assessed at rest, on movement, and in relation to daily activity and the patient’s analgesic schedule. Asking certain questions helps establish if the appropriate drug has been selected, dose efficacy, and if the time interval between doses for this patient is correct: “How much pain is

relieved when you take the pain medication?” “How long does the relief last?” and “Are side effects present?” A more global 24-hour assessment of the adequacy of pain management in general includes asking the patient his or her pain scores—“right now,” “at its best,” “at its worst,” and “on average” (National Cancer Institute at the National Institute of Health, 2012).

■ **Exacerbating and Relieving Factors.** Identifying factors that increase or relieve the patient’s pain can be helpful in arriving at a pain diagnosis and in giving the nurse the opportunity to reinforce techniques that the patient has found useful in the past to relieve pain. A patient with cancer who reports rapidly escalating back pain with a band-like quality that is worse when lying in bed and better when standing is considered to have cord compression until proved otherwise (Huff & Brenner, 2012). Early recognition of cord compression and treatment, frequently by steroids, radiation therapy, or both, may prevent paraplegia in the last few weeks or months of a patient’s life. Escalating back pain may be the only sign of the impending cord compression. It is critical that the nurse who is caring for a patient at the EOL recognizes the significance of escalating pain within the construct of that particular patient’s disease process and goals of care.

■ **Impact of the Pain on the Patient’s Psychological State.** The interface between pain and suffering has been well described (Cherney, 2010; Cherny & Coyle, 1994; Saunders, 1967). In clinical situations, when patients are asked, “What does this pain mean to you?” and “What do you think is causing the pain?” a flood of suffering and fear is often expressed. Patients are fearful of what their dying will be like, of uncontrolled and excruciating pain, of being a burden on their family, and of being “drugged out.” The same questions may be asked by the patient and family time and time again, and need to be responded to in a sensitive, accurate, and reassuring manner. Some clinicians, when meeting a patient in severe pain for the first time, ask if the pain has ever been so bad that the individual has thought of harming him- or herself. Again, the response may indicate that suicide has been considered as an option if the pain is not controlled or if things get “too bad.” These are important questions for an experienced clinician to ask so that the patient’s vulnerabilities and anxieties are verbalized, suicide vulnerability factors are identified, and education and support from other members of the interprofessional pain team, including psychiatrists, psychologists, social workers, and chaplains, are mobilized (Institute of Medicine Report, 2008; National Quality Forum, 2006). All of the patient’s



worries and fears need to be addressed if the pain is to be adequately controlled. This is an ongoing process.

■ **Pain Treatment History and Responses to Previous and Current Analgesic Regimens.** The patient needs to be asked very specifically about what approaches have been used to manage pain in the past—both pharmacological (including over-the-counter medication) and nonpharmacological—and how effective those approaches have been. Included should be analgesics that have been previously prescribed, dosages, time intervals, routes of administration, effects, side effects, and the reasons why a particular approach was discontinued. Additionally, discussion of previous use of illicit drug history can assist the practitioner to determine tolerance and risk for misuse and abuse (Reisfield, Paulian, & Wilson, 2009). Fear of recurrence of previously experienced side effects (e.g., sedation, nausea, mental haziness, and constipation) may make a patient reluctant to start a new analgesic regimen. Focusing attention on his or her concerns and a clear explanation of how side effects will be managed if they do occur can do much to allay these fears. This is a commitment that will require close monitoring of the patient's response to therapy and a rapid response to the management of any adverse side effects should they occur. It is important to understand that the metabolism of opioids can be affected by race, genetics, and medical condition of the patient (Smith, 2009).

■ **Examine the Patient and the Site of the Pain.** Examining the site of the pain and possible referral sites may help identify the source of the pain (Herr et al., 2011). This is always done within knowledge of the patient's disease process, extent of disease, possible referral sites of pain, and goals of care. The source of the pain may be obvious; for example, a distended abdomen associated with a full bladder, bowel obstruction or liver distention, a prior skin eruption with PHN, a bony deformity or inability to use a limb due to a pathological fracture, or an open fungating infected wound. In the advanced cancer patient and others with advanced illness and comorbidities, the cause of pain is frequently multifactorial requiring a multimodal approach (National Cancer Institute at the National Institute of Health, 2012). Whenever possible, within the constraints of nearness to death and goals of care, an attempt is made to treat the cause of the pain as well as the pain itself. The extent of the diagnostic workup depends on the goals of care and the likely impact of the results of the diagnostic workup on the patient's treatment plan and overall quality of life (QOL). The benefit-to-burden ratio to the patient is

of uppermost concern and needs to be discussed fully with the patient and family or the patient's health care agent (Pessin et al., 2008). Although most pain can be adequately controlled to the patient's satisfaction, and that is always the goal, the complete absence of pain is not possible for some patients. Realistic goal setting with the patient, and establishing what level of pain would be acceptable and would not interfere with QOL and function, is part of the assessment. The balance is to achieve maximum pain relief and minimal adverse effects of treatment. Realistic goal setting is likely to diminish later frustration and loss of trust in the clinician's competence.

## Components of Pain Management

Pain is a multidimensional experience that involves sensory, affective, cognitive, behavioral, and socio-cultural components (Huijter, Miaskowski, Quinn, & Twycross, 2013). Although pharmacotherapy is the foundation of pain management, pharmacotherapy alone will not be an effective approach to pain management at the EOL. A multimodal approach is usually required, including attention to the suffering and spiritual or existential component to the patient's pain (Cherny & Coyle, 1994; Huijter et al., 2013; Saunders, 1967). In addition, the needs of the family must be addressed (Herbert, Schulz, Copeland, & Arnold, 2008; National Cancer Institute at the National Institute of Health, 2013; Rhodes, Mitchell, Miller, Connor, & Teno, 2008). Table 19.3 illustrates factors that contribute to the concept of "total pain" at EOL and its multidimensional nature.

## ■ PHARMACOLOGICAL THERAPY

Inadequate knowledge of analgesic pharmacotherapy is one of the most commonly cited reasons for undertreatment of pain. Developing expertise in the use of analgesic drugs is an integral part of nursing care at the EOL.

Over two decades ago, an expert committee convened by the cancer unit of the World Health Organization (WHO) developed a three-step "analgesic ladder" approach to the selection of drugs for the treatment of cancer pain (WHO, 2010). The basic principles of analgesic selection developed by this committee apply to pain management at the EOL. Three categories of analgesic drugs are included in the three-step analgesic ladder: NSAIDs, opioids, and coanalgesics or adjuvant drugs. With a focus on EOL care, discussion around these groups of drugs will include rationale for selection, dose titration, routes of administration, and side effect management.

**TABLE 19.3 Factors Contributing to a Patient's "Total Pain" or "Existential Distress" at End-of-Life**

Tissue damage response associated with the disease or its treatment causing pain Nociceptive pain Neuropathic pain Mixed pain syndrome
Multiple other disease-related or treatment-related distressing symptoms Psychological, spiritual, and social distress
Anxiety, fear, and spiritual distress associated with Uncontrolled pain or other symptoms Perceived loss of dignity Loss of bodily control Uncertainty about the future Uncertainty about God Fear of death Fear of abandonment (by God, family, friends, the medical team) Worry about exhausting and burdening the family, friends, and medical team Worry about how he or she will be remembered Worry about finances and financially depleting the family
Depression associated with Loss of sense of "self" Loss of social position and role in the family Loss of control Sense of helplessness and demoralization Perceived loss of dignity Loss of meaning and purpose in continued life Loss of hope
Anger associated with Delays in diagnosis resulting in late diagnosis and diminished hope for a cure Bureaucratic bungling Therapeutic failures Insensitive communication Friends who do not visit

Of note, the above factors are interrelated. Their interrelatedness is dynamic and nonlinear. When one factor changes it influences other factors. The impact of each factor varies from patient to patient and within one patient at any given time. This list is not all-inclusive.

### Acetaminophen and Nonsteroidal Anti-Inflammatory Drugs

■ **Acetaminophen.** Although lacking in significant anti-inflammatory effects, acetaminophen is a useful analgesic in the management of mild acetaminophen pain or in combination with an opioid for the management of more intense pain syndromes. Acetaminophen

has fewer adverse effects than the NSAIDs. Gastrointestinal (GI) toxicity is rare, and there are no adverse effects on platelet function or cross-reactivity in patients with aspirin hypersensitivity (Risser, Donovan, Heintzman, & Page, 2009). Hepatic toxicity can occur, however, and patients with chronic alcoholism and liver disease can develop severe hepatotoxicity even when the drug is taken in usual therapeutic doses (Chandok & Watt, 2010). The U.S. Food and Drug Administration (U.S. FDA; 2011) limited the amount of acetaminophen in each tablet or capsule to no more than 325 mg and a 24-hour maximum dose not to exceed 4,000 mg. McNeil Consumer Healthcare, a division of Johnson & Johnson, the maker of the brand Tylenol<sup>®</sup> changed its packaging to recommend the daily dose not to exceed 3,000 mg in a 24-hour period (Medical News Today, 2011). Reduced doses or avoidance of acetaminophen is recommended in the face of renal insufficiency or severe liver compromise (Chandok & Watt, 2010).

■ **NSAIDs.** The NSAIDs include many subclasses, are frequently used in all steps of the "analgesic ladder" (National Cancer Institute at the National Institute of Health, 2013), and are analgesic, antipyretic, and anti-inflammatory. Table 19.4 shows guidelines for selection and use of NSAIDs. Aspirin is the prototype of the NSAIDs. NSAIDs are most effective in treating mild-to-moderate pain when there is an inflammatory component present and are used in Step 1 of the analgesic ladder. When greater relief is needed, they are continued along with the opioid drugs in Steps 2 and 3 of the analgesic ladder. The NSAIDs can be extremely effective when combined with an opioid drug in treating bone pain in cancer patients; prostaglandins, which are rich in the periosteum of the bone, are implicated in pain modulation. Unlike the opioid drugs, NSAIDs have a ceiling effect, that is, a dose beyond which added analgesia is not obtained (Becker, 2010). These drugs do not produce tolerance or physical dependence and are not associated with psychological dependence (addiction; Becker, 2010). This class of drugs may also have an opioid-sparing effect in some patients.

### Mechanism of Action

The NSAIDs mainly affect analgesia by reducing the biosynthesis of prostaglandins, inhibiting the cascade of inflammatory events that lead to nociception (Risser et al., 2009).

### Adverse Effects and Their Management

Patients, particularly at EOL, are very susceptible to adverse side effects of pharmacotherapy. A careful balance is needed between achieving the desired effect of the selected drug for the patient and the potential for adverse effects. This is particularly important



**TABLE 19.4** Key Points in the Selection and Use of NSAIDs and Acetaminophen

- The older adult with chronic heart failure, renal insufficiency, cirrhosis with ascites, significant atherosclerotic disease, or multiple myeloma is at risk for NSAID-induced renal failure or gastrointestinal bleeding.
- Unlike with opioids, the adverse side effects of NSAIDs often do not produce obvious symptoms until a major event such as a gastrointestinal event occurs.
- Selective-Cox-2 inhibitors differ in their side effect profile from nonselective NSAIDs in relation to potential for gastric irritation and interference with platelet aggregation. However, selective-Cox-2 inhibitors have similar adverse effects (e.g., sodium retention, edema, hypertension) to the nonselective NSAIDs.
- Avoid NSAIDs if possible in patient with gastroduodenopathy, bleeding diathesis, renal insufficiency, hypertension, severe encephalopathy, and cardiac failure.
- NSAIDs should not be used concomitantly with other drugs that have the potential to cause gastric erosion (e.g., corticosteroids).
- Avoid acetaminophen in patients with severe liver disease.
- Daily dose of acetaminophen should not exceed 3,000 mg/24.

NSAIDs, nonsteroidal anti-inflammatory drugs

with NSAIDs. Unlike the opioids where the adverse effects are usually dose-dependent and controllable, NSAIDs have a largely “hidden” side effects profile (Becker, 2010). Although they occur in a minority of patients, these adverse effects are often “silent,” that is, not producing symptoms until a major event, such as GI bleeding, occurs without prior warning. The nurse is an active participant in assessing this risk/benefit ratio for the patient and needs to become familiar with the relative side effect profile for each of the drugs within this category. The potential adverse effects of the NSAIDs include those affecting the hematologic, GI, renal, and CNSs (Becker, 2010; Risser et al., 2009). The selective Cox-2 inhibitors differ in their side effect profile from other NSAIDs in relation to potential for less gastric irritation (at least with short-term use) and interference with platelet aggregation. However, renal adverse effects are similar and concern about cardiovascular risks suggests that they should be used with caution in “at risk” patients (Becker, 2010).

## Principles of Administration of the Nonsteroidal Anti-Inflammatory Drugs

■ **Drug Selection.** A careful medical and pain history provides the nurse with information about potential benefits and risks for a patient about to receive a NSAID. An analgesic history should illuminate the patient’s prior exposure to the NSAIDs, including frequency of administration, analgesic effects, and side effects. Information regarding the timing interval of other analgesics is important so that a prescribed NSAID regimen fits in with the patient’s total analgesic plan. For example, if a patient was on an 8- or 12-hour dosing regimen of a controlled release morphine preparation, an NSAID with a similar dosing profile would be appropriate. This may aid patient compliance and cut down on the feeling of having to take medication constantly.

■ **Choice of Starting Dose and Dose Titration.** An NSAID is combined with an opioid drug in Steps 2 and 3 of the analgesic ladder. Doses are often started at the lower end of the recommended scale in these medically fragile individuals who are coming to the end of their lives and are increased as needed (refer to Table 19.5). Although several weeks are needed to evaluate the efficacy of a dose, when NSAIDs are used in the treatment of grossly inflammatory conditions such as arthritis, clinical observation suggests that a shorter time period, usually a week, is adequate for pain relief in a patient with cancer pain. Pain and other symptoms should be monitored before and after starting the NSAIDs to document any improvement or adverse effects. If no benefit is seen or if adverse effects are noted, consideration should be given to discontinuing the drug or switching to an alternate NSAID, as marked variability has been noted in patients’ response to different NSAIDs. Indicators of an effective response would be either a significant improvement in pain or a significant decrease in the opioid use with a subsequent reduction in opioid-related side effects. The degree of monitoring for adverse effects from the NSAIDs should be individualized to the patient. Tables 19.4 and 19.5 provide guidelines to the nurse for the selection and use of NSAIDs in the management of pain.

## The Opioid Drugs

A clear understanding of the clinical significance of tolerance, physical dependence, and psychological dependence, as these terms relate to the use of opioid drugs, is essential if nurses are to break down the pervasive barriers that surround the use of opioid analgesics and result in inadequate pain relief and much

**TABLE 19.5** Selective Coanalgesics/Adjuvant for Pain

Drug Class	Indications	Drug Examples of Drugs Starting Dose (Range)	Adverse Effects
Antidepressants (PO)	Neuropathic pain (burning quality) Added benefit for insomnia or depression	Amitriptyline 10–25 mg/qhs Nortriptyline 10–25 mg/qhs Desipramine 10–25 mg/qhs Venlafaxine 37.5 mg BID Duloxetine 30 mg BID	Anticholinergic effects Most prominent with amitriptyline Nausea; dizziness
Anticonvulsants (PO)	Neuropathic pain (sharp, shooting, electric shock-like quality)	Clonazepam 0.5–1 mg/qhs, BID or TID Gabapentin 100 mg TID Pregabalin 50 mg TID	Sedation Dizziness; LE edema—elderly and frail more at risk
Corticosteroids (PO, IV, SC)	Cord compression, bone pain, neuropathic pain, visceral pain, pain crisis	Dexamethasone 2–20 mg/day Give up to 100mg IV for pain crisis Prednisone 1530 mg TID or QID	“Steroid psychosis”—delirium Dyspepsia
Local anesthetics (PO, IV, SC, infusion, transdermal)	Neuropathic pain	Mexiletine 150 mg TID Lidocaine 1–5 mg/kg hourly Lidocaine patch 5% 12 h on 12 h off	Lightheadedness, tremor, paresthesias, arrhythmias
N-methyl-D-aspartate (NMDA) Receptor antagonists (IV, SC, PO)	Neuropathic pain	Ketamine 0.1–0.2 mg/kg per h 5 mg PO	Confusion, frightening dreams
Alpha-2 adrenergic agonists (PO, ED, transdermal)	Refractory pain. Can be used in combination with an opioid ED	Clonidine	
Bisphosphonates (IV)	Osteolytic bone pain	Pamidronate 60–90 mg	Pain flair over 2 h q 2–4 weeks
Antispasmodic (PO, IT)	Muscle spasms	Baclofen 10 mg (PO) qd or QID	Muscle weakness, cognitive changes
Botox (SC)	Dystonia Muscle spasms		
Calcitonin (SC, nasal)	Neuropathic pain, bone pain	25 IU/day	Hypersensitivity reaction nausea
Baclofen	Muscle spasm associated pain	10 mg PO daily or 3 times day	Muscle weakness; cognitive changes
Calcium channel blockers	Ischemic pain, neuropathic pain, smooth muscle spasms with pain	Nifedipine 10 mg PO TID	Bradycardia; hypotension

This table should be used as a guide only and not replace a more in-depth review. Individual dosing depends on each patient's particular situation and comprehensive assessment.

BID, morning and night; ED, epidural; h, hour; IU, international units; IV, intravenous; PO, by mouth; qd, daily; qhs, at bedtime; SC, subcutaneous; TID, three times a day. References cited in the section of text that discusses use of coanalgesics/adjuvants.



unnecessary suffering to patients and families (refer to Table 19.6).

*Tolerance* is the phenomenon characterized by the need for increasing dose to maintain the same drug effect (Pasero & McCaffery, 2011). Usually, the reason for dose escalation at the EOL occurs in the setting of increasing pain associated with progressive disease (National Cancer Institute at the National Institute of Health, 2013). Patients with stable disease do not usually require increasing opioid doses (Pasero & McCaffery, 2011). This observation, integrated with the knowledge that there is no “ceiling” effect to the opioid drugs, implies the following: (a) Concern about tolerance to analgesic effects should not impede the use of opioids early in the course of the disease, and (b) worsening pain in a patient on a stable dose of opioids is assumed to be evidence of disease progression until proven otherwise.

*Physical dependence* is an altered physiologic state that occurs in patients who use opioids on a long-term basis. If the drug is stopped abruptly or an antagonist is given, the patient exhibits signs of withdrawal. Signs of opioid withdrawal include anxiety, alternating hot flashes and cold chills, salivation, rhinorrhea, diaphoresis, piloerection, nausea, vomiting, abdominal cramping, and insomnia (Gordon & Dahl, 2011).

The time frame of the withdrawal syndrome depends on the half-life of the drug. For example, abstinence from drugs with a short half-life such as morphine and hydromorphone may occur within 6 to 12 hours of stopping the drug and be most severe after 24 to 72 hours. After withdrawal of drugs with a long half-life such as methadone, the symptoms may not occur for a day or longer (Gordon & Dahl, 2011). Gradual reduction of the opioid dose in the physically dependent patient who no longer has pain will prevent the withdrawal syndrome (Gowing, Farrel, Ali, & White, 2009). Clinical experience suggests that administering 25% of the previous analgesic dose will prevent the withdrawal syndrome in most patients (Gordon & Dahl, 2011). However, patients must be closely monitored during the tapering process to be sure they are not experiencing symptoms of withdrawal. A small proportion of patients require an extremely slow opioid taper because of persistent withdrawal symptoms.

The use of an antagonist such as naloxone in the physically dependent patient will precipitate acute withdrawal symptoms unless carefully titrated (Pasero & McCaffery, 2011). If a drug overdose is suspected in a patient who has received opioids for more than a few days, a dilute solution of naloxone can be used (0.4 mg in 10 mL of normal saline solution; APS, 2008). This may be administered in 1 mL bolus injections every one to three minutes until the patient becomes responsive. The goal is to reverse respiratory depression and not reverse the analgesic effect of opioids. It is reiterated that the need to use naloxone to reverse opioid-induced respiratory depression at EOL is exceedingly rare (National Cancer Institute at the National Institute of Health, 2013).

*Psychological dependence* (addiction) is defined as a pattern of compulsive drug use characterized by a continued craving for an opioid, loss of control, and continued use despite harm. Clinical experience with cancer patients and limited studies suggest that addiction is extremely uncommon in patients without a history of drug abuse who are receiving opioids for pain (Strassells, 2008). In patients who do have a history of drug abuse, the data are scant. Concerns about this outcome, however, continue to be a reason for undertreatment of pain (Oliver et al., 2012). In the setting of poorly relieved pain, “aberrant” drug-seeking behavior such as clock-watching requires careful nursing assessment. The term “pseudo-addiction” has been used to describe drug-seeking behavior reminiscent of addiction that occurs in the setting of inadequate pain relief and is eliminated by improved analgesia (Weissman, 2009). For the most part, this behavior signifies inadequate pain relief. Patients and their families need to be reassured that use of opioid drugs in the amount that is needed to control pain,

TABLE 19.6 Clarification of Terms

- **Addiction** is a primary, chronic, neurobiological disease, with genetic, psychosocial, and environmental factors influencing its development and manifestations. It is characterized by behaviors that include one or more of the following: impaired control over drug use, compulsive use, continued use despite harm, and craving.
- **Physical dependence** is a state of adaptation that is manifested by a drug-class-specific withdrawal syndrome that can be produced by abrupt cessation, rapid dose reduction, decreasing blood level of the drug, and/or administration of an antagonist.
- **Tolerance** is a state of adaptation in which exposure to a drug induces changes that result in diminution of one or more of the drug's effects over time. **Note:** Need for opioid escalation in a patient with cancer is usually associated with progressive disease rather than tolerance per se.
- **Pseudoaddiction** is the mistaken assumption of addiction in a patient seeking pain relief.
- **Diversion** is the shifting of legally obtainable drugs into illegal channels or the acquisition of a controlled substance by an illegal method

regardless of what that amount is, is unlikely to cause addiction if an individual does not have a history of drug abuse. In a patient who does have a history of previous drug abuse, there are minimal data in this respect; however, pain can still be well managed using this class of drug. The management of pain in patients with a history of drug abuse will be discussed in the section on special populations.

### ■ Opioids and the Three-Step Analgesic Ladder.

Opioid analgesics are the mainstay of pain treatment at the EOL. These drugs are used for moderate-to-severe pain in Steps 2 and 3 of the analgesic ladder. They are frequently used in combination with an NSAID (APS, 2008). When formulated in combination with an NSAID drug, dose escalation is limited by reaching the maximum recommended daily dose of the NSAID. When formulated as a single agent, however, there appears to be no ceiling effect (Motov, 2008). Dose escalation may be limited by adverse effects such as sedation, confusion, nausea and vomiting, myoclonus, and (rarely) respiratory depression (Motov, 2008). Dose escalation is governed by the balance between pain relief and intolerable and unmanageable side effects (Fine & Portenoy, 2011). This balance can be determined only by ongoing assessment and documentation of the effects and side effects produced by the opioid.

### Mechanism of Action

Opioids produce their effects through binding to receptors in the brain and spinal cord to prevent the release of neurotransmitters involved in pain transmission (Pasero & McCaffery, 2011). Opioids can also have a peripheral site of action in the presence of inflammation (Sehgal, Smith, & Manchikanti, 2011). In addition, opioid receptors are present in immunocompetent cells that migrate to inflamed tissue (APS, 2008). The opioids can be divided into agonists, agonist-antagonists, and antagonists classes based on their interactions with the receptor types. Pure opioid agonists (e.g., morphine, hydromorphone, oxycodone, fentanyl, and methadone) bind primarily to the mu receptors.

Partial agonists and mixed agonist-antagonists either block or remain neutral at the mu-opioid receptors while activating kappa-opioid receptors (Pasero & McCaffery, 2011). Partial agonists, for example, buprenorphine and pentazocine, have limited use in PC. Their pharmacology is characterized by a ceiling effect to analgesia and the ability to precipitate withdrawal symptoms in patients who are physically dependent on pure agonist drugs (e.g., morphine; National Cancer Institute at the National Institute of Health, 2013). The incidence of psychomimetic

effects (agitation, dysphoria, confusion) from the mixed agonist-antagonist is greater than that of pure agonists (morphine-like drugs; Pasero & McCaffery, 2011). The opioid antagonist drugs include naloxone and naltrexone. These drugs bind to opioid receptors and block the effect of morphine-like agonists. Opioid side effects and their management are described below. This is followed by a brief review of the most commonly used opioids in PC and EOL care.

### Opioid Side Effects and Their Management

■ **Constipation.** Constipation in the PC setting is common and usually multifactorial (National Cancer Institute at the National Institute of Health, 2013). It is the most frequently encountered side effect experienced during opioid therapy and the one to which patients rarely develop tolerance. Opioid binding to peripheral receptors in the gut prolongs colon transit time by increasing or decreasing segmental contractions and decreasing propulsive peristalsis (Coyle & Layman-Goldstein, 2007). Because the likelihood of constipation is so great in PC patients who are receiving opioid therapy, laxative medications should be prescribed in a preemptive manner (National Cancer Institute at the National Institute of Health, 2012). Most clinicians recommend a laxative/softener combination prophylactically. Bulking agents (e.g., psyllium) should be avoided as they tend to cause a large bulkier stool. Metoclopramide can minimize nausea and increase motility to minimize constipation but is contraindicated in the presence of a bowel obstruction, bowel perforation, or GI bleeding. In addition, debilitated patients are rarely able to take in sufficient fluid to facilitate the action of bulking agents. Polyethylene glycol (Miralax) is also well tolerated for opioid-induced constipation. A parenteral compound, methylnaltrexone (Relistor), has been shown to be effective in relieving opioid-induced constipation when given subcutaneously at doses of 0.15 mg/kg (Crowner & Zimmerman, 2010; Payton, 2010).

■ **Sedation.** Some level of sedation is experienced by many patients at the initiation of opioid therapy and during significant dose escalation. Patients usually develop tolerance to this effect in days to weeks (Pasero & McCaffery, 2011). Should sedation persist at a level that is unacceptable to the patient, a careful assessment by the nurse is needed. Confounding factors such as other sedating drugs, metabolic disturbances, sleep deprivation, and the somnolence that may occur at EOL must be identified. Management steps include elimination of nonessential drugs with



CNS depressant effects, reduction of the opioid dose if feasible, changing to an alternate opioid drug, and, if necessary, adding a psychostimulant such as modafinil or methylphenidate (Jackson & Block, 2009).

■ **Confusion and/or Delirium.** Like sedation, mild cognitive impairment is common after initiation of opioid therapy. Patients may express this as feeling “mentally hazy” or “not as sharp as before.” Patients should be reassured that these effects are transient in most individuals and last from a few days to a week or two (Swegle & Logemann, 2006). Persistent confusion attributable to opioids alone is uncommon. More commonly, confusion or delirium in patients at the EOL is multifactorial including electrolyte disorders, neoplastic involvement of the CNS, sepsis, vital organ failure, and hypoxia (Keeley, 2010). If confusion or delirium persists, opioid rotation may be warranted, especially if the current opioid has active metabolites that may be contributing to the delirium. A common example of this would be an elderly patient with renal impairment who is receiving escalating doses of morphine to manage the pain.

■ **Nausea and Vomiting.** Nausea and vomiting are common at the start of opioid therapy (Swegle & Logemann, 2006). According to Swegle and Logemann (2006), tolerance to this effect typically develops within days to weeks and the need for scheduled antiemetics decrease but should be made available on an as-needed basis. Both peripheral and central mechanisms are thought to be involved. Opioids stimulate the medullary chemoreceptor trigger zone and increase vestibular sensitivity. Direct effects on the GI tract include increased gastric antral tone, diminished motility, and delayed gastric emptying (Swegle & Logemann, 2006). Constipation may also be a contributing factor. Establishing the pattern of nausea may clarify the etiology of the symptom and guide management approaches. Frequently, a combination of cognitive and pharmacological approaches is used, depending on the pattern of the nausea and assumed underlying mechanism (National Cancer Institute at the National Institute of Health, 2013). Cognitive techniques might include relaxation training with focused breathing, guided imagery, and distraction. For nausea associated with early satiation and bloating, metoclopramide is often the initial pharmacologic approach. If vertigo or movement-induced nausea is the predominant feature, the patient may benefit from an antivertiginous drug such as scopolamine (transdermal) or meclazine. Scopolamine may cause confusion in the patient who is elderly or frail and so must be watched. Other options include trials

of alternative opioids, treatment with an antihistamine (e.g., hydroxyzine or diphenhydramine), neuroleptic (e.g., haloperidol or chlorpromazine), benzodiazepine (e.g., lorazepam), or a steroid (e.g., dexamethasone; Glare, Miller, Nikolova, & Tickoo, 2011). The role of serotonin antagonists (e.g., ondansetron) is primarily in chemotherapy-induced nausea and vomiting and has a limited role in PC (Glare et al., 2011).

■ **Multifocal Myoclonus.** Mild and infrequent multifocal myoclonus can occur with all opioids (Pasero & McCaffery, 2011). The effect is usually related to dose, in the presence of renal impairment, and glucuronide toxicity from morphine and hydromorphone metabolism (Kullgren, Le, & Wheeler, 2013). Myoclonus is extremely distressing to the patient, where the uncontrolled, abrupt, jerking movements of the patient's limbs or torso can increase already existing pain. The clinician may interpret the movements as increased signs of pain, escalating the dose or frequency of the opioid, further adding to the involuntary movements. Myoclonus can be a sign of opioid toxicity and is a reason to switch to an alternate opioid (Kullgren et al., 2013). Carefully reviewing the patient's renal function can assist in choosing the best opioid. In addition, a benzodiazepine, for example, clonazepam, can be used to treat the symptom (Caviness, 2013).

■ **Urinary Retention.** Urinary retention can occur in patients receiving opioid drugs, especially in those who require rapid escalation of the drug, are receiving other drugs with anticholinergic effects such as the tricyclic antidepressants (TCAs), or have compromised bladder function. Older men with an enlarged prostate are particularly at risk. Opioids increase smooth muscle tone and infrequently cause bladder spasm or an increase in sphincter tone, which may lead to urinary retention (Hanks et al., 2004). Opioid-induced urinary retention may require catheterization (Verhamme, Sturkenboom, Stricker, & Bosch, 2008). However, rotation to an alternative opioid may be helpful.

■ **Pruritus.** Pruritus can occur with any opioid, is associated with histamine release, and is most commonly seen with morphine use. Fentanyl and oxycodone may be associated with less histamine release (APS, 2008). Prescribing an antihistamine such as diphenhydramine or mirtazapine can minimize the side effect. Ondansetron has been reported to relieve opioid-related pruritus (Ferrell & Coyle, 2010).

■ **Respiratory Depression.** Respiratory depression is rarely a clinically significant problem in

an opioid-tolerant patient (Swegle & Logemann, 2006). Increased sedation precedes respiratory depression and can be identified early if a comprehensive assessment is completed. However, fear of respiratory depression is a frequently cited concern among medical and nursing staff when initiating opioid therapy or when rapidly increasing opioids to control pain or dyspnea in a debilitated patient at the EOL. Clinically significant respiratory depression is always accompanied by other signs of CNS depression, such as sedation and mental clouding, and is unusual in the patient receiving chronic opioid therapy unless other contributing factors are present. Pain antagonizes CNS depression, and respiratory effects are unlikely to occur in the presence of severe pain. With repeated administration of an opioid, tolerance develops rapidly to the respiratory depressant effects of the drug (Swegle & Logemann, 2006). Unwarranted fears of respiratory depression should not interfere with appropriate upward titration of opioids to relieve pain (APS, 2008; Spathis & Booth, 2008). Capnography and end-tidal carbon dioxide monitoring (ETCO<sub>2</sub>) can be used for patients who are at risk for respiratory depression or apnea (Burton, Harrah, Germann, & Dillon, 2008). The onset or exacerbation of existing sleep apnea in patients taking opioids for pain has been reported (APS, 2008). Risk factors appear to be the use of methadone, concomitant use of benzodiazepines or other sedative agents, respiratory infections, and obesity.

Occasionally, staff unfamiliar with the dying process and the altered breathing pattern that so frequently occurs at this time become concerned that continued use of opioids will hasten death, especially in the higher doses sometimes required to control pain at the EOL. The input and mentoring by a nurse who is knowledgeable in pain and PC will help refocus the more inexperienced staff on appropriate dosing strategies in the symptomatic dying patient. The principle of double effect can minimize the fears of the nurse while ensuring adequate pain at the EOL (D'Arcy, 2012).

### Commonly Used Opioids in Palliative Care

*Morphine* is the prototype of pure opioid agonist. Morphine is considered the standard base or “currency” for which other opioids are exchanged in order to determine the equivalency. The practitioner should calculate the oral morphine equivalents (OME) or morphine equivalent daily dose (MEDD), then use the number to determine the initial dose of the alternate opioid. It is essential to use a standardized conversion chart to determine equivalent doses.

WHO placed morphine on the essential drug list and requested that it be made available throughout the world for cancer pain relief (WHO, 2011). Morphine is available in tablet, elixir, suppository, and parenteral form. Various oral controlled-relief preparations provide analgesia with duration of 8 to 12 to 24 hours. Alternate routes of drug administration are available for patients who are unable to use the oral or rectal route.

Patients with severe pain are initially titrated with immediate-release morphine, or if in a hospital setting with parenteral opioids, and once stabilized are converted to a controlled-release preparation. To manage breakthrough pain or incident pain, immediate-release morphine should be made available to all patients receiving controlled-release preparations. Absorption of morphine after oral administration occurs mostly in the upper small bowel. The average bioavailability for oral morphine is 20% to 30% (National Cancer Institute at the National Institute of Health, 2013). This explains why there is a need to increase the patient's opioid dose when changing from the parenteral to the oral route of drug administration. In patients with normal renal function, the average plasma half-life is 2 to 3 hours, whereas the average duration of analgesia is about 4 hours (Smith, 2009). Morphine-3-glucuronide (M-3-G), an active metabolite of morphine, may accumulate in patients with impaired renal function. This accumulation may contribute to myoclonus, seizures, and hyperalgesia (increasing pain) in a dying patient with marked renal impairment (Kullgren et al., 2013). Because of these and other factors, the nurse must take note of the patient's renal status, especially in the older adult, when administering morphine and monitor accordingly for signs of opioid toxicity. If adverse effects exceed the analgesic benefit of the drug, the patient should be rotated to a different opioid.

*Hydromorphone* is a semisynthetic, short half-life opioid and is a useful alternative to patients who tolerate morphine poorly. Hydromorphone is more potent when compared milligram to milligram than morphine and can be administered by the oral, rectal, parenteral, subcutaneous, and intraspinal routes. The half-life of hydromorphone of 1/2 to 3 hours is slightly shorter than that of morphine, and it has an oral bioavailability of 30% to 40% (National Cancer Institute at the National Institute of Health, 2013). The comparative potency of the opioid drugs and bioavailability dependent on route of administration underscores the need for nurses to be competent in the use of the equianalgesic table (refer to Table 19.7). The main metabolite of hydromorphone, hydromorphone-3-glucuronide, may lead to



**TABLE 19.7 Equianalgesic Dose Table: Relative Potencies of Commonly Used Opioid Analgesics \***

Drug	Equianalgesic Parenteral Dose (mg)	Parenteral Oral Potency	Comment
Morphine	10	3	Standard of comparison for opioid analgesics. Multiple routes of administration. Controlled-release available. M-3-G accumulation in patients with renal failure. Lower doses for the elderly.
Oxymorphone	1	10	Available in suppository form as Numorphan.
Hydromorphone	1.5	5	Useful alternative for morphine. H-3-G accumulation in patients with renal failure. Multiple routes available.
Methadone	**	**	Long half-life.
Levorphanol	2	2	Long half-life.
Fentanyl	—	—	Short half-life when used acutely. Parenteral use via infusion. Clinical experience suggests 4 mg IV morphine sulfate/hr = 100 mcg transdermal patch. Patches available to deliver 12.5, 25, 50, 75, 100 mcg/hr. Transmucosal delivery systems available.
Oxycodone	Not available	2	Available in liquid or tablet preparation. Also in combination with a nonopioid. Controlled-release not available.
Codeine	130	1.5	Used orally for less severe pain. Usually combined with a nonopioid.
Hydrocodone	Not available		Usually combined with a nonopioid.

\* Note: This table should be used as a guide only and not replace a more in-depth review. Individual dosing and drug selection depends on each patient's particular situation and comprehensive assessment.

\*\* See text and Table 19.8.

Source: Reprinted from Lee, M. A., Leng, M. E., Tiernan, E. J. (2001). Retrospective study of the use of hydromorphone in palliative care patients with normal and abnormal urea and creatinine. *Palliative Medicine*, 15, 26–34.

CNS toxicity, including myoclonus, hyperalgesia, and seizure, especially in the setting of renal failure (Kullgren et al., 2013). Personal clinical experience suggests that these adverse effects usually occur in the setting of high parenteral doses being administered by continuous infusion. Hydromorphone is available in controlled-release formulation known as Exalgo.

*Oxycodone* is a semisynthetic opioid. The equianalgesic ratio to that of morphine is approximately 20–30:30. It has a half-life of 2 to 4 hours

and is mainly excreted by the kidneys. Oxycodone is available in combination with aspirin (Percodan) or acetaminophen (Percocet), oral solution (Oxydose, Oxyfast, or Roxicodone Intensol), or as a single immediate-release or controlled-release tablet. The controlled-release tablet (OxyContin) provides the patient with analgesia for 8 to 12 hours. Both hydromorphone and oxycodone are used in Steps 2 and 3 of the analgesic ladder. Oxycodone is not available in parenteral form in the United States.

*Fentanyl* is a lipid soluble potent opioid that is being used with increasing frequency in PC, especially in the transdermal form. Because of its potency, fentanyl dosing is usually in micrograms. Clinical experience with cancer patients suggests that a 100 mcg/hr fentanyl patch is equianalgesic to 2 to 4 mg of parenteral morphine per hour (Twycross, 2011). Although most patients maintain satisfactory pain control with a patch change every 72 hours, some patients require the patch to be changed after 48 hours. Careful monitoring of adequacy of pain relief and evidence of EOL failure will guide the nurse in the needs of the particular patient. It is important that the nurse also realizes that there is a lag in absorbing fentanyl through the skin. It takes 12 to 16 hours for the patient to see a substantial therapeutic effect (Twycross, 2011). Availability of a different route of drug administration is therefore necessary during the 12 to 16 hours following the initial patch placement. An alternate route of drug administration is also required for breakthrough pain medication. Significant concentrations of fentanyl remain in the plasma for about 24 hours after removal of the patch because of delayed release from the tissues and subcutaneous depots. Drug side effects (if present) may persist for that length of time. Fever, cachexia, obesity, edema, and ascites may all have a significant effect on absorption and clinical effect (Heiskanen et al., 2009). Patches range in strength from 12.5 to 100 mcg. A 12.5 mcg patch releases 12.5 mcg of fentanyl per hour while a 100 mcg patch releases 100 mcg of fentanyl per hour.

*Oral transmucosal fentanyl* (OTFC) provides a useful mode of delivering a potent, short-half-life opioid to a patient who requires a potent drug with a rapid onset of action and short duration of effect for severe breakthrough pain (APS, 2008; Zeppetella, 2008). OTFC citrate is approved for breakthrough treatment in opioid-tolerant cancer patients only but has proven safe in severe non-malignant pain with the recommendation that the product is only to be used in patients who are opioid tolerant and who are receiving the equivalent of no less than 60 mg of oral morphine a day or transdermal fentanyl 50 mcg every 3 days. OTFC differs from other breakthrough pain medication in that there is no relationship between the baseline dose of the patient's pain medication and the microgram dose of OTFC required to relieve breakthrough pain (APS, 2008; Coluzzi et al., 2001). In all other opioid drugs, there is a relation between the two. With OTFC, the smallest available dose is initially chosen (200 mcg) and titrated up depending on the patient's response (available strengths range from 200 to 1,600 mcg/unit). Pain relief can usually be

expected in about 5 minutes after beginning use (Gordon & Schroeder, 2008). Patients should use OTFC over a period of 15 minutes because too rapid use will result in more of the agent being swallowed than absorbed transmucosally.

*Buccal fentanyl* tablets, when compared with OTFC, may provide more rapid onset of pain relief and greater extent of absorption (Darwish, Kirby, Robertson, Tracewell, & Jiang, 2007). The adverse effects are similar to those of other opioids. A small group of patients cannot tolerate the sensation of the tablet effervescing in the buccal space. For patients who are unable to place the tablet buccally (between the gum and cheek pouch), sublingual (under the tongue) absorption appears to be comparable (Darwish, Kirby, Jiang, Tracewell, & Robertson, 2008). Buccal fentanyl (Actiq) has a bioavailability approximately half of the transdermal route (Gordon & Schroeder, 2008). Actiq and buccal fentanyl should not be referred to as a lollipop or sucker to minimize the attraction to children (Pasero & McCaffery, 2011).

Nurses should also be aware that the short-acting fentanyl preparations are affected by the risk evaluation and mitigation strategy (REMS). REMS, instituted by the FDA, is part of a government effort to reduce the safety risks associated with Schedule II opioid medications. At present only these short-acting fentanyl preparations are affected but other Schedule II opioid analgesics may be covered by REMS regulations in the future. Only licensed practitioners registered in the REMS program can prescribe REMS-regulated medications and they will need to establish a REMS contract with each individual patient who received a REMS-regulated prescription. REMS-regulated prescriptions can only be filled at REMS-registered pharmacies. These regulations may not only help reduce safety issues but also be a barrier to patients using some of these medications in their analgesic regimen (Peppin, Coleman, & Kirsh, 2011).

*Methadone* is another useful synthetic opioid for the management of pain, including pain at the EOL. It is especially useful for patients who have not done well on other opioids (Mannino, Coyne, Swainey, Hansen, & Lyckholm, 2006). Patients, however, may be reluctant to use methadone for pain because of its association with addiction. Methadone is primarily metabolized by cytochrome P450 (CYP) enzymes. Drugs that induce CYP enzymes, for example, dexamethasone, carbamazepine, phenytoin, and barbiturates, may accelerate the metabolism of methadone, resulting in decreased plasma levels of the drug and decreased pain relief. On the other hand, drugs that inhibit CYP enzymes, for example ketoconazole, omeprazole, and selective serotonin reuptake inhibitor



(SSRI) antidepressants, may potentially slow down the metabolism of methadone, leading to sedation and the possibility of respirator depression (Paice & Ferrell, 2011). Awareness by the nurse of any changes in the patient's medication regimen and the potential effect on the patient's pain relief or development of adverse effects is an integral aspect of pain management. Methadone in inexperienced hands is a potentially dangerous drug because of its variable long half-life (range, 13 hours to over 100 hours; Coyle & Layman-Goldstein, 2007) and a discrepancy between drug half-life and the duration of analgesic effect (4 to 8 hours). Patients are at increased risk for drug accumulation and subsequent toxicity when treatment is initiated, the dose is increased, or multiple organ failure develops. Warning signs of drug accumulation are, for example, a patient who becomes confused and increasingly sedated during the titration phase. Because of this risk, methadone should only be prescribed by experienced clinicians (Coyle & Layman-Goldstein, 2007).

The equianalgesic dose ratio of morphine to methadone has been a matter of controversy and confusing lack of clarity for clinicians (Knotkova, Fine, & Portney, 2009). Available data indicate that the ratio correlates with the total opioid dose administered before switching to methadone (Plonk, 2005; Walker et al., 2008; Weschules & Bain, 2008).

For example, when rotating a patient from morphine to methadone, the higher the current 24-hour dose of morphine the patient has been receiving, the larger the conversion ratio needs to be to provide pain relief. For example, if a patient is receiving from 30 to 90 mg morphine in 24 hours, the morphine to methadone ratio is 4:1. If the patient has been receiving 91 to 300 mg of morphine in 24 hours, the morphine to methadone ratio is 9:1, and if the patient has been receiving greater than 300 mg of morphine in 24 hours, the morphine to methadone ratio is 12:1 or higher (Benítez-Rosaria, Salinas-Martín, Aguirre-Jaime, Pérez-Méndez, & Fera, 2009; refer to Table 19.8). Questions have been raised regarding the effect of methadone on cardiac conduction. Prolonged QTc intervals have been reported in patients receiving both oral and parenteral methadone (Cruiciani, 2008).

■ **Other Opioids.** Oxymorphone (Opana, Opana ER) is a semisynthetic opioid available in parenteral and more recently oral immediate-release and controlled-release formulations. Its safety and efficacy profile is similar to other opioids. Its milligram potency is double that of oxycodone (Palangio et al., 2002). Codeine, hydrocodone, levorphanol, and tramadol are other opioids available in the United States for pain. Tapentadol (Nucynta), a central acting analgesic, was

**TABLE 19.8** Guide for Rotation to Methadone From Morphine

- If oral morphine is less than 100 mg/24 hours, change to methadone 5 mg every 8 hours and discontinue previous opioids
- If oral morphine is less than 100 mg/24 hours, use 3-day rotation period:
  - Day 1—reduce oral morphine dose by 30% to 50% and replace with methadone using a 10:1 ratio. Administer methadone every 8 hours
  - Day 2—Reduce oral morphine by another 30% to 50% of original dose and increase methadone if pain is moderate to severe. Supplement with short-acting opioids
  - Day 3—Discontinue oral methadone and titrate methadone dose daily

Alternate approach when rotating morphine to methadone. Conversion can be accomplished in one step using the following morphine to methadone ratios:

- Morphine 30–90 mg/24 hours, use 4:1 ratio
  - Morphine 91–300 mg/24 hours, use 8:1 ratio
  - Morphine greater than 300 mg/24 hours, use 12:1 ratio
- (Higher doses requires higher ratios)

Sources: Mannino, et al., 2006; Paice & Fevel, 2011; Coyle et al., 2007; Knotkova et al., 2009; Plonk, 2005; Walk et al., 2008; Weschule & Bain, 2008; Cruiciani, 2008.

approved by the FDA for moderate-to-severe acute pain. It can be used in acute and chronic pain as well as neuropathic and inflammatory pain (Fidman & Nogid, 2010).

*Meperidine* is *not* indicated for the management of chronic pain either at the EOL or earlier in the disease process. Meperidine has an active metabolite, normeperidine, that is twice as potent as a convulsant and half as potent as an analgesic as its parent compound (Simopoulos, Smith, Peeters-Asdourian, & Stevens, 2002). Meperidine's effect on rigors and shivering have shown beneficial effects in both hypothermic and normothermic patients, especially in the postanesthesia care area. (Miller, 2011). Naloxone does not reverse meperidine-induced seizures and potentially could precipitate seizures by blocking the depressant effects of meperidine and allowing the convulsant effects of normeperidine to become manifest (O'Connor, Schug, & Cardwell, 2000).

## Principles of Opioid Selection and Administration

Numerous factors, both patient-related and drug-related, must be considered in the selection of an appropriate opioid for a patient (Pasero & McCaffery,

2011). The opioid should be compatible with the patient's pain severity, age, dosing and route requirements, underlying illness, and metabolic state. Selection of an opioid that is available as a controlled-release formulation, such as morphine or oxycodone, may be an important consideration for some patients. In addition, cost may be a factor for patients being cared for at home. For the older adult or those who have major organ dysfunction, an opioid without known active metabolites and with a short half-life, such as fentanyl, hydromorphone, or oxycodone, may be preferable. Patients with marked renal insufficiency must be monitored closely for signs of opioid toxicity.

The potential for additive side effects and serious toxicities from drug combinations must be recognized by the nurse each time a new drug is added to a patient's regimen (Chau, Walker, Pai, & Cho, 2008). Patients frequently have many distressing symptoms and are receiving multiple drugs. The impact of each new drug added to the patient's regimen must be carefully weighed for benefit versus burden.

■ **Opioid Rotation.** Sequential trials of opioid drugs may be needed to find the most favorable balance for the patient between pain relief and adverse effects (Pasero & McCaffery, 2011). The patient and family should be warned that this is a possibility so that they do not become discouraged during the process. Usually if one or two side effects are present and pain control is good, an attempt is made to treat the side effects and maintain the current opioid. If more than two side effects are present (excluding constipation), opioid rotation is probably warranted (refer to Table 19.9). The steps followed when rotating opioids are based on the following assessment:

1. Is the pain control good but significant side effects are present? If so, reduce the equianalgesic dose of the new opioid by 50% (to accommodate for cross-tolerance) and continue to monitor the patient for resolution of adverse side effects and adequacy of pain control. Frequent rescue doses should be available to the patient.
2. Is the pain control poor and are significant side effects present? If so, reduce the equianalgesic dose by 25% to 50% and continue to monitor the patient closely for resolution of adverse side effects and improvement in pain control. Frequent rescue doses should be available to the patient.
3. Is the plan to convert the patient to methadone? If so, the ATC equianalgesic dose of methadone should be decreased by 90%, with provision for frequent rescue doses and careful monitoring of the patient for signs of drug accumulation and toxicity, especially sedation (refer to Table 19.8).

**TABLE 19.9 Guidelines When Switching From One Opioid to Another—Opioid Rotation**

■ If one or two side effects present and pain control is good, treat the side effects and maintain the present opioid.
■ If more than two side effects are present, refer to the equianalgesic dose table (Table 19.7) prior to switching the opioid.
■ In a minority of patients, two to three different opioids will need to be tried before a balance is reached between adequate pain relief and manageable side effects.
■ A large interpatient variability is present in the way opioids are metabolized
■ If the pain control is good but significant side effects are present, reduce the equianalgesic dose of the new opioid by 25% to 50% (accommodates for cross-tolerance). Continue to monitor the patient for reduction in adverse side effects and adequacy of pain relief. Provide for rescue doses.
■ If pain control is poor and significant side effects are present, rotate opioids without reduction in the equianalgesic dose. Continue to monitor the patient for reduction in adverse side effects and adequacy of pain relief. Provide for rescue doses.
■ If converting to methadone, refer to Table 19.8.
■ In all situations of opioid rotation, monitor the patient closely for adequacy of pain relief and gradual clearing of adverse effects.

Because of the large interpatient variability, in all instances when an opioid dose is decreased or the drug is changed, the patient must be closely monitored for adequacy of pain relief or presence of adverse side effects (Hanks et al., 2004).

This monitoring is a critical nursing function.

■ **Choice of Starting Dose and Dose Titration.** A patient who is relatively opioid-naïve should generally begin treatment at an opioid dose equivalent to 5 to 10 mg of parenteral morphine every 4 hours (APS, 2008, NCCN, 2012). Titration of the opioid dose is usually necessary at the start of pain therapy and at different points during the disease course. At all times, inadequate relief should be addressed with dose escalation until relief is reported or until intolerable and unmanageable side effects occur. Integration of ATC dosing with supplemental rescue doses provides a rational stepwise approach to dose escalation and is appropriate to all routes of drug administration.



Patients who require more than four to six rescue doses per day should generally undergo escalation of the baseline dose. In all cases, escalation of the baseline dose should be accompanied by a proportional increase in the rescue dose so that the size of the supplemental dose remains a constant percentage of the fixed dose (refer to Table 19.10). Nursing assessment of the patient's pattern of pain, rescue use, and level of pain relief is essential for appropriate dose titration. Table 19.11 summarizes the basic principles in the use of opioid drugs to manage pain.

■ **Selecting a Route.** The least invasive and safest route capable of producing adequate analgesia should be considered when selecting the route of administration. Clinical experience indicates that the majority of patients can use the oral route of drug administration throughout the course of most of their disease. However, at times some patients become unable to use this route and require an alternate approach (National Cancer Institute at the National Institute of Health, 2013). Nurses need to be skilled in selecting among the alternate routes to meet the needs of a particular patient. The most commonly used alternate routes include rectal, sublingual, transmucosal, transdermal, subcutaneous, IV, epidural, and intrathecal. Intramuscular (IM) administration should be avoided to minimize the pain (APS, 2008).

A switch in route of opioid administration requires that the nurse have knowledge of relative potencies, to

avoid overdosing or underdosing (refer to Table 19.7). During transition from one drug or route to another, the patient is at risk for pain escalation or the development of adverse side effects. Frequent assessment is therefore required during the transition period. The equianalgesic dose table provides a guide to dose selection when these changes are made. The calculated equianalgesic dose is usually reduced 25% to 50% when switching drugs to account for incomplete cross-tolerance (APS, 2008; NCCN, 2012). As noted previously, a much larger reduction (sometimes as much as 80%–90%) is necessary when switching to methadone.

■ **Dosing Interval.** Patients with continuous or frequently occurring pain generally benefit from scheduled ATC dosing. This provides a more stable plasma level of the drug and helps prevent pain from recurring. A rescue dose is offered on a PRN basis and provides a means to treat pain that breaks through the fixed analgesic schedule. The drug used for breakthrough pain is usually the same as that administered on a regular basis. An alternative short-half-life drug is recommended when using methadone or transdermal fentanyl while waiting to reach steady state (Mercadante, Villari, Ferrera, Casuccio, & Gambaro, 2007). However, some clinicians prefer to use methadone as the rescue drug if a patient is already on methadone. The breakthrough or rescue dose should be 10% of the total 24-hour dose given every 1 to 2 hours as needed and 5% for the elderly (Schneider, Yale, & Larson, 2003). For example, for a patient receiving 60 mg of a controlled-release oral morphine preparation every 12 hours, the total 24-hour dose is 120 mg. The rescue dose should have a rescue or supplemental dose of 10 to 15 mg of immediate-release morphine available on a 1- to 2-hour basis as needed. The number of rescue doses used by the patient in a 24-hour period is a guide to titration of their ATC dosage.

■ **Patient-Controlled Analgesia.** PCA in the PC arena is a method that refers to parenteral drug administration in which the patient controls a pump that delivers analgesics according to parameters set by the nurse practitioner (NP) or physician. These parameters include concentration of the drug, basal infusion rate, and bolus dose with permitted intervals between doses for breakthrough pain (Craft, 2010). Use of a PCA device is fairly common in PC patients who require a parenteral route of drug administration or severe pain to be brought rapidly under control. This technique can be managed safely at home by most patients, providing a system of education, monitoring, and support is in place. In the event the patient cannot use the function of the PCA, nurse-controlled analgesia (NCA) is an alternative. Use of the PCA by

**TABLE 19.10 Guidelines for Opioid Titration**

*Three choices are available when upward titration of an opioid dose is needed. The choice in approach is based on assessment of the patient's pain—both baseline pain and breakthrough pain.*

- Increase the basal or around-the-clock (ATC) dose (oral, transdermal, subcutaneous, IV).
- Increase the rescue dose.
- Increase both the basal (ATC) dose and the rescue dose.

*Most patients will require an increase in both the basal (ATC) dose and rescue dose.*

- Calculate the number of rescue doses the patient has used in the past 24 hours.
- Increase the basal (ATC) dose by that amount or increase by 25% or 50% for moderate-to-severe pain.
- Also increase the rescue dose by 10% to 15% of the new 24-hour dose

*Monitor closely for the effectiveness of the new dose and presence of adverse effects such as sedation and/or confusion.*

**TABLE 19.11 Principles of Opioid Use in the Management of Pain**

■ Select analgesic(s) from Steps 1, 2, and/or 3 of the analgesic ladder appropriate to the patient's inferred pain mechanism(s), analgesic history, and severity of the pain.
■ Take into consideration patient's age, metabolic state, presence of major organ failure (renal, hepatic, lung), and presence of coexisting disease.
■ Consider pharmacologic issues (e.g., potential accumulation of active metabolites, effects of concurrent drugs, and possible drug interactions).
■ Know the drug class (e.g., agonist, agonist/antagonist) duration of analgesic effects and pharmacokinetic properties.
■ Be aware of the various drug formulations available for the opioid selected (e.g., immediate release, controlled release, liquid, transmucosal).
■ Be aware of the available routes of administration for the opioid selected (e.g., oral, rectal, transdermal, transmucosal, subcutaneous, intravenous, epidural, intrathecal).
■ Select the least invasive route to meet the patient's needs.
■ Consider issues that may affect patient ability to follow the prescribed regimen (e.g., convenience, ease for home management, cost).
■ Administer the analgesic on a regular basis for persistent pain. Make sure that "rescue" doses are available for breakthrough or incident pain.
■ Titrate to achieve a favorable balance between good pain relief and minimal adverse effects.
■ Use drug combinations where appropriate to provide added analgesia (e.g., NSAIDs and coanalgesics).
■ Avoid drug combinations that increase sedation without enhancing analgesia.
■ Anticipate and treat distressing side effects (e.g., constipation).
■ If one or two distressing side effects are present, treat the side effects and continue on the current opioid. If more than two side effects are present (excluding constipation), consider opioid rotation.
■ Prevent precipitation of an acute withdrawal syndrome through abruptly discontinuing an opioid in the patient who has been on an ATC regimen of an opioid for greater than 1 week. Taper the opioids if they are to be discontinued.
■ Systematically evaluate effectiveness of analgesic regimen (e.g., amount of pain relief, duration of relief, frequency of breakthrough pain, frequency and pattern of "rescue" dose use, presence of adverse side effects, and satisfaction with mode of therapy).
■ Teach the patient and family the principles of analgesic therapy. Address the frequently held misconceptions regarding addiction and tolerance.

proxy is when activation by someone other than the patient is used for analgesia. The American Society of Pain Management Nursing supports the use of "PCA by Proxy" by the nurse (NCA) and the nonprofessional, such as the parent or significant other, but not an unauthorized user (Wuhrman et al., 2007).

### Coanalgesic or Adjuvant Analgesics

Coanalgesic or adjuvant analgesics are those drugs that have a primary indication other than pain but are analgesic in certain pain states (Portenoy, Ahmed, & Keilson, 2013). They can be used at any step of the analgesic ladder. As with the institution of any analgesic regimen, their use is based on a careful assessment of the pain, inferred pain mechanism(s),

and analgesic history. Coanalgesics or adjuvant drugs in the PC setting are typically used to enhance the effects of the opioid drugs or to allow for dose reduction because of adverse opioid side effects (Portenoy et al., 2013). In the PC setting, it is useful to classify the adjuvant analgesics into three broad groups: multipurpose adjuvant analgesics, adjuvant analgesics used primarily for neuropathic pain, and adjuvant analgesics used for bone pain. Table 19.5 provides a guide to the commonly used coanalgesic/adjuvant drugs. As a general principle, low initial doses are suggested with dose titration until symptom relief is achieved.

■ **Multipurpose Analgesics.** *Corticosteroids* are used to treat various types of neuropathic pain resulting from tumor infiltrating or compressing neural



## Exhibit 19.1

### Practice Guidelines, Websites, and Other Resources Related to Pain Management

#### Organizations:

- American Pain Society; [www.ampainsoc.org](http://www.ampainsoc.org)
- American Society for Pain Management Nursing (ASPMN); [www.aspmn.org](http://www.aspmn.org)
- American Society of Perianesthesia Nurses (ASPAN); [www.aspan.org](http://www.aspan.org)
- American Medical Association; Pain Management: The Online Series: <https://www.ama-assn.org/ama/pub/physician-resources/pain-management.page>
- World Union of Wound Healing Societies Consensus Statement: [www.wuwhs.org/consensus/index.html](http://www.wuwhs.org/consensus/index.html)
- American Chronic Pain Association: [www.theacpa.org](http://www.theacpa.org)
- American Pain Foundation (APF); [www.painfoundation.org](http://www.painfoundation.org)
- Southern California Cancer Pain Initiative: <http://sccpi.coh.org>
- National Cancer Institute: <http://www.cancer.gov>
- Center to Advance Palliative Care: <http://www.capc.org>
- Hospice and Palliative Nurses Association: <http://www.hpna.org>
- Partners Against Pain: <http://www.partnersagainstpain.com/pain-management-resources/tips.aspx>
- World Health Organization (WHO) pain relief ladder: [www.who.int/cancer/palliative/painladder/en](http://www.who.int/cancer/palliative/painladder/en)
- World Health Organization (WHO). (2011). WHO model list of essential medicine: [www.who.int/medicines/publications/essentialmedicines/en/index.html](http://www.who.int/medicines/publications/essentialmedicines/en/index.html)

#### Practice guidelines:

- American College of Critical Care Medicine and Society of Critical Care Medicine Task Force. (2002). Clinical practice guidelines for sustained use of sedatives and analgesics in the critically ill adult. *Critical Care Medicine*, 30(1), 119–141.
- American Nurses Association. (2011). *Position statement index*. Retrieved from <http://ana.nursingworld.org/MainMenuCategories/HealthcareandPolicyIssues/ANAPositionStatements/All-Position-Statements.aspx>
- American Society of Anesthesiologists. (2010). Practice guidelines for chronic pain management: An updated report by the American Society of Anesthesiologists Task Force on Chronic Pain Management and The American Society of Regional Anesthesia and Pain Management. *Anesthesiology*, 112(4), 810–833.
- American Society for Pain Management Nursing. (2006). *Authorized and unauthorized ("PCA by Proxy") dosing of analgesic infusion pumps: The Society for Pain Management Nursing Position Statement*. Retrieved from [http://www.aspmn.org/organization/documents/PCAbProxy-final-EW\\_004.pdf](http://www.aspmn.org/organization/documents/PCAbProxy-final-EW_004.pdf)
- The Joint Commission: Pain Management (2013). [http://www.jointcommission.org/topics/pain\\_management.aspx](http://www.jointcommission.org/topics/pain_management.aspx)
- Clinical practice guidelines (arthritis, sickle cell, cancer, fibromyalgia), consensus statements and guidelines
- Advocacy & Policy Position Statements/AmericanPainSociety.org: [www.americanpainsociety.org/advocacy/content/advocacy-policy-statements.html](http://www.americanpainsociety.org/advocacy/content/advocacy-policy-statements.html)
- American Academy of Pain Medicine—Position Statements: <http://www.painmed.org/PatientCenter/position-statements/>
- HPNA Position Statement—Hospice and Palliative Nurses Association: [www.hpna.org/pdf/providing\\_opioid\\_at\\_the\\_end\\_of\\_life\\_position\\_statement.pdf](http://www.hpna.org/pdf/providing_opioid_at_the_end_of_life_position_statement.pdf)

#### Additional websites:

- <http://www.aacn.nche.edu/elnc>
- <http://www.epec.net>
- <http://www.eperc.mcw.edu/EPERC>
- <http://www.capc.org>
- <http://www.aspmn.org>
- <http://cancer.gov/cancertopics/pdq/supportivecare/pain/HealthProfessional>
- <http://www.nursecredentialing.org/NurseSpecialties/PainManagement.aspx>
- <http://hpna.org/Default2.aspx>
- <http://www.cancer.org/>
- <http://cms-sp.cityofhope.org/education/health-professional-education/nursing-education/pain-resource-nurse-training/Pages/default.aspx>
- Pain-Topics.org: Wide variety of pain information, research, tools for professionals <http://pain-topics.org>

structures such as nerve, plexus, root, or spinal cord. Corticosteroids can be extremely useful in the acute management of a pain crisis when neural structures or bone are involved. Dexamethasone (16–24 mg/day), in combination with an opioid, may be used to treat

bone pain, neuropathic pain, back pain associated with cord compression, headaches associated with brain tumors, and pain associated with liver capsule distension (APS, 2008). Pain relief is assumed to be associated with anti-inflammatory and antiedema effects

(Vyvey, 2010). Adverse effects of corticosteroids include hyperglycemia, gastric irritation, dysphoria, delirium, and myopathy. Lower dose corticosteroids (2–4 mg dexamethasone) can improve mood and appetite. These drugs should not be used concurrently with an NSAID, and their chronic use should be combined with gastroprotective therapy. Be aware that a patient who is on steroids for reasons other than pain may experience increased pain or analgesic requirements if these steroids are tapered down.

*Antidepressants* are nonspecific analgesics that are used predominantly for the continuous dysesthetic component of neuropathic pain. Analgesia can occur in the absence of mood changes, and the effective analgesic dose in the PC population is usually lower than that required to treat depression (Jefferies, 2010). Their analgesic effect appears to be related to inhibition of norepinephrine and serotonin (Sindrup, Otto, Finnerup, & Jensen, 2005). Common dose-related side effects include sedation, orthostatic hypotension, constipation, dry mouth, and dizziness. TCAs are relatively contraindicated in patients with coronary disease in whom they can worsen ventricular arrhythmias (Kemp, Malhotra, Franco, Tesar, & Bronson, 2013). Current evidence-based guidelines recommend the use of TCAs and serotonin–norepinephrine reuptake inhibitors (SNRIs) as first-line options for the treatment of neuropathic pain (Moultry, 2009). In elderly patients, serotonin reuptake inhibitors seem to be safer and better tolerated than the TCAs (Kahwam, Laurencic, & Malone, 2005).

*Anticonvulsants* are used to control the sharp, shooting, stabbing quality of neuropathic pain. Carbamazepine, phenytoin, valproate, and gabapentin and pregabalin have all been used in the management of neuropathic pain. Carbamazepine reduces pain by blocking sodium channels (Sullivan & Robinson, 2005). Gabapentin (Neurontin) and pregabalin (Lyrica), a newer anticonvulsant, have been found to be useful in the management of both the dysesthetic and electric shock–like components of neuropathic pain and have a more favorable side effect profile than other anticonvulsants (Sullivan & Robinson, 2005). Pregabalin was the first drug approved by the FDA for the treatment of fibromyalgia (U.S. FDA, 2007b). Both gabapentin and pregabalin are hepatically metabolized. Pregabalin is distinguished from gabapentin in that it is more efficiently absorbed through the GI track, and the extent of absorption is proportional to the dose. Titration to the analgesic dose is likely to require just two or three steps rather than the multiple steps typically required with gabapentin (Bockbrader et al., 2010).

*Gamma-aminobutyric acid (GABA-B) agonists* include baclofen, an agonist at the GABA-B receptor.

Baclofen is primarily used for spasticity but is potentially analgesic for lancinating or paroxysmal pains associated with neural injury of any kind (Saulino & Jacobs, 2006). Baclofen may interfere with mechanisms involved in neuropathic pain. The starting dose is 5 mg two to three times/day, and the dose can be titrated upward to a range of 30 to 60 mg/day. The side effect profile includes dizziness, somnolence, feelings of confusion, and hallucinations. Slow upward dose titration is suggested in the PC setting. Abrupt discontinuation following prolonged use can result in a withdrawal syndrome, including delirium and seizures. Doses should therefore always be tapered before discontinuation. There are beneficial effects on singultus, commonly known as hiccups, with the use of baclofen (Lee et al., 2010).

*Alpha-2 adrenergic antagonists* include clonidine, the most commonly used alpha-2 adrenergic antagonist for neuropathic pain refractory to opioids and other coanalgesics or adjuvants. Systemic administration of clonidine via the oral or transdermal routes or intraspinal infusions have been used (Luisser & Portenoy, 2003).

*Muscle relaxants* are used to control involuntary muscle spasms that can occur in some conditions such as cerebral palsy or multiple sclerosis. Benzodiazepines are effective in controlling the spasms but the centrally acting medications have questionable merit (van Tulder, Touray, Furlan, Solway, & Bouter, 2003). Carisoprodol (Soma), which is metabolized to the nonbarbiturate sedative hypnotic meprobamate, is not recommended; it has been abused and is a controlled substance in some states (van Tulder et al., 2003).

*Local anesthetics* are generally considered second-line drugs in the management of neuropathic pain. They can be given orally, topically, IV, subcutaneously, or spinally (Moulin et al., 2007). A brief IV infusion of lidocaine or procaine has been used to relieve severe neuropathic pain that has not responded promptly to an opioid and adjuvant drugs and requires immediate relief (Moulin et al., 2007). Oral local anesthetics used in neuropathic pain include tocainide, mexiletine, and flecainide. The analgesic effects of local anesthetics are thought to derive from suppression of aberrant electrical activity or hypersensitivity in neural structures involved in the pathogenesis of neuropathic pain (Hara & Sata, 2007). Local anesthetics produce dose-dependent adverse effects that involve the CNS and cardiovascular system including dizziness, tremor, unsteadiness, paresthesias, nausea, bradycardia, and other arrhythmias (Windle, 2013). Their use should be avoided in patients with a history of cardiac arrhythmias or cardiac insufficiency.



*Topical local anesthetics*, for example, the eutectic mixture of local anesthetics (EMLA) cream, when applied locally, produce a dense cutaneous local anesthesia that can be very soothing to patients with PHN. Lidocaine patches (Lidoderm; 5%) to the site of the pain—12 hours on and 12 hours off—and can also provide relief in some patients (Roseilee, 2006). Topical lidocaine in the form of a 5% lidocaine gel can also be effective in patients with PHN. The risk of toxicity from systemic absorption of a topical local anesthetic appears small.

*Topical capsaicin* may be useful to control the constant, burning, local, dysesthetic pain of PHN for some patients. An unpleasant burning sensation, however, may follow topical application, making its use intolerable for some patients. This burning sensation may lessen or disappear after days or weeks of continued use. Capsaicin is thought to lessen pain by reducing the concentration of small peptides (including substance P) in primary afferent neurons, which activate nociceptive systems in the dorsal horn of the spinal cord (Derry, Sven-Rice, Cole, Tan, & Moore, 2013). Topical transdermal capsaicin patches (Qutenza) were released in 2009 specifically for the treatment of PHN.

*NMDA receptor antagonists* are believed to block the binding of excitatory amino acids in the spinal cord. These antagonists, in combination with the opioids, are being increasingly used in the management of difficult to control neuropathic pain or when opioid dose reduction is the goal. Neuropathic pain includes a large number of diverse pain syndromes, some of which are thought to be mediated by NMDA receptors in the spinal cord (Woolf, 2011).

*Ketamine*, a potent analgesic at low dose and a dissociative anesthetic at higher doses, is included in this class of drugs (Visser & Schrug, 2006). Ketamine can produce psychomimetic effects (delirium, nightmares, hallucinations, and dysphoria). Assessment for these symptoms prior to initiating the infusion and on an ongoing basis is necessary. Haloperidol can be used to treat the hallucinations and scopolamine or glycopyrrolate may be needed to reduce the excess salivation sometimes seen with this drug (Amr, Shams, & Al-Wadani, 2013; Bickel & Arnold, 2009). As with an infusion of local anesthetics, anesthesia members of the pain and PC team are usually involved in decisions surrounding a ketamine infusion in PC. A ketamine trial can be initiated at low doses of 0.1 to 0.15 mg/kg for a brief infusion or 0.1 to 0.15 mg/kg/hour for a continuous infusion (Moryl, Coyle, & Foley, 2008). Case reports suggest that IV or oral ketamine can be used in children and adolescents (Finkel, Pestieau, & Quezado, 2007).

## Adjuvant Analgesics for Bone Pain

Bone pain can be an extremely troublesome problem for cancer patients, especially those with advanced disease and multiple bone metastasis. As previously described, NSAIDs can be helpful in combination with the opioid drugs (Steps 2 and 3 of the analgesic ladder). Parenteral NSAIDs or corticosteroids can produce dramatic relief in difficult cases as previously reviewed, for example, the patient with bone pain who presents in a pain crisis. A concentrated course of radiation should also be considered for patients with focal bone pain (Sejpal, Bhate, & Small, 2007). Palliative radiation can be beneficial in managing pain in advanced malignancy. Painful osseous metastasis is common in oncologic practice. Although treatment can be effective for patients with mild, moderate, or severe pain, early intervention may be useful in maintaining QOL and minimizing side effects of analgesic medications (Kachnic & Di Biase, 2013).

*Bisphosphonates* inhibit osteoclast-mediated bone reabsorption and can reduce pain related to metastatic bone disease and multiple myeloma. Pamidronate disodium has been shown to reduce pain, hypercalcemia, and skeletal morbidity associated with breast cancer and multiple myeloma. Dosing is generally repeated every 4 weeks with the analgesic effects occurring after 2 to 4 weeks. Zoledronic acid can relieve pain due to metastatic bone disease and be infused over a shorter period of time (Polascik & Mouraviev, 2008).

*Radiopharmaceuticals* such as strontium-89 and samarium-153 have been shown to be effective in reducing metastatic bone pain (Lam, de Klerk, van Rijk, & Zonnenberg, 2007). Thrombocytopenia and leukopenia are relative contraindications to the use of strontium-89 (Portenoy & Koh, 2009). Because of the lag in response time to treatment of 2 to 3 weeks to beneficial effects, this approach is not appropriate for patients who are very close to death. Patients should be advised that transient pain flair may occur following treatment and additional analgesia should be available in case of need.

*Calcitonin* is also an inhibitor of osteoclast-induced bone reabsorption and may be considered for patients with refractory bone pain or neuropathic pain although results are inconclusive (National Cancer Institute at the National Institute of Health, 2013). It can be administered via the subcutaneous or nasal route.

*Hormone therapy* is often prescribed in metastatic breast and prostate cancers (Riccio, Wodajo, & Malawer, 2007). Prostate cancer treatment with

diethylstilbestrol has shown to reduce pain and improve the ability to ambulate in 40% to 70% of patients (Riccio et al., 2007).

*Surgical management* is used to decrease pain and increase functional status as in the case of orthopedic fractures. If the life expectancy is less than 4 weeks, overall poor health is observed, or poor cognitive function is present, surgical intervention is contraindicated (Riccio et al., 2007).

## Managing a Pain Crisis

A pain crisis can be defined as pain that is severe, uncontrolled, and distressing to the patient (Moryl et al., 2008). It may be acute in onset or may have progressed gradually in severity. A pain crisis is considered a medical and nursing care emergency for those at the EOL. At the same time the pain is being managed, the probable etiology of the pain is assessed within the framework of the previous pattern of pain, probable cause of present pain crisis, goals of care, and the most effective long-term management approaches (Moryl et al., 2008).

In patients who do not respond to opioid titration, or who develop intolerable side effects, the following adjuvants should be considered: (a) a parenteral NSAID, for example, ketorolac, for no longer than 5 days. During this period, other longer term approaches for pain relief should be considered; (b) parenteral steroids, for example, dexamethasone, with the dose being gradually tapered down to the lowest effective dose for the patient. Anecdotal experience has shown the use of parenteral NSAIDs or steroids to be effective in a pain crisis associated with bone pain and neuropathic pain; (c) if the pain is predominantly neuropathic, IV lidocaine or ketamine can be helpful for some patients (Vlainich, Issy, & Sakata, 2011). The efficacy of a nerve block or spinal delivery system of drug administration for this particular clinical situation should be considered (Ferrell & Coyle, 2010).

## Sedation at the End of Life

A proportion of patients at the EOL will experience refractory symptoms, including pain that is not possible to control in the absence of sedation, despite the use of state-of-the-art techniques. The number of patients involved is not clear. Palliative sedation at EOL is always an option for these individuals (Barathi & Chandra, 2013). Clear documentation and communication among the team members and with the family is essential when the plan is to provide palliative sedation at EOL to ease intractable symptoms. It should reflect the goals

of care clearly stated in unambiguous terms with resuscitation status established; discussion with the patient or health care proxy with informed consent; symptom being treated and management approach selected; and endpoint to be achieved and monitoring parameters (Hospice and Palliative Nurses Association [HPNA], 2011). Opioid or sedative drug dose escalation without clear indications should not occur. In this way, the integrity of the process is maintained.

## SECTION 2: PAIN MANAGEMENT IN SPECIAL POPULATIONS

The principles discussed concerning the assessment of the patient in pain, and the use of pharmacologic interventions in the comprehensive pain management plan, can be applied to all patients. However, there are issues specific to special populations that play a role in their pain assessment and pain management plan at EOL. The purpose of this section is to highlight briefly EOL pain-related issues in four populations as an example of some of the concerns in special populations and is not intended as a comprehensive approach. The following section will look at issues specific to the following four groups: those with a history of substance abuse, those with impaired communication, older adults, and pediatrics. These four groups were chosen because they are frequently encountered. Cultural factors and religious factors play a role in the pain management of certain groups. Sometimes there is a mismatch between the normative values of the patient and the health care provider. It is the practice setting that frequently determines which populations a nurse cares for. It is the responsibility of the nurse to know the needs and special concerns of the populations that he or she cares for most often.

### Special Considerations in Those With a History of Substance Abuse

The prevalence of substance abuse (or chemical dependency) in the United States and the association between drug abuse and life-threatening diseases such as hepatitis C and some types of cancers make it likely that nurses caring for patients at the EOL will work with some individuals who have a history of substance abuse (Oliver et al., 2012). As a group, it is very heterogeneous with very diverse clinical problems. It will include individuals who are living drug-free lives, those in methadone maintenance programs (MMP), and those who are currently abusing drugs. It is not uncommon to find individuals with addictive



disease who also have a concurrent psychiatric illness such as anxiety, depression, bipolar disorder, or schizophrenia (Oliver et al., 2012). Changes in comorbid physical and psychosocial factors, which drugs an individual has abused, and with what frequency, can further complicate issues that clinicians face.

The challenge is to provide humane, high-quality care to people at the EOL who have a history of drug abuse in a society context that often views addiction from a moral or criminal perspective (Oliver et al., 2012). The field of addiction medicine is a developing science that is based upon recent neuroscience advances that include identification of the brain mechanisms involved with addiction, vulnerability, and nociception. Despite this developing scientific understanding of the disease of addiction, individuals with a substance addiction are rarely cared for in an approach that draws upon this knowledge and their pain is frequently undertreated (Oliver et al., 2012). This is true even in the area of PC. Formal involvements by experts from the fields of pain management and chemical dependency are working to remedy this problem.

The following points are helpful to keep in mind when working with PC patients who have a history of substance abuse (Claxton & Arnold, 2011; Oliver et al., 2012; Passik & Kirsh, 2008; Reisfield et al., 2009; Savage, Kirsh, & Passik, 2008; Smith, Kirsh, & Passik, 2009).

- In order to maintain an objective, nonjudgmental approach, be aware of one's own reaction when asked to administer an opioid to a patient with a history of substance abuse.
- Recognize that addiction is a chronic, relapsing illness—and respond with increasing structure and compassion.
- Treat pain aggressively; poorly treated pain can increase substance abuse behaviors.
- Use nonopioid analgesics and nonpharmacological measures to their full potential.
- Individuals with a history of substance abuse, past or present, will be tolerant to opioids and will require higher doses of opioid to effectively treat pain than those with no history of drug abuse.
- Staff's reluctance to administer opioids in adequate amounts to relieve pain because of concerns of worsening addiction or "readdicting" contribute to the problem of undermedication.
- Identify whether the individual has a far distant history of drug abuse, is in an MMP, or is actively abusing substances.
- Patients who have a far distant history of drug abuse or who are in MMP may be reluctant to take opioids because of fear of readdiction.
- Patients who are actively abusing substances are the most challenging of the three groups to work with. An interprofessional team that emphasizes clear communication is most effective in addressing the multiple medical, psychosocial, and administrative problems present.
- If a patient is currently in MMP, permission must be obtained to contact the program and coordinate therapy. Some MMP providers wish to remain actively involved at the EOL and others do not.
- Many MMP patients at the EOL frequently keep the methadone dose taken for addiction separate from whatever medication they take for pain control. For others, however, it may be useful to incorporate the equianalgesic daily methadone dose into their analgesic regimen, especially for those who are unable to swallow.
- Although sometimes time-consuming, support of the patient in managing his or her addictions can help support the integrity of the individual patient and in turn help reduce his or her suffering.
- Encourage participation in recovery programs (e.g., 12 step) if the patient is willing and physically able. Consider consultation with an addictions/mental health professional.
- Methadone may be stigmatized as an analgesic in patients who have a history of substance abuse. Patients and their families and friends may need education about the effectiveness of methadone as an analgesic.
- Providers need to be aware of the need for more frequent dosing of methadone when given for analgesia, usually at least every 6 to 8 hours. Some patients require an every 4 hours schedule for adequate pain control.
- One NP or physician should be identified to write all analgesic orders or prescriptions. This needs to be communicated to all caring for the patient.
- Formalize a treatment plan and coordinate it with all other health professionals involved.
- Consider use of a written opioid agreement with carefully defined patient and provider expectations.
- Consistent documentation that shows the assessment of the four domains of functioning—pain relief, patient functioning, adverse effects, and drug-related behaviors—is important in the care of all patients receiving chronic opioid therapy, including those who have a history of substance abuse.
- Individuals with a history of substance abuse frequently have difficulties handling stress and will need extra support at the EOL. Psychiatric symptoms and comorbidities such as anxiety, depression, and bipolar disorders are frequently encountered and are to be treated.

- Nondrug methods can be employed, as appropriate, in any pain management plan for dying patients, but these methods should not be used as substitutes for medications to treat pain, depression, anxiety, or other symptoms.
- Individuals with a history of substance abuse who want to die at home need a careful assessment of their home environment to ensure adequate pain management and safety at home.

### Special Considerations in Those With Impaired Communication

A language barrier can cause impaired communication where the patient's primary language is not that spoken by the nurse or caregivers. The impaired communication can also be from an organic or functional etiology. This can include sensory impairment, cognitive impairment, aphasia, and others. This impairment may or may not be a result of the life-threatening illness the patient is experiencing. Because of the difficulties that these patients have with communication, they may not report their pain in an accurate or timely fashion. Avoid using families for interpreters as they may filter the information and have an emotional connection to the patient. Use of a translator who has completed appropriate training is the recommendation from the National Council on Interpreting in Health Care (Haffner, 2003). Inadequate communication can cause their pain to be undertreated. Other factors that can impede the communication of pain are the religious or cultural background of a patient. Cultural or linguistic differences may impair adequate assessment of pain and also may inhibit the patient's willingness to accept treatment for pain.

The APS (2008) recommends those patients who are unable to communicate and who undergo a procedure that would be painful for others be treated presumptively for pain. The American Society of Pain Management Nursing (2011) recommends that if pain is suspected, an analgesic trial can be made to diagnose pain as well as to treat it. Terminally ill patients who are unable to speak and who are known to have pain are likely to continue to have pain and should have continuing pain treatment.

In caring for dying individuals with impaired communication, the following are useful:

- Identify the communication deficit that is impeding the patient's ability to report pain and pain relief and to comply with the pain management plan.
- Obtain the appropriate pain assessment tools and place at the patient's bedside.
- If the patient and his or her caretakers do not speak the same language, identify the patient's language and identify available translators. Obtain a pain scale in the patient's language and review it with the patient and translator. It is helpful to write keywords or phrases in both the patient's language and the corresponding translations in the caregiver's language.
- Provide more frequent pain assessments if a patient is unable to ask for pain medication or does not reliably ask for pain medication. Use a reliable and validated assessment tool:
- If the patient cannot communicate, it is useful to collaborate with the patient's family and caregivers to determine what behavioral activities may indicate pain for this patient. These may be grimacing, pacing, restlessness, moaning, lying still, or guarding (Herr et al., 2011).
- Document possible pain behaviors and any tools needed for pain assessment in the patient's record to assist other caregivers in providing continuity of care.
- If the patient is to die at home, issues related to impaired communication need to be addressed in the home setting. Family members and other caregivers may need extra education and support. In some communities, it may be possible to obtain nurses or home health aides who speak the patient's language if language barrier is an issue.

### ■ SPECIAL CONSIDERATIONS FOR OLDER ADULTS

The probability is high that the older patient will experience pain at the EOL. Pain prevalence increases significantly with age and is due to both malignant and nonmalignant causes. Aggressive pain management is as necessary for those who are elderly as it is for younger individuals. In elderly patients, pain is frequently undertreated across all practice settings. The dying older patient may be cared for at home, in a nursing home, or in a hospital. In any setting, untreated pain can lead to loss of function and psychological complications in this vulnerable population.

Misconceptions regarding pain in the older adult can interfere with good pain management (American Geriatrics Society, 2009; Pasero & McCaffery, 2011) reported that common misconceptions may include the following: (a) pain is a normal or expected part of aging; (b) if individuals do not complain of pain, they must not have much pain; and (c) the side effects from opioids make them too dangerous to use with elderly people. Nurses need to reinforce that pain is not an inevitable part of aging. Pain in the older patient is to be evaluated and treated.

In treating pain in the older adult, it is important to be aware of the effects of age on the pharmacokinetic



and pharmacodynamic responses to analgesic medications including risk of drug accumulation. The general rule for using medications with the older adult is to “start low and go slow.” Those caring for dying older adult patients with pain need to be aware of the following (Bjoro & Herr, 2008; Brown, Kirkpatrick, Swanson, & McKenzie, 2011; Etzioni, Chodosh, Ferrell, & MacLean, 2007; Ferrell & Coyle, 2010; Ferrell, Levy, & Paice, 2008; Hadjistavropoulos et al., 2007; Herr, Bjoro, & Decker, 2006; Kirsh & Smith, 2008; Morrison & Morrison, 2006):

- Pain assessment can be disproportionately confounded by cognitive impairment or dysfunction, memory difficulties, depression, and abuse of alcohol.
- The presence of multimodal medications or analgesic stacking, multiple diagnosis, and complex symptoms from comorbid conditions may further complicate the pain experience.
- The patient’s ability to self-medicate independently and participate in the pain management plan may be affected by functional factors, such as impaired vision, impaired fine motor skills of hands, memory problems, and cognitive impairments.
- Identify the caregiver. The caregiver may be an older person, or the patient may live alone with the caregiver living elsewhere. Evaluate the ability, availability, and desire of the caregiver and of other family and friends to assist with care, administer pain medications, and participate in the pain management plan.
- Assess the role of the dying older patient within his or her family and community. Because of pain or disease, he or she may no longer be able to function in roles he or she had previously performed, such as care of a spouse or family member. The nurse may wish to facilitate discussion of the redistribution of roles and responsibilities

### ■ SPECIAL CONSIDERATIONS IN PEDIATRIC PATIENTS

Until recently, the dying child with pain was not viewed as a significant problem. Children were not considered to feel pain as intensely as adults and were therefore considered not to need aggressive pain management. Fortunately, the literature on pediatric pain has expanded significantly since the 1970s and pediatric pain is viewed as a specialty in its own right. Nurses have played a significant role in this development with such programs as Pediatric ELNECPPC and Education in Palliative and End-of-Life Care (EPEC; American Association of Colleges of Nursing, 2013; Education in Palliative

and End-of-Life Care, 2013; IPPC, 2013). The nurse caring for the dying child needs to be well versed in how to manage pain in children, using a multidimensional approach with an awareness of issues specific to the pediatric population (Kars, Grypdonck, & van Delden, 2011).

The following pointers are helpful in working with the children with pain at the EOL (Friebert, 2008; Hooke et al., 2007; Houlahan, Branowicki, Mack, Dinning, & McCabe, 2006; Michelson & Steinhorn, 2007; National Consensus Project, 2011; Wolfe et al., 2008):

- The child and family is the unit of care.
- Parents and caregivers must be incorporated into the pain management plan as part of the therapeutic alliance, which also includes the child and the health care providers.
- Address family concerns regarding the risk of addiction in the medically ill child.
- Pain assessment is dependent upon the child’s age and cognitive development stage.
- A child’s self-report of pain is considered the most reliable and valid indicator for estimate of pain location and intensity.
- It is helpful to initiate discussions about pain and to learn the individual child’s word for pain.
- Developmentally appropriate tools exist to evaluate the child in pain.
- Behavioral observation is the primary assessment measure for preverbal or nonverbal children. Observed pain behaviors may include vocalizations, facial expressions, body movements, autonomic responses, or changes in daily activities, usual behaviors, appetite, or sleep.
- The goal of pain management in children is to prevent as much pain as possible and to treat procedural pain aggressively.
- It is important to consider the child’s age, developmental level, verbal capabilities, past experiences, cultural factors, type of pain, and context when developing a pain management plan.
- The pharmacologic management principles—by the ladder, by the clock, by the appropriate route, and by the child—are similar to those used with adults with the exception that the starting doses are determined by chronological age and body weight (milligrams or micrograms per kilogram). The child is frequently assessed and doses are titrated to effect.
- The oral route is the desired route whenever possible. Avoid rectal; consider transdermal, IV, and topical routes when oral is available.
- Avoid IM injections.
- Obtain assent or involve them in permission to participate in treatment and decision making (Gibson & Twycross, 2007).

### CASE STUDY *Conclusion*

The case described earlier illustrates a man with advanced cancer who had a variety of pain syndromes—somatic pain, neuropathic pain, incident pain, and breakthrough pain. It also illustrated the need of many patients for opioids rotation and a switch in route of drug administration. The use of radiation therapy and coanalgesics in pain control are also seen as well as the management of opioid side effects. The need to know a patient's insurance outpatient drug coverage is also shown and the problems that it can create for the patient. When appropriate, hospice can assist the patient and family at the EOL. Early referrals to hospice can guide the family during the dying process and the survivors are able to receive bereavement counseling following the death of their loved one (Center to Advance Palliative Care, 2013).

### CASE STUDY

Mr. R., a 74-year-old married Hispanic man recently diagnosed with pancreatic cancer, was sent home on an analgesic regimen of ATC-sustained release oxycodone with immediate-release oxycodone for breakthrough pain. At the time of his discharge his pain was well managed.

Two weeks later, he comes for an ambulatory oncology clinic visit and is found to be in significant pain. Evaluation by the ambulatory nurse revealed that his wife had not been consistently giving him his ATC-sustained release oxycodone. Discussion with his wife revealed that although she spoke English, she was unable to read the English patient education materials that had been given to her when her husband was in the hospital and did not understand the pain management plan of care. She also reported being afraid that her husband “might become addicted” if he took this medicine on a regular basis. At that time, the nurse addressed Mrs. R.'s concerns, reviewed the pain management plan, and gave her appropriate educational materials written in Spanish. Mr. and Mrs. R. were encouraged to try using the pain diary that was included as part of the materials.

Three weeks later, they both returned to the oncology clinic. Mr. R.'s pain is better managed. Review of his pain diary by a nurse literate in Spanish revealed that to be comfortable, Mr. R. was taking PRN oxycodone six to seven times a day. This was brought to the attention of the oncologist seeing Mr. R. and his ATC sustained-release oxycodone dose was increased.

### ■ NONDRUG AND NONPHARMACOLOGICAL INTERVENTIONS

In addition to the pharmacological approach to pain management at the EOL, there are other approaches that may be useful. These nondrug or nonpharmacological interventions or techniques can complement the treatment of the underlying pain etiology and the mainstay pharmacological approach to pain management. Nondrug interventions cover a broad spectrum of approaches. These types of interventions can modify the pain experience and give individuals an increased sense of control, decrease anxiety, improve mood, and improve sleep.

Some of the nondrug approaches that will be discussed are considered mainstream, traditional

Western medicine. Other nonconventional therapies fall under the heading of complementary or alternative. Although complementary and alternative therapies are often grouped together under the heading of complementary and alternative medicine (CAM), they are very different. Complementary therapies are used in addition to conventional therapies and in some settings are labeled “integrative.” Alternative therapies are used in place of traditional, mainstream treatment (Hawk, Ndetan, & Evans, 2012). The National Center for Complementary and Alternative Medicine (NCCAM) groups the CAM modalities into five main areas: (a) alternative medical systems, (b) mind-body interventions, (c) biologically based therapies, (d) manipulative and body-based therapies, and (e) energy-based therapies. The nondrug interventions



that are discussed in this chapter, either traditional or complementary/integrative, are considered a part of the overall pain management plan.

There are a variety of factors that promote or inhibit the use of nondrug techniques. On their own, patients often initiate nondrug interventions such as application of heat or use of vibration. The different methods chosen by patients are often based on previous use of a particular intervention or on home remedies and may or may not be an optimal method to relieve a particular type of pain. In 2002, The NCCAM released a study showing that six of the top nine reasons that people use complementary medicine are pain related. Although the inclusions of pharmacologic interventions are usually a well-thought-out part of the plan, the use of nondrug interventions often is not. There may be little input from an individual's doctor or nurse in initiating an intervention (Nahin, Barnes, Stussman, & Bloom, 2009). Many insurance plans do not currently cover nondrug methods even when prescribed by a licensed provider as part of a well-thought-out pain management plan. There is movement in congress to pass legislation to include CAM in health care. The National Health Statistic Report (2009) revealed in the United States there are over 300 million visits yearly to a CAM provider with billions of dollars spent to provide this care, much of this out of pocket.

Patients using nondrug methods may report reduced distress, a sense of control, improved mood, or more bearable pain. Some patients strongly believe that nondrug interventions should be used instead of analgesics or to increase the time between doses of analgesics. For most patients, the maximum benefit from nondrug interventions is obtained when they are used in addition to analgesics (Ventola, 2010).

Compared to the extensive studies that support the use of pharmacologic techniques, the strong scientific evidence supporting the use of many of these techniques is just being established (Ventola, 2008). Much of the work that has been done in this area explores the use on nondrug interventions in cancer populations, although people dying from nonmalignant disease can also have significant pain that can benefit from nondrug interventions (Tsao, 2007). In 1999, the Center of Complementary and Alternative Medicine was established under the auspices of the National Institutes of Health (NIH) to establish an information clearing house and to establish data for evaluating the clinical usefulness of various nontraditional interventions (Hawk et al., 2012). It is hoped that as more money and energy go into the rigorous evaluation of integrative techniques, it will be easier to appropriately add these interventions into an individual's plan of care. In 2009, the Cochrane Pain, Palliative and Supportive Care groups concluded that

despite 10 years of solid achievement, many important questions in PC have not yet been answered because the relevant, rigorous studies have not yet been done (Wiffen & Eccleston, 2009). Yet, despite the current situation, patients express benefit from these methods and there are reasons to pursue their use (Tsao, 2007).

The five main categories of nondrug approaches to pain management are (a) psychological interventions; (b) physiatrist interventions; (c) neurostimulatory interventions; (d) invasive interventions; and (e) integrative interventions. In the following discussion, various techniques will be placed in the context of these categories. However, there is no common taxonomy and no uniformly accepted classification system for nonpharmacologic interventions (Devine, 2003). Often, an intervention may fall into more than one category or subcategory.

When reviewing the nondrug techniques for use in PC, it is useful to consider whether a specific intervention will need high or low levels of patient and caregiver involvement, and whether it is noninvasive or invasive. Some of the interventions, such as acupuncture, are invasive and should only be done by skilled practitioners. Because of this and other factors, it may or may not be possible to facilitate use of some of the nondrug techniques in individuals with advanced disease. The Clinical Practice Guidelines for the Management of Cancer Pain Panel Consensus (1994) stated, "with rare exceptions, noninvasive approaches should precede invasive palliative approaches."

## ■ PSYCHOLOGICAL INTERVENTIONS

A PC patient needs a biopsychosocial approach to pain management, one that includes the body, mind, and emotions. Incorporation of these elements into a patient's plan of care can lead to more effective pain management. Psychological interventions can help to do this. These interventions can primarily be classified as psychoeducational, cognitive, behavioral, or psychotherapeutic. They can include such things as patient and family education, distraction, self-statements, relaxation techniques, guided imagery and hypnosis, patient pain diaries, and cognitive-behavioral therapy (CBT). Devine's (2003) meta-analysis of the effects on pain of nonpharmacologic interventions, such as educational, psychosocial, and cognitive-behavioral interventions in adults with cancer, supported the use of these interventions as an adjuvant to analgesic therapy. The Clinical Practice Guidelines for the Management of Cancer Pain Panel (Jacox et al., 1994) and the NCCN Cancer Pain Guidelines for Adults (2012) encourage the use of psychosocial interventions for pain management early in the

course of disease as part of a multimodal approach. The nurse who is caring for an individual with a life-threatening illness may find that this person is well versed in using specific psychological approaches and is open to using these techniques to aid in coping with pain and other symptoms. On the other hand, the person for whom the nurse may be caring may be too weak, debilitated, and cognitively impaired to be taught or even to use a simple, previously utilized relaxation technique. A thorough assessment is key to developing a realistic plan. The intervention must match the specific problem with an appreciation for the patient's abilities and motivations.

## Psychoeducational

*Patient and family education* regarding pain management is an intervention that can increase an individual's sense of control. Ideally, at the EOL, patients, their families, and their caregivers will be well informed about pain management. However, the nurse working with these individuals often will find that this is not the case, especially in individuals who initially present with advanced disease. Whatever the circumstances, it is necessary to maintain ongoing assessment and reinforcement of educational information as the clinical situation and patient's needs change. Lack of knowledge regarding pain management is a well-established barrier to good pain control (Pasero & McCaffery, 2011). A 2009 systematic review and meta-analysis by Bennett, Bagnall, and Jose Closs (2009) of the effectiveness of patient-based educational interventions in the management of cancer pain showed modest but significant benefits and suggested that this intervention is likely underutilized.

In the PC setting, especially for EOL pain management, the inclusion of family, supportive friends, and caregivers is essential. They too have important educational needs and their role in successful pain management cannot be underestimated. A study by Ferrell, Grant, Chan, Ahn, and Ferrell (1995) showed that a structured pain education program improved QOL outcomes for both elderly patients and their family caregivers. The case for community-based interventions for cancer pain management utilizing care givers, community nurses, and pharmacists was further supported by Bourbonniere and Kagan (2004).

Knowledge regarding pain management reviewed earlier should include pain and its etiology; the principles and methods of pain management; types of analgesics; potential side effects of analgesics and their management; equipment and devices used to deliver analgesics; the concepts of physical dependence; tolerance; and addiction; nonpharmacologic

interventions; and expected participation in pain management (Reisfield et al., 2009). Recent work suggests that to implement a pain management regimen successfully at home, patients and families will also need other knowledge to assist them in problem solving to improve pain control. Challenges include obtaining and processing further information, obtaining prescribed analgesics, applying prescribed regimens to their very individual situation, managing new or changed pain, and managing side effects and other concurrently occurring symptoms (Strouse, Flanagan, Kerrihand, Williams, & Wolcott, 2006). Knowledge of how to approach these challenges will enable individuals and their families to be active, informed participants in the plan of care. Knowledge deficits related to pain management encompass all dimensions of learning: cognitive, psychomotor, and affective. It is especially important to allay fears and concerns about opioid use, specifically, addiction, tolerance, and physical dependence. Individuals who need equipment to relieve their pain will need special opportunities for their families and themselves to practice with that equipment management (Reinhard, Given, Petlick, & Bernis, 2008).

There are several well-developed references that elaborate on teaching pain management information to patients, families, and caregivers that can be useful to nurses (Ferrell & Coyle, 2010; McCaffery & Pasero, 2011). Readers are encouraged to review these references for more detailed information. An evaluation of all learners prior to any educational efforts will help to determine priorities and focus efforts. It is best to wait until pain is adequately controlled before giving patients and their families too much information. Teaching sessions may need to be brief with the most important information presented first and continually repeated. A wide variety of written, audio, CD, and DVD learning tools on pain management are available to reinforce information. All educational efforts are to be documented within the patient's medical record. This will improve continuity of care and provide a mechanism for identifying continuing education needs.

Ideal outcomes of a successful pain management educational intervention will include the patient, family, or caregivers being able to notify the physician, NP, physician's assistant, or RN of any new or unrelieved pain; change in pain location, quality, or intensity, and any side effects experienced; identify the cause of pain; state the rationale of the prescribed analgesic regimen; identify the medications, doses, route, frequency, and potential side effects of an analgesic regimen; if indicated, use equipment related to pain management properly (such as PCA pump); comply with the analgesic regimen, using nonpharmacologic methods appropriately; and express understanding



of the differences among tolerance, physical dependence, and addiction.

A small study by Oliver, Kravitz, Kaplan, and Meyers (2001) compared standard educational instruction on controlling cancer pain to an individualized education and coaching session in the outpatient setting, and showed an improvement in average pain outcomes for those in the individualized educational and coaching group.

In 2003, Devine performed a meta-analysis on the effect of nondrug interventions such as educational, psychosocial, and cognitive-behavioral interventions on adults with cancer-related pain by reviewing 25 interventional studies published from 1978 through 2001. Six of these studies tested the effect of education. A homogeneous small-to-moderate statistically significant beneficial effect on pain was found. In her discussion, Devine pointed out that because of the widely accepted strong mandate to educate patients about their pain and its management, there may not be much of a difference between experimental and control content (Devine, 2003).

A study of 64 patients with cancer-related pain and their primary caregivers was conducted to determine whether patients who were given access to continued information—either through a pain hot line or weekly provider-initiated follow-up calls for 1 month following the education program—had improved pain control during a 6-month follow-up period (Wells, Hepworth, Murphy, Wujcik, & Johnson, 2003). The basic pain management program that all study participants received included both structured and tailored components. Following this baseline education, all patient and caregiver study participants showed an improvement in knowledge and beliefs. The long-term outcomes of pain intensity, interference due to pain, analgesic adequacy, and relief from pain were not affected by continued access to pain information. It is important to note that the analgesic regimen of patients who had access to pain information was not adjusted by the nurse making the follow-up calls or by the hotline respondent.

Psychoeducational approaches have been effective in decreasing pain. In a study of 79 patients by Salvetti et al. (2012), cognitive-based strategies, using a multidisciplinary approach, resulted in decreased pain, reduced disability, and symptoms of depression.

Education about pain and its management is an important component of any pain management plan. However, additional education without a systematic approach that addresses other barriers, such as inadequate analgesic titration or untreated side effects, may not enhance pain control (Wells et al., 2003). The PRO-SELF pain control program “uses education along with repeated reinforcement, skill building, and ongoing nursing support to improve self-care

pain management in patients with cancer and their family caregivers” (West et al., 2003). It has been successful in improving the management of cancer pain (Miaskowski et al., 2005).

A combination approach may be the wave of the future. The literature reveals four general categories that are useful in assisting patients with pain: (a) self-care management; (b) information, decision making, and problem solving; (c) communication with health care professionals; and (d) counseling and support (Given et al., 2004). Future work will evaluate whether this approach that combines education with ongoing nurse coaching and interactive nursing support may prove to be useful to patients and caregivers in other noncancer pain populations and how to best enhance outcomes for patients and their families.

## Cognitive

*Cognitive interventions* are often discussed under the topic of mind–body therapies, which are techniques whose goal is to enhance a person’s mental ability to reduce symptoms and enhance function (Deng, Cassileth, & Simon, 2004; Given et al., 2004). This discussion covers the areas of distraction, self-statements, relaxation, guided imagery, and hypnosis, which can be useful to individuals with pain at the end of their life.

*Distraction* is an intervention that focuses on the cognitive component of the pain experience and is sometimes referred to as cognitive refocusing or attention diversion. This technique’s goal is to divert attention away from the pain onto something else (American Cancer Society, 2013). It is thought that because a person has a limited capacity for processing information, the individual who focuses on something other than the pain pays less attention to the pain and is distracted from the pain. This distraction can be passive or active (Wohlheiter & Dahlquis, 2013). Passive distraction can include such things as listening to music, watching a ball game, or watching a movie. Active distraction is a dynamic process where the individual participates in activities including problem solving, singing, or playing video games. With the advancement in technology, interactive electronic gaming has shown to be effective in pain management in adolescents and children (and adults) and is recommended to be age appropriate (Jameson, Trevena, & Swain, 2011; Wohlheiter & Dahlquis, 2013). Other disciplines have expanded this knowledge and the American Dental Association has trialed virtual reality as a form of distraction during painful dental procedures resulting in a decrease in pain levels as reported by the patients (Furman et al., 2009).

Often, for distraction to be effective, its focus must be of interest to the individual. The distraction strategy for a particular individual will depend upon the individual's ability to concentrate and his or her energy level. At the EOL, however, a patient's energy level is not predictable. It is suggested that effective distraction strategies should stimulate the four major sensory modalities of sound, sight, touch, and movement.

The use of distraction for short periods of time for such things as painful procedures, especially with children, is well established. Its use is thought to increase self-control and pain tolerance, and decrease pain intensity (Jacox et al., 1994). It has been associated with positive mood changes and decreases in pain intensity. It is imperative that the nurse be cognizant of the patient who self-employs techniques of distraction when assessing for pain.

Humor can be used to decrease pain but the practitioner needs to be considerate of events and timing to prevent the patient from feeling the health care team is laughing at him or her and not with him or her (Penson et al., 2005). There are documented benefits of humor and laughter, including improving immune function, increased pain tolerance, and decreased stress (MacDonald, 2004). The Association for Applied and Therapeutic Humor is an organization that focuses on humor therapy. A study is underway to determine the impact of comedy on symptoms that include anxiety, pain, and fatigue (Osterland, 2009).

Following the use of distraction, an individual may be fatigued, irritable, and more aware of the pain. Also, without education, family and caregivers may feel that the individual who is utilizing distraction does not have the pain or the degree of pain that he or she says. This can lead to a variety of negative situations, including a reluctance to administer analgesics.

*Self-statements* can be helpful in getting one through a painful experience. The use of self-statements is based on Bandura's theory of self-efficacy. This theory focuses on a person's beliefs regarding his or her ability to perform behaviors that will produce certain outcomes. Self-affirmation statements have been beneficial in managing pain (Caudill, 2009). Using a self-feedback system involves teaching the patient methods the patient can use to lessen the severity of pain or improve the ability to cope with the pain. Practicing and reinforcement of these methods is important.

All people carry on internal dialogues that both manifest and influence their belief systems. By becoming aware of the ongoing self-statements, one can gain insight into perceptions and appraisals. Once an appraisal is accessed, a determination is made concerning the helpfulness of the belief system. Clinicians

can help patients to use cognitive coping statements to enhance adaptations and to counteract the maladaptive thought processes (Caudill, 2009).

Through the use of *relaxation techniques*, a person can be taught behaviors to independently release skeletal muscle tension and reduce the emotional stress that can make pain worse. The effects of relaxation and guided imagery can vary from patient to patient (Kwekkeboom, Hau, Wanta, & Bumpus, 2008). These techniques are helpful for people whose pain experience causes them to feel out of control, those who will be experiencing procedures or activities that may be stressful or uncomfortable, and those who have successfully used relaxation techniques in the past, including meditation, yoga, and Lamaze.

The NIH Technology Panel evaluated the effects of relaxation on pain and sleep and provided strong evidence for the use of relaxation techniques to reduce pain. In its review, the panel divided relaxation techniques into brief and deep methods. In general, the brief methods take less time to acquire or practice. Very often brief methods are abbreviated forms of a corresponding deep method. The brief methods include deep breathing, focused breathing, paced respiration, and self-control. Deep methods include such techniques as progressive muscle relaxation (PMR), autogenic training, and meditation (Naglatzki et al., 2012). To use autogenic training, one is taught to imagine a peaceful environment and focus on a "heaviness in the limbs, warmth in the limbs, cardiac regulation, centering on breathing, warmth in the upper abdomen, and coolness in the forehead" (Naglatzki et al., 2012). The use of PMR involves the tensing and then relaxing in sequence of each of the 15 major muscle groups.

Health professionals may benefit from practicing relaxation techniques on themselves before attempting to assist patients in its use. It is useful to have beginning practitioners practice with each other to gain experience and to provide each other with feedback. It is important to set the right tone before instructing individuals in relaxation techniques. Ideally, the environment should be as quiet and as calm as possible. This is often challenging, if not impossible, in hospital environments. How the nurse enters the room, what the nurse says, and how the nurse communicates his or her sense of competence are all important. The nurse may be able to influence a patient's sense of control and ability to cope. It is important when working with patients' families to calm them, increase their confidence, and engage them as collaborators.

*Guided imagery and hypnosis* are related cognitive techniques used to manage pain. Guided imagery can be used to distract the individual's attention away from his or her pain or to change or transform the pain sensations (Kwekkeboom et al., 2008). Guided



imagery is a mind–body exercise based on prompting patients to formulate meaningful mental pictures to achieve relaxation and reduce anxiety (Cooper & Stollings, 2009).

Although imagery can be a very useful technique, it may not be helpful for all individuals. Individuals who are not candidates for imagery include those with a history of mental illness such as psychosis or those with dementia or delirium (a common problem at the EOL). It is important to monitor an individual for distress, restlessness, or agitation during the use of imagery. Individuals must be taught that they are in complete control of the situation at all times.

A debriefing after the use of imagery can be helpful to identify what did or did not work and to determine how to proceed. In particular, guided imagery may trigger flashbacks in patients with posttraumatic stress disorder, and it is relatively contraindicated in these patients. It is also contraindicated in patients who have hallucinations or delusions, delirium, or severe obsessive compulsive disorder (Cooper & Stollings, 2009).

## Behavioral

A *pain diary* is a tool that is especially useful for the ambulatory population of patients. Clinicians can review this diary with patients over the phone, at home, or on clinic visits.

It can be as simple or as sophisticated as the patient using it. The amount of information included often is a reflection of the patient's energy level. Essential information includes date and time of events, medication, dose of medication, and pain intensity before and after interventions. It is helpful if patients include their activities, periods of rest and sleep, pain quality, mood, and other symptoms, but this is up to the individual patient. Some prefer to use preprinted forms provided by pharmaceutical companies or other sources, whereas others prefer to use their computer or smart phone. Many free and low-cost applications are available on mobile devices that make real-time documentation possible. A pain diary can give a patient a sense of control and puts words to feelings that he or she can share with the family and others. A recent randomized crossover study found that patients used an electronic diary more frequently than a paper pain diary (Luckman & Vidal, 2010; Marceau, Link, Smith, Carolan, & Jamison, 2010). Patients in this study felt using the electronic pain diary led them to a more regular intake of their medicine. The reason for this may be related to the messages they received from the study manager that were generated by each log in, or from the built-in acoustic memory function. A study of 134 patients by Marceau et al. (2010) revealed that less than 15% of patients felt that

physicians made changes based on the results of the pain diary. These findings are troublesome.

## Psychotherapeutic

CBT was originally developed by psychologists to treat anxiety, stress, and depression, using some of the psychoeducational, cognitive, and behavioral techniques previously described. CBT has been used to treat individuals in a variety of situations with the goal of therapy based upon the situation. For the individual with cancer-related pain, the goal of CBT is to enhance the sense of self-efficacy or personal control (Greer, Park, & Safren, 2010).

Four core modules comprise the cognitive-behavioral intervention for individuals with anxiety and advanced cancer: (a) psychoeducation and goal setting; (b) relaxation training; (c) coping with cancer fears; and (d) activity planning and pacing (Greer et al., 2010). It works best in a series of structured sessions that are flexible and modifiable, according to the developing needs of the individual, no matter what the format. Greer et al. (2010) suggest that there be clear and explicit goal setting and treatment goals. These goals are to be developed collaboratively by therapist and patient. Together, they look at the range of problems present and prioritize them, review the list on a regular basis, and have it reprioritized as personal, social, and medical changes develop. Based on this list, appropriate interventions to address these problems are determined. The purpose of the interventions is to resolve specifically defined current problems and not long-term personality and social relations disturbances. Also, the interventions are made in a standard and systematic manner. Model 1 goals include the following: (a) elicit patients' understanding of their anxiety symptoms; (b) provide an overview of the cognitive-behavioral model of therapy; and (c) increase motivation for treatment by clarifying patients' goals and role for CBT to aid in achieving these goals (Greer et al., 2010). Model 2 relaxation goals include the following: (a) help patients understand the nature of the acute stress response and ways that physiological anxiety may exacerbate symptoms; (b) build mastery in coping with dyspnea and other somatic symptoms through breathing retraining and practice of autogenic relaxation. Model 3 includes the following: (a) help patients identify types of automatic thoughts and differentiate worries that are realistic from those that are biased or too negative; (b) teach adaptive thinking skills for managing various kinds of worries using traditional cognitive restructuring techniques as well as present-focused coping strategies; and (c) identify and problem-solve any avoidance that

may be interfering with the patient's functioning or cancer treatment. Finally, Model 4 includes activity planning and pacing (a) to help patients prepare and adjust for fluctuations in stamina; (b) to teach skills for prioritizing activities, including daily responsibilities as well as pleasurable events; and (c) to plan and pace activities according to patients' priorities and required exertion with the goal of maintaining function and engagement.

Ideally, work with CBT occurs early in the treatment phase of an illness. As disease progresses, an individual may experience cognitive impairment from a variety of causes that make it impossible to employ psychology. It may be necessary to focus more on the family and caregivers as the disease progresses. In this situation, the goal still is to maximize their coping skills and increase their sense of control.

CBT, a pragmatic psychological approach, and its techniques can be taught to interested clinicians who do not have specialized training in psychology or psychopathology.

Techniques that tailor cognitive behavioral approaches to individual patients (Dalton & Coyne, 2003; Dalton, Keefe, Carlson, & Youngblood, 2004) and those that combine education with ongoing nurse coaching and interactive nursing support build upon the foundation of CBT. Research that evaluates the effectiveness of these approaches may lead to better assistance to individuals who choose to control their response to pain and suffering.

## ■ PHYSIATRIC INTERVENTIONS

Physiatric interventions are another kind of nondrug intervention that can be helpful in the pain management plan. These interventions include positioning and movement; application of modalities such as heat, cold, vibration, and massage; and the use of supportive orthotic devices. Physical rehabilitation professionals are the experts in the use of physiatric interventions. The fact that pain is disabling is well established. The experts strive to achieve mutually agreed upon goals that will allow patients to maintain or achieve their highest level of physical function. In addition to their role in the maintenance and restoration of physical function and health, physical therapists are also involved in the promotion of health and wellness, prevention of physical dysfunction and disability, and public health initiatives (Ohtake, 2013). The rehabilitation expert looks at an individual with cancer-related disability from four rehabilitation perspectives: (a) preventive—to minimize the effects of predictive disabilities; (b) adaptive—to assist the individual to adapt to definite changes; (c) maintenance—that is, maintaining the individual at the current level

of functioning; and (d) palliative rehabilitation—keeping the individual functioning and involved in the environment (American Physician Therapy Association, 2003). For nurses to set realistic, achievable goals with the patient with pain at the EOL, it is useful to consider these four possibilities as goals of care change and evolve.

## Positioning and Movement

A debilitated individual with pain may be in static positions for extraordinary lengths of time. This in itself can exacerbate existing pain or produce new pain, including pressure sores and painful joint conditions. Healthy individuals are unconsciously and continuously initiating pain-relieving movements. A nurse can assist patients and their caregivers to promote positions or postures that maintain or facilitate normal physiologic function of the musculoskeletal system. When properly done, positioning places minimal stress on the joint capsule, tendons, and muscle structure (American Physical Therapy Association, 2003). Basic nursing texts give thorough overviews of the basic principles of positioning and movement that are so essential to good nursing care at the EOL. For some patients, however, turning and repositioning is extremely painful. If patients experience pain with movement, every effort should be taken to medicate them prior to positioning. This will prevent unnecessary suffering and fear of movement (Czarnecki et al., 2011).

For the PC patient who is not so close to death, range of motion (ROM), either active (AROM), active assisted (AAROM), or passive (PROM), can promote comfort and maintain or restore the integrity of muscles, ligaments, joints, bones, and nerves used in movement. It is hoped this will in turn prevent the development of additional complications. An individual who lacks the energy for AROM may attempt AAROM or PROM (for the patient who is neurologically impaired or unconscious). The American Society for Pain Management Nursing position statement on procedural pain is beneficial for the health care provider to understand management of painful procedures including turning and repositioning (Czarnecki et al., 2011).

## Supportive Orthotic Devices

In attempting to decrease pain and increase functioning at the EOL, it may be helpful to consult with a physical therapist or rehabilitation-medicine physician to evaluate the possible use of a supportive orthotic device such as a splint, sling, brace, or corset. Their use can immobilize or provide support to



painful tissues and maximize the use of weakened tissues to promote functioning. Appropriate use of such a device may decrease incident or mechanical-type pain for certain patients (American Physical Therapy Association, 2003). Also, the use of certain devices for patients with bone metastasis may immobilize areas of potential fractures to prevent this painful complication (Jacox et al., 1994).

*Assistive devices* such as canes, walkers, and wheelchairs, when appropriately used, can promote mobility, decrease pain, and prevent injury (American Physical Therapy Association, 2003). Consulting with a rehabilitative specialist to obtain the correct assistive device for an individual patient and teaching the patient and the caregivers the proper use of such devices can be invaluable. Often, an evaluation of the home situation will be necessary to recommend the most appropriate device to maximize an individual's rehabilitation efforts.

*Other modalities*, such as the application of heat, cold, vibrations, and massage, also fall under the heading of physiatric methods. Some would argue that these techniques actually are neurostimulatory because of their activation of the large diameter nerve fibers. The gate control theory proposed that activation of the large diameter fibers inhibited the smaller "pain" fibers and closed the gate to the transmission of stimuli by smaller nerve fibers. These techniques frequently are referred to as cutaneous stimulation techniques. As more information about the underlying mechanisms of pain has become known, the gate control theory gradually has been replaced. However, the actual mechanisms that affect pain relief from cutaneous stimulation are unclear. One of the most common forms of cutaneous intervention is the transcutaneous electrical nerve stimulation (TENS; Kaye, 2013). All of these methods are thought to possibly reduce pain, inflammation, and muscle spasm. They are noninvasive, relatively low cost, easy to use, and often can be done by the patients themselves or by their caregivers (Jacox et al., 1994).

*Superficial heating or cooling* can cause a decrease in sensitivity to pain. There is a lack of well-controlled studies concerning the use of heat and cold. Most of the information discussed is based on clinical experiences presented in the literature. Despite the lack of firm evidence, the Management of Cancer Pain Guideline Panel recommends the offering of cutaneous stimulation techniques, such as applications of superficial heat and cold, to alleviate pain (Jacox et al., 1994). Patients with aching muscles, muscle spasm, joint stiffness, low back pain, or itching may benefit from the use of superficial heating or cooling. Their use seems to be most effective for well-localized pain (Jelinek & Barnden, 2012). It is important to consider patient safety and comfort when using these

interventions. Heat should not be used in the following patient situations: an inability to communicate, significant cognitive impairment; ischemia; bleeding disorders; neuropathic pain characterized by a hypersensitivity to touch; areas where the skin is broken; and recently irradiated skin (Strax, Gonzales, & Cuccurullo, 2004). In 2007, the FDA issued a warning that patients with transdermal fentanyl patches should not be exposed to external heat sources as this will increase the drug to be released and can be life threatening (U.S. FDA, 2007a). Cold should not be used in the following patient situations: if an individual has a history of peripheral vascular disease (such as Raynaud's disease); arterial insufficiency; cognitive or communication impairments; connective tissue disease; or impaired sensation of the skin (Jelinek & Barnden, 2012).

Most hospitalized individuals will need an order or institutional protocol before initiation of superficial heating or cooling. There are several convenient ways of utilizing these modalities for palliative patients. For example, cold application can be done safely using gel packs that are kept in the refrigerator, homemade cold packs (sealed plastic bags filled with 1/3 alcohol and 2/3 water placed in freezer), or 1-lb bags of frozen peas or corn (which have been hit gently to separate contents). Heat can be administered by heating pad, hot packs, immersion in water, or retention of body heat with plastic wraps. Care must be taken with both modalities to protect the skin with at least a layer of terry cloth or pillowcase. Moisture increases the intensity of the heat or cold. Patients are to be discouraged from lying on heat sources. The skin must be inspected at regular intervals for irritation, swelling, blistering, excessive redness that does not subside between treatments, or bleeding. Some patients develop a "hunting reaction," in which the skin alternatively blanches and turns red after the application of cold. If this occurs, the use of cold should be immediately discontinued. Extreme vigilance is necessary for patients with impaired or decreased sensation, cognitive impairment, or who are unconscious and may be considered a relative contraindication. Treatment should be discontinued if the patient asks or if pain or any form of skin irritation occurs (Jacox et al., 1994; Jelinek & Barnden, 2012). Patient and family or caregiver education is needed before introducing these measures (van Middelkoop et al., 2011).

Although helpful for some painful situations, methods of applying deep heat, diathermy, microwave diathermy, and ultrasound will not be discussed in detail here. It is thought that they increase blood flow and metabolic rate even more than superficial heat does. Methods that deliver deep heat must be used with caution in patients with active cancer and

are not to be used over areas of active tumor (Strax et al., 2004). Also, methods that deliver deep heat may be fairly challenging to use with PC patients who have advanced disease. Consultation with a physiatrist is necessary when considering the use of deep heat.

*Massage*, another form of cutaneous stimulation, uses touch in the various forms of pressure, friction, and vibration to muscle and connective tissue, potentially to reduce pain and tension, improve circulation, promote relaxation (Deng et al., 2004), and communicate care and concern, especially in patients who have a communication impairment or language barrier. Even children with pain can potentially benefit from massage. Pediatric nurses are instrumental in implementing massage into a child's plan of care (Hughes, Ladas, Rooney, & Kelly, 2008). It is thought to decrease pain by increasing superficial circulation and, in some situations, by relaxing muscles.

The NCCAM recommends massage for refractory cancer pain (Abrams, Wesa, & Rosenthal, 2009). The Integrative Oncology Practice Guidelines published in 2007 made a strong recommendation based on low- or very low-quality evidence that cancer patients who have pain have massage therapy given by an oncology-trained massage therapist as the benefits clearly outweigh the risks and burdens (Deng et al., 2007).

Massage is contraindicated over sites of tissue damage (such as open wounds or tissue undergoing irradiation), in patients with bleeding disorders or thrombophlebitis, patients uncomfortable with touch, or those who might misinterpret touch as sexual (although this might be acceptable if the massager was a spouse or close partner). In working with cancer patients, light pressure is best, and deep or intense pressure is to be avoided (Deng et al., 2004, 2007). When considering massage, it is important for the nurse to consider the patient's comfort with touch, previous experiences with massage, and preferred techniques (Wells, Pasero, & McCaffery, 2008).

Massage to the site of pain may or may not serve to decrease pain at that site. PC patients may not be up to an extensive massage but may find massage of limited sites beneficial and not requiring much effort on their part. For example, massage of the neck, back, or shoulders may be sufficient to promote comfort. Some may find this too strenuous. For these patients, the nurse could consider massage to the hands or feet. Massage movements can include rhythmic stroking, kneading, or circular, distal-to-proximal movements. Effleurage, using slow, smooth, long strokes, is usually done to promote relaxation. The patient should be involved in choosing the sites and massage movements that provide the most comfort along with how long the massage should last. It may be helpful to

try different types of strokes with varying degrees of pressure in an effort to find what is most effective for an individual (Jacox et al., 1994; Wells et al., 2008). The patient may be sitting in a chair, or lying on his or her side, or prone on a bed or table. It is helpful to determine with the individual if the room will be quiet, if music will be played, or if conversation will take place during the massage (Wells et al., 2008).

During the actual massage, ideally both the nurse and patient will be as relaxed as possible. The patient should be in a position that is supported and easy to maintain for the duration of the massage. The massager should be in a position that utilizes good body mechanics. Patient comfort and modesty are to be maintained with sheets, blankets, or towels. The use of a warmed, alcohol-free lotion will decrease friction. One hand should be on the patient at all times until the massage is over. For example, the right hand could begin its stroke as the left hand is completing its stroke. Removing both hands can communicate to the patient that the massage is over. Patients may fall asleep during massage (Adams, White, & Beckett, 2010). Feedback from the patient, if possible, is useful for future planning. If patients find massage helpful, it should be scheduled on a regular basis. The decrease in pain management when combined with massage in a Mayo Clinic study revealed the need for decreased doses of opioid medication, and now the Mayo Clinic employs a full-time massage therapist on the cardiac units (Cutshall et al., 2007). Massage can be quite comforting to dying patients who are often deprived of human touch at the EOL. Family members and caregivers, if not overwhelmed or feeling overburdened, may wish to be instructed or included in this pain-relieving intervention. Massage therapy can provide pain relief and relaxation, can support a patient's emotional well-being and recovery, and can ultimately aid in the healing process for hospitalized patients (Adams et al., 2010).

## ■ INVASIVE INTERVENTIONS

Invasive interventions can be considered for a small percentage of palliative patients whose pain cannot be adequately controlled by pharmacologic means. This population includes individuals whose pain is localized to one or two areas and is expected to persist, and who cannot achieve an acceptable balance between analgesia and intolerable, dose-limiting side effects from these analgesics.

In evaluating patients for invasive approaches, it is important to clarify that all feasible primary therapies that are likely to improve patient outcomes have been initiated, that the opioid dose has been titrated up to the maximal tolerated dose, that side effects have



been treated with appropriate medication therapy or through opioid rotation, that appropriate adjuvant analgesics have been considered or tried, and that the appropriate routes of drug administration have been instituted. Invasive interventions to relieve pain include nerve blocks, surgically implanted devices, or neurolytic agents

*Neural blockade* is an anesthetic intervention for either temporary or permanent effect and is commonly called a nerve block. A local anesthetic (usually lidocaine or bupivacaine) is injected into or around a nerve. Nerve blocks can be considered diagnostic, prognostic, therapeutic, or preemptive/prophylactic. A *diagnostic nerve block* is done to determine the specific pain pathway and to aid in the differential diagnosis. A *prognostic nerve block* is one that is done to predict the efficacy of a permanent ablating procedure. A *therapeutic nerve block* is done to provide temporary pain relief in a pain crisis or to treat painful conditions that respond to these blocks (e.g., a celiac block for the relief of pain due to pancreatic cancer). A *preemptive/prophylactic nerve block* is done proactively to prevent the development of a chronic pain syndrome. Neurolysis, or nerve destroying, is a permanent procedure that interferes with the transmission of a painful stimulus by injection of a chemical substance such as alcohol or phenol to destroy or ablate the nerve (Miguel, 2000). This procedure has decreased in popularity with the advancement of spinal analgesia and the increase in life expectancy but is still a viable option. QOL and side effects must be evaluated before proceeding. One of the distressing side effects is sphincter weakness, which many patients find unacceptable (Miguel, 2000).

A successful prognostic nerve block may not always mean a successful neurolysis. This may be due to such things as analgesic and sedating premedications, placebo response, spread of local anesthetic to adjacent neural structures, or systemic absorption of local anesthetics. Contraindications to an individual undergoing a nerve block include infection, coagulopathies, ineffective prognostic block, inadequate patient and family preparation, patient refusal, inability to understand and sign informed consent, and inability to cooperate during the procedure. The use of ultrasound guidance—a more recent development that allows the anesthesiologist to position the needle more accurately and monitor the distribution of the local anesthetic medication—has improved both safety and efficacy of neural blockade (Marhofer & Chan, 2007; Marhofer, Greher, & Kapral, 2005).

General types of neural blockade are peripheral blocks (including brachial plexus, and cranial, intercostal, and sacral nerves), neuroaxial blocks (including epidural and intrathecal), and sympathetic nerve blocks (including celiac plexus block and superior

hypogastric block; Latifzai, Sites, & Koval, 2008). Specific nerve blocks are identified by the anatomical location where they are performed. Depending on the location of the block, some of the risks or complications include fatigue, oversedation (if analgesics administered via other routes are not decreased in relation to decreased pain), sensory loss, motor weakness, altered bowel and bladder function, altered sexual function, intravascular injection, hematoma, and new pain. It is estimated that 14% to 30% of individuals undergoing peripheral neurolytic blockade will develop neuropathic pain as a result (Soloman, Mekhail, & Mekhail, 2010). Side effects from nerve blocks can include Horner's syndrome, characterized by constricted pupil, ptosis, "and decreased sweating resulting from interruption of the sympathetic pathways to the eye," numbness, weakness, increased warmth, diarrhea, and lowered blood pressure (Soloman et al., 2010). These effects are temporary, if done with a local anesthetic, or long lasting or permanent, if done with alcohol or phenol (as with a neurodestructive block). A recent systematic review of neurological complications after regional anesthesia found a neurological complication at 0.04% with permanent neurological injury rarely occurring (Brull, McCartney, Chan, & El-Beheiry, 2007). It is the responsibility of nurses caring for individuals undergoing these procedures to be knowledgeable about the side effects and alert to developing complications. *Cordotomy* is a neuroablative, rarely done neurosurgical procedure that involves making a lesion in the anterior spinothalamic tract, contralaterally to the pain site, either percutaneously or with an open surgical approach, to destroy the function of a portion of the particular spinothalamic tract that innervates the site of pain.

*Rhizotomy* is a disruption of the cranial or spinal nerve root through chemicals or radio waves. Selective dorsal rhizotomy has been successful in the pediatric population to decrease spasticity from many neurological disorders (Hesselgard, Reinstrup, Stromblad, Undén, & Romner, 2007).

## ■ INTEGRATIVE INTERVENTIONS

In reviewing integrative interventions, it may be helpful to consider the five major classifications or domains used by the NCCAM. These are alternative medical systems, mind–body interventions, biologically based therapies, manipulative and body-based methods, and energy therapies. The following review will include useful evidence-based techniques for pain management at the EOL from all of the NCCAM classifications except from the biologically based therapies. Acupuncture, mind–body therapy, and massage

therapy are shown in studies to have the strongest evidence for their clinical use in pain control (Deng et al., 2004).

## Alternative Medical Systems

*Acupuncture*, a treatment from traditional Chinese medicine (TCM), has been shown to treat pain, depression, nausea, and other health problems effectively (Deng et al., 2004; National Cancer Institute at the National Institute of Health, 2013). Despite more evidence in the literature supporting the use of acupuncture, it still is underutilized in EOL PC (Standish, Kozak, & Congdon, 2008). In this holistic, energy-based approach, thin, disposable needles, heat, pressure, and other treatments to certain places on the skin cause a change in the physical functions of the body (National Cancer Institute at the National Institute of Health, 2013). *Acupressure* is a type of massage therapy in which the fingers are used to press on an acupoint. In cancer patients, acupressure has been used to control symptoms such as pain or nausea and vomiting. *Moxibustion* is a type of heat therapy in which an herb is burned above the body to warm a meridian at an acupoint and increase the flow of blood and *chi*. The herb may be placed directly on the skin, held close to the skin for several minutes, or placed on the tip of an acupuncture needle. Heat lamps may also be used to warm the acupoints (National Cancer Institute at the National Institute of Health, 2013). Reflexology is a form of acupressure that has been successful in reducing migraine pain, back pain, muscle pain, end-stage cancer pain, and side effects of chemotherapy, as well as increasing quality of life (Quattrin et al., 2006). Other variations in acupuncture stimulation of sites include the use of electrical stimulators or lasers. The NIH Consensus Conference Acupuncture (1998) found that the incidence of adverse effects from acupuncture is substantially lower than for many standard medical procedures or medications used for the same conditions (JAMA, 1998).

In TCM, it is thought that good health depends on the balance of energy in the body. Energy, called *chi* or *qi*, is thought to be constantly circulating in the body. Acupuncture acts to promote circulation of chi or qi vital energy. Acupuncture is based on a holistic, energy-focused approach to individuals, not on a disease-oriented, diagnostic treatment approach. The fact that acupuncture causes a multitude of biological responses has been demonstrated clearly. Much work is currently underway to understand better the anatomy and physiology of the acupuncture points (NIH Consensus Conference Acupuncture, 1998). Western medicine considers the proposed mechanisms of action for pain relief by acupuncture to include

endorphin release, mediation of pain-producing neurotransmitters, and stress-induced analgesia (Kravitz & Berenson, 2010).

In their review of the data, the NIH Consensus Conference Acupuncture (1998) stated that at present the “data in support of acupuncture are as strong as those for many accepted Western medical therapies.” At present, there are fairly convincing data showing the effectiveness of acupuncture in postoperative dental pain and in adult postoperative and chemotherapy nausea and vomiting. Some studies indicate that it may be helpful as an adjunct treatment in painful situations such as headache, menstrual cramps, fibromyalgia, myofascial pain, osteoarthritis, and low back pain. Its effectiveness in relieving musculoskeletal pain remains controversial (Deng et al., 2004). The Integrative Oncology Practice Guidelines published in 2007 strongly recommended acupuncture as “a complementary therapy when pain is poorly controlled” based on high-quality evidence (Deng et al., 2007). Controlled studies using acupuncture in PC patients are in the process of development. In this population, it may be both difficult and controversial to implement an acupuncture study comparing acupuncture to placebo or sham under controlled conditions, utilizing standardized outcomes. It is encouraging that a recent pilot study looked at using electrostimulation of acupuncture points in sedated, ventilated patients in an ICU (Nayak et al., 2008). Ideally, as more research is done and acupuncture is further incorporated into the mainstream health care system, more informed decisions regarding the appropriateness of acupuncture for patients in varying situations would be made (NIH Consensus Conference Acupuncture, 1998). As health care professionals, it is important to guide patients from a perspective of evidence, not marketing.

More and more patients are seeking acupuncture treatments. It has been used to treat a variety of conditions (including pain) in children (Kundu & Berman, 2007; Libonate, Evans, & Tsao, 2008). Acupuncture is gaining more practitioners with Western medicine backgrounds and more general support from Western practitioners. Along with others, some nurses are going through extensive training to become licensed practitioners of acupuncture. Issues of training, licensure, and accreditation are in the process of being clarified. In the United States, educational standards have been developed for the training of practitioners. An agency recognized by the U.S. Department of Education has accredited many of the acupuncture educational programs. Physician acupuncturists can sit for a nationally recognized exam. Nonphysician acupuncturists can sit for an entry-level competency exam that is offered by a national credentialing agency. Unfortunately, there is much variation



from state to state. This includes differences in the requirements to obtain licensure and in the titles conferred. This variation leads to confusion and to less confidence in the qualifications of acupuncture practitioners. It is important that nurses be aware of the requirements and titles conferred in the states in which they practice in order to guide patients who desire a TCM evaluation for acupuncture to the most qualified, safe practitioners (NIH Consensus Conference Acupuncture, 1998).

A more detailed discussion of acupressure and acupuncture is beyond the scope of this text. Nurse educators desiring to include more information of these techniques in the nursing curriculum are encouraged to seek out licensed practitioners of acupuncture for collaboration. Some schools of nursing have faculty who are also licensed acupuncturists. At this time, most insurance policies do not cover acupuncture or other integrative approaches, and most patients and families have to pay out of pocket for these interventions.

## Mind–Body Interventions

*Music* has been shown to be an effective intervention for pain control through a variety of physiological and psychological effects. Affective, cognitive, and sensory processes can be engaged, activated, and altered by music. In PC, music therapy “strives to promote well-being and quality of life for patients and caregivers” (Magil, 2009, p. 37). This is done by processes such as use of prior skills, relaxation, distraction, alteration of mood, and improved sense of control. Physical effects include increasing or decreasing pulse and blood pressure (Cincinnati Children’s Hospital Medical Center, 2012).

In using music with an individual, music therapists evaluate the patient’s medical situation, the person’s social and cultural history, and how emotions are affecting that person’s pain. The music therapist can then utilize a variety of techniques to help ameliorate pain and suffering. Vocal techniques can include toning, chanting, singing precomposed songs, writing songs, and singing improvisations. Listening techniques and use of prerecorded or live instrumental music can provide opportunities for exploration and expression (Magill, 2009).

A patient’s needs may change daily. Because of this, the music selection is best done with the individual on a day-to-day basis. “The aim is always to promote comfort, healing, and a decreased sense of pain” (Magill, 2009, p. 34) Working in collaboration with other pain modification approaches, music therapy can help soothe pain as well as heal suffering. Music therapy can (a) promote wellness, manage

stress, alleviate pain, express feelings, enhance memory, improve communication, and promote physical rehabilitation (Magill, 2009; Music Therapy Association, 2013)

A recent Cochrane Review (Cepeda, Carr, Lau, & Alvarez, 2006) looked at the use of music for pain relief and concluded that music should not be considered the first-line treatment for pain. Fifty-one randomized controlled trials (RCTs) of adults or children met criteria to look at the effect of music on acute, chronic, or cancer pain. Despite the finding that music reduced pain and reduced requirements for morphine-like analgesics, the magnitude of the positive response was small. Also of note, it may be that the types of pain included in studies that met criteria (acute postoperative pain, as well as chronic, labor, procedural, or experimental pain, with the majority involving procedural or postoperative pain) may not readily generalize to pain in individuals at the EOL. Clearly, more rigorous, well-designed studies looking at the use of music as part of a pain management plan for individuals at the EOL are needed.

The cognitive interventions discussed earlier under the umbrella of psychological interventions, such as relaxation, guided imagery, and hypnosis, also fall under the NCCAM category of mind–body methods that may be helpful to the individual with pain.

## Manipulative and Body-Based Methods

The use of massage, a manipulative mind–body technique, is covered under the physiatric intervention section as a cutaneous stimulation technique. However, readers desiring to learn more about the use of massage may also find information from integrative or CAM sources (Deng et al., 2004).

## Energy Therapies

*Therapeutic touch* (TT) is a complementary technique based on systems theory of the multidimensional nature of the individual and the homeostatic concepts of balance and wholeness, which work with energy fields in promoting relaxation states, reducing pain, and promoting healing. It was developed by Dolores Krieger, a nurse professor, in conjunction with Dora Kunz, a healer, in the 1960s and 1970s to develop a more personal relationship between nurses and patients (University of New Hampshire Health Sciences, 2013).

Despite its name, TT does not involve physical touching. It involves a conscious intention on the part of the healer to help the client through an energy field. The practitioner of TT first centers him- or herself

in order to relax and be focused. Then the practitioner does an assessment of the client's energy field for symmetry by placing his or her hands 4 to 6 inches from the body, moving up and down the length of the body. The energy field is then "unruffled" by the practitioner's performing rhythmic motions of the hands to smooth out the energy field. During the next phase, the treatment phase, the practitioner channels energy to areas of the field that the practitioner senses are imbalanced or void. Finally, in the last phase, reassessment, the energy field is reevaluated for reпат-terning of energy flow (University of New Hampshire Health Sciences, 2013).

Use of this technique for palliative patients who are interested may be useful because it involves no effort or expenditure of any energy on the part of the patient. Patients who are debilitated do not have to learn new skills at a time when they may be unable to do so. Also, there do not seem to be any adverse effects. It is thought to promote a profound relaxation response that alleviates the pain (University of New Hampshire Health Sciences, 2013).

TT has been taught and researched since the 1970s. However, in recent years, its use has become more controversial. Mainstream American medicine is unconvinced about the value of TT. In 1998, one study was published in the very major mainstream *Journal of the American Medical Association*. It concluded that because 21 experienced practitioners of TT were unable to detect the investigator's "energy field" at a rate greater than chance, there was unfuted evidence that the "claims of TT were groundless and that further professional use is unjustified" (Rosa, Rosa, Sarner, & Barrett, 1998). Some question the validity of this study and the biases inherent in the peer review. However, because this was published in a leading peer-reviewed medical journal, many in mainstream Western medicine are unsupportive of the use of TT. Eskinazi and Muehsam (1999) point out those conventional journals may have difficulty evaluating integrative techniques fairly because some of the concepts implicit in these techniques are outside the current biomedical framework.

*Reiki*, a Japanese term for universal life energy, is another energy therapy. This therapy is currently being studied to evaluate its role in symptom management, including that of pain. Reiki is defined as a vibrational or subtle energy most commonly facilitated by light touch, the use of which is thought to balance the biofield and strengthen the body's ability to heal itself. Reiki practitioners gently place their hands on a fully clothed individual's head, back, front, and the site of discomfort (if the person desires) to promote relaxation and decrease pain (Kravitz & Berenson, 2005; Vitale, 2012). Fifteen percent of

American hospitals (more than 800 facilities) offered Reiki as a hospital service (Gill, 2008).

A Cochrane Database Systematic review of touch therapies for pain relief in adults looked at the effectiveness of TT, Reiki, and Healing Touch. Developed by Janet Mentgen, RN, based on energy healing practices (So, Jiang, & Qin, 2008). Only 3 studies met criteria for Reiki, 5 for Healing Touch, and 17 for TT. It found that these touch therapies may have a modest effect on pain relief. Of interest, it found that studies that utilized more experienced practitioners had greater reduction of pain. It concluded that more studies, especially those looking at the effect of touch therapies in children, are needed to provide sufficient evidence to promote the use of these interventions for pain relief.

Complementary services are being offered more frequently to patients at the EOL. A hospice survey found that 60% of 169 hospices offered complementary therapies to patients (Demmer, 2004). A follow-up study conducted by Running, Shreffler-Grant, and Andrews (2008) revealed that a majority of hospices surveyed stated that they had complementary therapy available but few of the patients actually received this benefit. Massage therapy and music therapy, which are shown to have a positive effect on pain, were among the most popular. Barriers to providing integrative interventions were mostly limited to program constraints. These included lack of knowledge regarding these therapies and how to offer them. Lack of qualified staff and funding problems also played a role.

## ■ SPECIAL POPULATIONS

### Children

Children, like adults, experience pain at the EOL. Pain management for dying children is an important concern for both parents and clinicians. Although infants, children, and adolescents who may have many different life-threatening conditions such as sickle cell disease or cystic fibrosis experience pain, most of the work of documenting pain and its management has taken place in the field of oncology. Many of the principles of pain assessment and management reviewed in this chapter and the previous chapter can be applied to children. However, children should not be viewed as miniadults. Nurses caring for children need to be mindful of several important points (Layman-Goldstein & Sakae, 2010):

1. Pain assessment is dependent upon a child's chronological age and developmental state. A detailed review of pediatric pain assessment is beyond the scope of the chapter. Readers are directed to other resources when selecting age- and



population-specific pediatric pain assessment tools that may be observational or a self-report, depending upon the clinical situation and the infant's or child's developmental stage and ability to verbalize (Crellin, Sullivan, Babl, O'Sullivan, & Hutchinson, 2007; Ghai, Kaur-Makkar, & Wig, 2008; Hockenberry & Wilson, 2007). The Pediatric Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials ([www.immpact.org](http://www.immpact.org)) commissioned a review of observational scales of pain for children aged 3 years through 18 years. The goal was to identify particular scales that might be used as an outcome measure in clinical trials. This group found that no single observational measure could be recommended for pain assessment across all clinical contexts (von Baeyer & Spagrud, 2007). As noted earlier, analgesic doses are initiated according to the child's chronological age and body weight.

2. Effective incorporations of nondrug pain interventions into a child's pain management plan is based upon the child's past experiences, developmental level, present response, and physical, emotional, and cultural factors. Similar to adults, the nurse needs to consider what has worked well and what has not for a particular child. For some children, there are religious or cultural issues or concerns that would make certain interventions inappropriate for them or their families. A proposed intervention must be consistent with the developmental level of an individual child. The nurse also needs to keep in mind that just as with adults, the stress and fatigue from a prolonged illness may make it difficult for the child or family members to concentrate, follow directions, or learn new information.
3. It is important to keep in mind that the child and parent together constitute the unit of care. Successful interventions can only happen when parents are included in the assessment and pain management plans. No one knows a child better than his or her parents; therefore, no one is better able to advocate for the child than the parents of that child.

Over the past 20 years, the use of anesthetic techniques such as regional nerve blocks and use of intraspinal opioids has been established as safe and effective for children of all ages with specific needs who meet criteria for their use in acute, procedural, and chronic pain situations. Saroyan, Schechter, Tresgallo, and Granowetter (2005) described the use of an implanted infusion system in a 15-year-old girl dying of sarcoma to successfully manage what had been intractable pain that could not be managed with systemic therapy because of side effects. Through careful planning and education of all involved in her care, this girl was able to return

home to die in her home country with her extended family present. In this situation and other less dramatic ones, special education and training for physicians and nurses using epidural analgesia in children is necessary. The nurse's role in setting institutional standards in using anesthetic techniques in children is important. Issues to be addressed include careful calculations and administration of medications, developmentally and situationally appropriate post-procedural assessment, and adequate nurse staffing (Hughes, 2008).

Use of nondrug pain interventions is well established in the pediatric population for procedural pain and acute pain (Evans & Tsao, 2008; Rheinans, 2007). There are many personnel in the pediatric practice setting, such as child life workers and pediatric social workers, who are knowledgeable resources in the use of developmentally appropriate nondrug pain interventions. Perhaps as many as 30% to 84% of children incorporate complementary and alternative interventions into their care (Kundu & Berman, 2007). Many of the modalities, such as hypnosis, music therapy, and acupuncture, appear promising. Yet, expert after expert is looking for large, well-designed, rigorous studies in children to better establish these interventions as safe, effective, and acceptable. These studies could help establish more credible choices to help children and their families manage pain at the EOL (Evans & Tsao, 2008; Libonate et al., 2008; Rheinans, 2007).

## Older Adults

Pain in the older adult or pain in aging has emerged as a new subfield in pain research. Research indicates that pain in older adults has some differences from pain in younger adults. Differences noted include increased difficulty using visual analogue pain scales, decreasing abilities to self-report pain in individuals with dementing illness, increased risk to develop neuropathic pain, and prolonged hyperalgesia following tissue and nerve injury. The differences in psychosocial factors that influence how older adults adjust to pain compared with younger adults may influence how psychological nondrug pain management interventions are implemented in geriatric patients. It is hoped that as more is known, age-tailored prevention, assessment, and intervention protocols will lead to better QOL for older adults (Gagliese, 2009).

At the moment, it is not clear how these and other factors play a role in the utilization of nondrug pain interventions for older adults. A study completed by Bennett, Closs, and Chatwin (2008) found that pain or pain management did not seem to be influenced

by age. Obviously age-related changes in vision and hearing in the patient or caregiver play a role in educational strategies. Bourbonniere and Kagan (2004) are among the many researchers who advocate for looking at interventions that result in more effective care for older adults. The evidence has yet to evolve.

### ■ HOW TO INTEGRATE NONDRUG INTERVENTIONS INTO A COMPREHENSIVE PAIN MANAGEMENT PLAN

A successful pain management plan is based on a comprehensive pain assessment and, on that basis, incorporates the components of treating underlying disease, pharmacologic interventions, psychological intervention, physiatric interventions, neurostimulatory interventions, invasive interventions, and integrative interventions. At the EOL, it may or may not be appropriate or feasible to treat underlying disease. Certainly, the patient with advanced disease may not be able to tolerate a surgery to remove a pain-producing tumor. Yet, some interventions aimed at treating underlying disease may be useful. For example, palliative radiation to areas of bony metastases may be well tolerated and decrease bone pain (Jacox et al., 1994). Pain caused by infection, such as pelvic abscess or occult infections from ulcerating tumors, may be relieved by treatment with appropriate antibiotics (Amasha & Cristo, 2012). The importance of pharmacological interventions, the mainstay of pain relief at the EOL, and how to integrate these interventions into the pain management plan has been reviewed earlier. As part of the interprofessional team caring for a patient at the EOL, it is important for the nurse to understand how the nondrug interventions (psychological, physiatric, neurostimulatory, invasive, and integrative) are incorporated into the pain management plan. The availability of experienced consultants to perform certain interventions also plays a role. If no one is available to perform a specific intervention, it cannot be offered as an option in the pain management plan for that individual at that point in time. A PC team may need to work on system issues to improve access to specialists that may be helpful to their patients. Financial factors play a role in which resources are available to meet individual patient-identified medical needs (Giordano & Schatman, 2008). Home health and hospice agencies have to keep financial and reimbursement issues in mind when incorporating integrative therapies into their programs. Ideas to consider include training current staff in techniques that could be incorporated into routine care while bearing in mind the scope of practice covered in each state or utilizing trained, certified volunteers (Johnson & O'Brien, 2009).

The use of any intervention is based upon the assessment of the patient. It is important to evaluate the individual carefully and apply what is appropriate for that individual in a particular situation. After the initiation of systemic analgesic therapy and treatment of underlying disease when possible, the next step would be to consider the addition of nonpharmacological treatments for pain management. While medical drugs are being used for treating the somatic (physiological) dimension of the pain, nonpharmacological therapies aim to treat the affective, cognitive, behavioral, and sociocultural dimensions of the pain to improve control and possibly improve the balance between analgesia and side effects (Demir, 2012). If these measures are not effective, the use of invasive techniques can be considered. Palliative sedation at EOL for intractable symptoms is also an option.

### ■ THE ROLE OF NURSES IN IMPLEMENTING NONDRUG INTERVENTIONS

Nurses caring for patients at the EOL have both collaborative and independent functions in implementing nondrug interventions. First, nurses must be aware of which interventions they are able to perform. Factors to consider when making this determination include education in the use of particular techniques, comfort in teaching or implementing a particular technique, patient and family educational materials available, availability and affordability of specific necessary devices and materials, and time available to an individual nurse to initiate a particular intervention. Psychological interventions that an individual nurse should be comfortable initiating include patient and family education; cognitive interventions such as distraction, self-statements; brief-method relaxation techniques; and behavioral interventions such as a pain diary. Physiatric interventions that an individual nurse might initiate for an EOL patient's pain control include positioning and movement, use of superficial heat or cooling, massage, or vibration. (Depending on the practice setting, the nurse may need to obtain orders for some of the physiatric interventions.) If the nurse has had additional training, he or she may consider the use of TT, deep relaxation methods, or CBT. In addition, the nurse needs to know which members of the immediate primary team can perform nondrug interventions that may be useful as part of a comprehensive pain management plan. Also to be determined is the availability of special consultants, such as neurosurgeons, anesthesiologists, hypnotherapists, or acupuncturists, for consultation and intervention as necessary. The nurse may need to assist in making appropriate referrals to these consultants. Finally, in order to be successful, the preferences of the patient are of primary importance (Demir, 2012).



As with the pharmacological interventions, the nondrug interventions need to be directed at etiologic factors. For example, when applied with moderate pressure and vibration, a physiatric modality can help to relieve pain by decreasing sensation to a painful area and may act to decrease tension in muscles in addition to sensation, which can be pleasant (Sagar, Dryden, & Wong, 2007). This would make this approach a useful addition to the pharmacologic regimen already in place for an individual found to have pain from muscle spasm.

It is also important to consider whether a patient or the family has the physical, mental, or emotional energy necessary to participate in a particular intervention. Nondrug interventions that need a high level of patient involvement may not be possible when an individual is debilitated or when the caregiver is totally exhausted from the experience. Assessment needs to include a patient's ability to concentrate and follow directions, level of fatigue, and cognitive status (Sagar et al., 2007). Education of the patient, family, and caregivers regarding the nondrug intervention in the pain management plan can elicit cooperation and promote successful use of the intervention. It is important to stress that nondrug interventions are not a replacement for analgesics. Patients and/or families should be encouraged to modify, discontinue, or replace any nondrug intervention that they chose.

Benefits from nondrug therapy can be influenced by the patient's attitude and expectations (Sagar et al., 2007). Additionally, ambient factors such as environment, aroma, and music can affect patient responses. Nondrug therapies have benefits that include (a) increasing the individual's sense of control; (b) decreasing the feeling of weakness; (c) improving the activity level and functional capacity; (d) reducing stress and anxiety; (e) reducing pain behavior and pain focus; and (f) reducing analgesic dosage without escalation of pain, thus decreasing the side effects of the treatment (Demur, 2012).

## ■ CONCLUSION

The assessment and pharmacologic management of pain in patients with life-threatening, progressive illness underscores the importance of integrating assessment and treatment strategies to address the needs of the individual patient. From the moment they graduate, nurses are expected to care for those who are seriously ill and dying. The delivery of optimal therapy depends on an understanding of the clinical pharmacology of the analgesic drugs and comprehensive assessment of the pain; the patient's medical condition and psychosocial state; and goals of care. Although the nurse will usually be part of an interprofessional team, he or she will often be the one responsible for assessing pain, administering analgesics, monitoring for adequacy of pain relief and presence of side effects, communicating with other members of the team, and ensuring continuity of pain management across care settings. These responsibilities cannot be met unless the nurse is knowledgeable in the basic principles of pain assessment and pharmacological management, and in the recognition of patients who are at risk for inadequate pain assessment and control. In addition, recognition and respectful acknowledgment of the central role the family plays in managing pain in the home at EOL has major implications for nurses in their responsibility to educate and support families in this task. In few areas does the advanced practice nurse have a greater potential to impact on QOL for those who are dying and their families than in facilitating effective pain management.

## ■ FUTURE RESEARCH RECOMMENDATIONS

Future research recommendations in the field of pain management include the integration of computers to augment the electronic health record, increased research in the field of virtual reality, and alternative and complementary medicine expansion as the more mainstream approach to pain management.

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### CASE STUDY Conclusion

Mr. R.'s pancreatic cancer progressed and he was readmitted to the hospital for uncontrolled pain several months after being successfully managed with oral systemic pain medications at home. Because there was an experienced anesthesiologist available, Mr. R. was evaluated for a celiac block. Imaging studies revealed that a successful block was possible. Mr. R. underwent an ultrasound guided celiac plexus block with good results and a significant reduction in his analgesic requirements. This allowed him to return home to be successfully managed until his death 6 weeks later.

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# Dyspnea

## CHAPTER

**KEY POINTS**

- Dyspnea is a multidimensional symptom and assessment based on the patient's report.
- Assess dyspnea with an appropriate tool.
- Treatment should be aimed at the underlying cause(s) of the dyspnea when possible.
- Pharmacological mainstays in the management of dyspnea are opioids and anxiolytics.
- Complementary and behavioral therapies should be considered and offered to the patient in addition to pharmacological treatment.

**CASE STUDY**

I first met Sam on the unit one Wednesday evening; he was 68 years old and retired from the military. He struggled with the symptoms of emphysema, a result of smoking two packs per day for nearly 50 years, although he had been smoke-free for the last 7 years. He also had severe rheumatoid arthritis that crippled his extremities and caused a condition known as rheumatoid lung that resulted in having both restrictive and obstructive lung disorders simultaneously. It was not surprising that he was huffing and puffing at rest. Initially, I assessed his level of understanding of his disease. He was fairly knowledgeable but admitted he often denied the severity of his illness, causing him to avoid follow-up physician visits and to ignore his symptoms.

Finally, when he could not deny them any longer, he sought assistance, this hospitalization being the result of such action. He spoke of how scary it was for him; he had been in intensive care for 2 weeks without much improvement. His poor condition upon arrival set the stage for a long uphill climb to recovery. He agreed that in the future early recognition and acknowledgment of his symptoms would be necessary to maintain his health. We reviewed the signs and symptoms of worsening chronic obstructive pulmonary disease (COPD) that would be a reason to consult with the doctor. Over the weeks that I continued to work with Sam and his wife, a positive relationship developed. Sam typically welcomed me with a “play by play” account of his day. However, he grew depressed at his lack of progress on the subacute unit. He easily tired and remained extremely short of breath, rating his dyspnea an 8/10 with even slight activity. It varied between 6 at rest and 10 with physical exertion.

Muscle atrophy of his lower extremities caused weakness that made it even more difficult for him to meet the demands of physical therapy. Pursed-lip breathing helped, but this was sometimes not enough. Energy conservation measures became essential; an occupational therapist worked with him daily to teach various techniques that allowed him to breathe more easily while performing activities of daily living. Anxiolytic agents and an antidepressant were added to combat the psychological effects of his illness, namely, anxiety and depression. On the weekends, pet therapy was ordered to help lift his spirits. His wife, the primary support for him at home, was encouraged to make frequent visits.

## ■ DYSPNEA

According to the American Thoracic Society's (ATS) 2012 official statement, dyspnea is "a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity. The experience derives from interactions among multiple physiological, psychological, social and environmental factors, and may induce secondary physiological and behavioral responses" (ATS, 2012, pp. 436–437). In general, the definition of dyspnea is the sensation of difficulty breathing, including the person's reaction to that sensation. Dyspnea can be acute, chronic, or terminal (Spector & Klein, 2002).

Acute dyspnea consists of high intensity, time-limited shortness of breath that occurs as an immediate response to an acute physiological or psychological event, seen in such conditions as myocardial infarction (MI), pulmonary emboli, or hyperventilation from an excitatory state. Chronic dyspnea is persistent shortness of breath of variable intensity, usually seen in chronic conditions, such as COPD or congestive heart failure (CHF). Terminal dyspnea (constant or episodic) occurs in people with end-stage diseases and is one of the most common symptoms reported in the last 48 hours of life (Hall, Schroder, & Weaver, 2002). However, it is important to note that the etiology of dyspnea often changes over the course of an illness, requiring different treatment approaches (Selecky et al., 2005). Indeed, episodic dyspnea has recently been described by Simon et al. (2013) as distinguishable from usual dyspnea and requiring a tailored management strategy.

Common descriptions of dyspnea fall into the categories of difficulty with air movement, increased effort, and general distress (Kamal, Maguire, Wheeler, Currow, & Abernethy, 2011). Such descriptors include air hunger, choking, smothering, congestion, tightness, suffocation, and strangling as well as emotional responses such as panic, fear, worry, frustration, and an inability to stop thinking about breathing (Elia & Thomas, 2008; Schwartzstein, 1999). Clearly, dyspnea is more than "just another symptom" to manage; "it threatens a person's very existence, psychological

well-being, and social functioning" (Currow et al., 2011, p. 389).

## ■ INCIDENCE

Dyspnea is a frequent and devastating symptom that occurs in as many as 94% of patients with advanced diseases, primarily those with lung cancer and end-stage heart or lung disease (Bruera, Macmillan, Pither, & MacDonald, 1990; Charles, Reymond, & Israel, 2008; Dudgeon, Kristjanson, Sloan, Lertzman, & Clement, 2001; Edmonds, Karlsen, Khan, & Addington-Hall, 2001). However, 24% of terminal patients participating in the National Hospice Study reported dyspnea despite the absence of pulmonary or cardiac disease (Reuben & Mor, 1986). In fact, dyspnea occurs in greater than 50% of individuals with breast, lymphoma, genitourinary, and head/neck cancers (Dudgeon et al., 2001). Moreover, 41% of patients in palliative care (PC) experience dyspnea and 46% of those describe the severity as moderate to severe (Charles et al., 2008; Cleary & Carbone, 1997; Currow, 2008). Consequently, dyspnea accounts for more than 10% of PC consults and is the fourth most common reason for patients receiving PC to visit the emergency department (Barbera, Taylor, & Dudgeon, 2010; Kamal et al., 2011). It follows that dyspnea is the primary factor for inpatient hospitalization (Skaug, Eide, & Gulsvik, 2009).

Dyspnea can seriously affect the quality of life (QOL) in those who experience it and may limit activity to the extent that even the slightest exertion may precipitate breathlessness. For example, eating may cause significant respiratory distress, which will impact an individual's nutritional state as well as mobility and functional status. However, in patients with advanced noncardiopulmonary disease, an overall decline in functional status may be the primary reason for shortness of breath (Currow et al., 2010). Regardless, health-related QOL, as measured by the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire–Core 30, decreases significantly over the last 3 months of



life, with an increase from 14% (3 months) to 43% (1 month) of patients reporting difficulty with self-care activities (Elmqvist, Jordhoy, Bjordal, Kaasa, & Jannert, 2009).

In the terminal phase of the illness, fear of suffocation may be experienced. The frequency and severity of dyspnea often increases with the progression of disease and/or when death is approaching. Other contributing factors include a history of or current smoking, environmental exposures, chemotherapy, radiation treatment, Karnofsky less than or equal to 40, cough, pain, anxiety, fatigue, depression, and vital capacity or maximal inspiratory pressure less than 80% predicted (Bruera, Schmitz, Pither, Neumann, & Hanson, 2000; Dudgeon et al., 2001). In advanced cancer patients, dyspnea is considered a prognostic indicator of decreased survival time, whether alone or in association with other symptoms and/or performance status (Ben-Aharon, Gafter-Gvili, Paul, Leibovici, & Stemmer, 2008; Maltoni et al., 1995). Mercadante, Casuccio, and Fulfaro (2000) reported that advanced cancer patients treated at home experienced worsening dyspnea with advancing disease, peaking in the last week of life. This correlated with a reduction in performance status and a survival range of 4 to 6 days.

## ■ MECHANISMS OF DYSPNEA

Although the mechanisms of dyspnea are complex and not well understood, it may help to review the control of respiration. The respiratory center in the medulla activates the muscles that expand the chest wall, inflate the lungs, and produce ventilation. The process of breathing regulates the oxygen and carbon dioxide balance and hydrogen ion concentration in the blood and body tissues. The automatic regulation of breathing is controlled by chemoreceptor in the blood and brain. Changes in  $PCO_2$  and  $PO_2$  are sensed by central chemoreceptors in the medulla and peripheral chemoreceptors in the carotid and aortic bodies, which send feedback to the brainstem respiratory centers to adjust breathing to maintain blood-gas and acid-base homeostasis (ATS, 1999). All the input returned to the brain from body sensors contributes in some fashion to the individual's perception of dyspnea.

Since the ATS statement in 2012, “new evidence has emerged that reliably associates distinct physiologic mechanisms and afferent pathways with different sensory qualities related to the sensation of dyspnea, namely work/effort, tightness, and air hunger or unsatisfactory inspiration” (ATS, 2012, p. 436). Three mechanisms remain dominant and interrelated in the creation of the dyspneic sensation:

(a) A conscious awareness of the neuromotor command to the respiratory muscles similar to the sensation in exercising muscle; for example, an increased sense of effort experienced with aging, malnutrition, deconditioning, and hypoxemia. (b) Stimulation of the receptors in the airways, lungs, and chest wall, which detect changes in lung volume, stretch, and pressure and are responsible for the feeling of tightness; for example, the sensation of respiratory muscle abnormalities, such as those found in neuromuscular conditions and respiratory muscle fatigue, as well as diseases that inhibit normal airflow and ventilation, such as COPD, asthma, and pulmonary fibrosis. (c) Last is the stimulation of the chemoreceptors; for example, the sensation of blood-gas abnormalities (e.g., hypoxia and hypercapnia) that indirectly trigger ventilation, thereby causing air hunger or unsatisfied inspiration. Moreover, it is likely that more than one mechanism is involved in any singular report of dyspnea (Spector & Klein, 2002).

These mechanisms support the idea that dyspnea is caused by an imbalance or “mismatch” between central respiratory motor activity and feedback from receptors in the airways, lungs, and chest wall. However, psychological, social, spiritual, and environmental factors interact with the physiological ones to produce the subjective sensation of dyspnea. In other words, the sensation of dyspnea is produced by various physiological mechanisms (neural activation); however, the perception of dyspnea is the reaction to the sensation as determined in the cortical and limbic areas of the brain that also subserve interoceptive awareness and nociceptive sensations such as pain (ATS, 1999). Without recognizing all of the components contributing to the total suffering of dyspnea, successful management is difficult to achieve (Currow, 2008; Zepetella, 1998). Symptom control, therefore, is less frequently obtained than with other symptoms common in advanced disease (Williams, 2006).

## ■ ASSESSMENT

Dyspnea is a personal experience that accounts for a high proportion of disability, impaired QOL, and suffering. The thorough interprofessional assessment includes a careful, comprehensive history to obtain a complete understanding of the patient's experience with dyspnea. Specific information about dyspnea, including its timing, precipitating factors, associated symptoms, alleviating factors, and quality of the symptom, should be assessed. The influences of culture, race, age, and gender should also be taken into account.

## Timing

Duration, frequency, and onset may provide insight into the etiology and management of dyspnea. For example, dyspnea that comes on suddenly may reflect bronchoconstriction, pulmonary embolism, cardiac ischemia, or abrupt airway occlusion. Chronic dyspnea occurs gradually and is likely to be manifested in slowly progressive disorders such as COPD, interstitial lung disease, or a slow growing tumor. If the dyspnea occurs more at night, then it may be secondary to the redistribution of fluid in the supine position from diseases such as CHF. Dyspnea can also result from an exacerbation of gastroesophageal reflux disease (GERD) that triggers bronchoconstriction. Assessing whether dyspnea is present with activity and/or at rest offers a better understanding of the severity of the condition.

## Precipitating Factors

Identification of precipitating factors assists in determining the underlying cause of the dyspnea (Hasson et al., 2008; Henoch, Bergman, & Danielson, 2008; Shumway, Wilson, Howard, Parker, & Eliasson, 2008). Exercise or overexertion commonly precipitates dyspnea in most chronic cardiopulmonary conditions, as does a change in position. Often patients with COPD or CHF feel dyspneic when supine, while those with cirrhosis or pneumonectomy may feel the sensation when upright. Anticipation of stressful events is another typical precipitant. Inhalation of allergens (pollen, grass, and weeds), smoke, fumes, and other aerosolized substances may trigger bronchospasm in patients with COPD and asthma. Respiratory infections usually cause an exacerbation of symptoms.

## Associated Symptoms

Dyspnea is rarely an isolated problem. Concurrent symptoms can help clinicians identify the underlying pathophysiology. Clutching sternal chest pain is most likely indicative of myocardial ischemia, while brief, sharp lateral chest pain suggests pulmonary embolism, pneumothorax, or pleurisy. Wheezing is usually a sign of asthma, COPD, or CHF (Hasson et al., 2008). Coughing, if productive, may indicate the presence of an infection, especially if there is a change in color, consistency, or volume of sputum. Nonproductive coughing occurs with rhinitis, reactive airway disease, interstitial fibrosis, GERD, and others. Hemoptysis is most common with tuberculosis, lung cancer, and pulmonary embolism. Weight loss is another problem that occurs often in patients with cancer, cardiopulmonary diseases, and AIDS. Psychological symptoms

are equally as important since anxiety has been found to correlate with the intensity of dyspnea in patients with cancer and lung disease (De Peuter et al., 2004; Smith et al., 2001). This requires tactful questioning and skillful observation, as the patient may not admit to anxiety as a symptom. Often, caregivers can assist with this component of the assessment.

## Alleviating Factors

Pharmacological and nonpharmacological strategies are necessary to relieve dyspnea and associated discomfort. Medications should be prescribed based on the identified etiology of dyspnea, such as cardiac or pulmonary problems (Lanken et al., 2008). Bronchodilators relax bronchial smooth muscle and work well in diseases such as COPD and asthma (Williams, 2006). Nitroglycerin is the initial drug of choice for myocardial ischemia, which may cause dyspnea (Spector, Connolly, & Carlson, 2007). Benzodiazepines often provide relaxation by decreasing the anxiety that frequently accompanies shortness of breath (Elia & Thomas, 2008). Position changes can also offer clues as to etiology. Sitting up in a high Fowler's position or standing may relieve shortness of breath by allowing for better diaphragmatic expansion in the case of pulmonary disease or promoting redistribution of fluid in CHF (Spector et al., 2007).

## Quality of Dyspnea

Schwartzstein (1999) documented that dyspnea is composed of many distinct sensations that are distinguishable by patients; patients' descriptive language of dyspnea can lead to a better understanding of etiology and management (Caroci & Lareau, 2004; Hasson et al., 2008; Hechler et al., 2008; Henoch et al., 2008; Mahler & Harver, 2000; Scano, Stendardi, & Grazzini, 2005; Schwartzstein, 1999; Wilcock et al., 2002). It is important to carefully question the patient about the quality and characteristics of the dyspnea experienced. For example, adults with more severe dyspnea may say they have an "urge to breathe," "need more air," or report a "sense of suffocation." Those with neuromuscular or chest wall disease may describe it as "heavy breathing." Still others, especially those with cardiac disease, may call it "chest tightness."

The assessment should include a thorough review of the patient's past medical history including all current and recent medications. Some medications become problematically related to drug-drug interactions that occur secondary to multiple prescribers. Beta-blockers, for example, antagonize beta-2 receptors and inhibit their potential bronchodilating effect



(Henoch et al., 2008). An adequate nutritional history is valuable because malnutrition contributes to respiratory muscle fatigue and, thus, promotes dyspnea. Information about exposure to chemicals, smoke, fumes, and other environmental pollutants adds to the data obtained from the history.

## Physical Examination

A focused physical examination of the head, neck, and chest will yield specific information about the patient's condition and assist with identification of treatment options. Inspection should include the color of skin, nails, lips, nutritional state, sternal/spinal deformities, chest shape and movement, breathing rate and rhythm (full minute), capillary refill, the presence/absence of nasal flaring, tracheal deviation, jugular venous distention, costal retractions, accessory muscle use, and clubbing. Other clues include facial/oral expression and inspiration:expiration ratio. Palpation can yield information about tenderness, fremitus, masses, nodes, and crepitus. Percussion of the chest will indicate the degree of resonance, where dull is consolidation of tissue and tympanic is the presence of air. Auscultation of the lungs will detect adventitious or diminished breath sounds, voice sounds, or pleural friction rubs.

## Diagnostic Tests

Based on the need to determine the underlying cause(s) of dyspnea, several diagnostic tests may be of value. These include chest radiography, spirometry and/or pulmonary function tests, pulse oximetry (preferred) or arterial blood-gas analysis, EKG, electrolyte profile, and complete blood count. Performance of any test should take into consideration the risk/benefit ratio, the patient and his or her family's wishes, the prognosis, and goals of care.

## ■ MEASUREMENT OF DYSPNEA

Dyspnea is a subjective, multidimensional symptom; therefore, it is important that instruments used to measure it take into account the sensation, the impact of it on QOL (patient and caregivers), and response to interventions. In 2007, a systematic review of tools to measure dyspnea in advanced disease was conducted by Bausewein, Farquhar, Booth, Gysels, and Higginson (2007). Seventy-three studies were identified from 1966 to August 2005 involving the development or validation of a tool to measure dyspnea. A total of 35 tools were reviewed but two were excluded due to the measurement of physical activity only. Of

the 33 tools examined, 29 were multidimensional and 4 were unidimensional. Of the multidimensional instruments, 11 were dyspnea-specific and 18 were disease-specific. The majority of the latter have been validated primarily for chronic obstructive pulmonary disease (COPD), reducing the applicability for other conditions. No one tool assessed all dimensions (psychosocial, physical) of the symptom. This same conclusion was noted by other researchers (Dorman, Byrne, & Edwards, 2007). However, given the clinical diversity of patients experiencing dyspnea near the end of life (EOL), it is unlikely that one tool will ever be established as the gold standard. Therefore, clinicians and researchers must choose the appropriate tool based on criteria such as the definition of dyspnea, setting, diagnostic group, disease stage, sensitivity required, and variables involved (Bausewein et al., 2007).

In general, the Visual Analogue Scale (VAS), Numerical Rating Scale (NRS), or the Modified Borg Scale provides useful assessment data. If there is a specific focus on QOL, multidimensional tools such as the Chronic Respiratory Questionnaire (CRQ) or Lung Cancer Symptom Scale (LCSS) would be best. If the focus is more on the sensation and its impact on function, then the Cancer Dyspnea Scale (CDS) is most appropriate. Researchers should consider using both uni- and multidimensional instruments in order to understand the full impact on the patient and caregivers.

A VAS is recommended due to its ease of use and availability. On either a 100-mm horizontal or vertical line, the anchors "not at all breathless" on the low end and "severely breathless" at the high end represent the extremes of dyspnea (Gift, 1989; Martinez et al., 2000). The VAS can measure even minute changes when used consistently. Another commonly used tool is the Modified Borg Scale, which has the numbers 0 to 10 listed horizontally with descriptors along the line. On both, the patient is asked only to rate the shortness of breath; no other dimensions are measured. While nonverbal adults can simply point to a number or position, some may find it difficult and need assistance to rate their symptom. For this reason, another choice would be an NRS as patients generally find it easier to verbally pick a number from a simple scale such as 0 to 5. Nevertheless, each of these unidimensional tools is reliable and valid and can be helpful when assessing dyspnea in a variety of settings. All are self-administered, quick, and can be used over the phone. Recently, Currow et al. (2011) reported that a 1-point reduction in intensity is clinically meaningful, thereby emphasizing the importance of repeated measurements.

For patients with advanced disease, the CDS is a 12-question self-report of shortness of breath that

includes aspects of dyspnea such as sense of effort, anxiety, and discomfort, which continues to be validated and evaluated, most recently as an English version in patients with advanced cancer (Hench, Bergman, & Gaston-Johansson, 2006; Tanaka, Akechi, Okuyama, Nishiwaki, & Uchitomi, 2000). The CRQ has demonstrated validity, reliability, and responsiveness but only in the populations of chronic lung disease and heart failure (HF). Further evaluation of these and other tools will benefit the patients, caregivers, and health care providers in dyspnea assessment.

Whichever instrument is used, the patient and family should feel comfortable and encouraged to utilize it in order to evaluate current therapeutic interventions. Consistency over time will maximize the relevance and usefulness of the measurement. It is important to reemphasize that physiological parameters may not always correlate with the degree of dyspnea reported. The patient must remain the singular authority on the symptom; if the patient is unable to communicate, objective indicators of dyspnea can be used, such as tachypnea, gasping, use of accessory muscles, anxiety, restlessness, agitation, grimacing, and tachycardia. Because patients unable to self-report are often undertreated (Campbell, Templin, & Walch, 2009), Campbell, Templin, and Walch (2010) developed the Respiratory Distress Observation Scale (RDOS), an eight-item tool that measures objective indicators for those who cannot communicate their needs. Validity and reliability have been documented in adolescents and adults but requires RN assessment (Campbell et al., 2010).

■ **Gerontological Considerations.** Three major factors contribute to the effects of aging on the pulmonary system: an increase in chest wall stiffness; a decline in respiratory muscle strength; and a decrease in lung elasticity (Mahler, Rosiello, & Loke, 1986; Tan et al., 2009; see Table 20.1). Respiratory infections and inhalation of allergens, smoke, fumes, and other aerosolized substances are more likely to result in dyspnea in older adults as aging increases susceptibility to both infections and allergens due to a diminished immune system (Sheahan & Musialowski, 2001). Other effects of aging include a prevalence of silent GERD and sleep apnea secondary to disorganized activity of the upper airway muscles and the diaphragm. In a study conducted by Johansson et al. (2012), community dwelling elders experienced nighttime dyspnea, palpitations, and pain, which significantly affected sleep and indirectly affected the presence of depressive symptoms, regardless of the presence or absence of illness. Neurologically, age reduces chemoreceptor functioning, causing an inadequate ventilatory

response to hypercapnia and acute hypoxia (Thompson, 1996). This makes older adults more sensitive and vulnerable to adverse outcomes from conditions that produce lower oxygen levels, such as pneumonia and COPD. Therefore, in the dyspneic elder, it is essential to take into consideration any underlying diseases and/or comorbidities, such as renal disease, CHF, or COPD, in order to formulate a successful treatment plan for dyspnea.

For example, in the case of COPD, reduced ventilator capacity from respiratory muscle weakness, increased ventilator demand from anaerobic metabolism, and the presence of psychosocial and environmental factors often increase oxygen requirements (Fried, Vax Fragoso, & Rabow, 2012). Therefore, the elderly with COPD need to be monitored more carefully for the possibility of carbon dioxide retention and subsequent acidosis (Ofir, Laveneziana, Webb, Lam, & O'Donnell, 2008). Ade-Oshifogun (2012) found that dyspnea along with a 6-minute walk distance and diffusion capacities were direct predictors of functional performance in elders with COPD, regardless of truncal obesity. However, the investigator reported an indirect effect of obesity on functional performance due to increased dyspnea, resulting in a recommendation for nurses to consider a weight-loss intervention with obese older adults. In elders with HF (greater than or equal to 75 years of age), dyspnea is the most frequently self-reported symptom (Goldberg et al., 2010). Dyspnea, along with fatigue, limits activities of daily living, causing dependency and resulting in poor health-related QOL (Falk, Ekman, Anderson, Fu, & Granger, 2013). Johansson et al. (2010) found five times the prevalence of sleep-disordered breathing and insomnia among elders with HF when compared with controls. Renal or hepatic impairment will impact the dosages/frequencies of certain medications for elders with these conditions.

Nursing interventions similar to those offered in pulmonary rehabilitation have been found to help elders focus on attainable goals and learn techniques to enhance their QOL (Booth, Farquhar, Gysels, Bausewein, & Higginson, 2006). Indeed, the nurse may need to utilize person-centered techniques to gain mutual understanding as older patients have more difficulty in detecting and interpreting the symptom of dyspnea (Riegel et al., 2010). In studies of symptom recognition for elders with HF, elders were twice as likely to report a different level of shortness of breath than the health care provider assessed (Barnes et al., 2006; Riegel et al., 2010). Lastly, due to the thoracic changes attributable to aging, positioning, as described earlier, becomes a major factor in managing the symptom for the dyspneic elder.



**TABLE 20.1** Effects of the Aging Process on the Pulmonary System

Structural Changes (Pediatric)	Result (Pediatric)	Structural Changes (Geriatric)	Result (Geriatric)
<b>Upper Airways</b>			
Infants = nasal breathers	Nasal congestion = airway obstruction	Nasal cartilage weakens, causing obstruction	Difficulty breathing through the nose
Large tongue	Easily occludes airway	Nasal blood flow decreases	Drying of secretions; nasal congestion
Narrowed cricoid cartilage	Potential for airway obstruction	Nasal turbinates shrink	Drying of secretions; nasal congestion
Cartilaginous larynx	Susceptible to edema, airway obstruction	Mucus increases in viscosity	Lodges in nasopharynx and stimulates coughing
<b>Large Airways</b>			
Trachea = diameter small finger of child	Easily obstructed	Trachea and large bronchi stiffen	Decreases air exchange
<b>Small Airways</b>			
Diameter increases over time		Diameter decreases	
		Alveolar ducts dilate	
Alveolar surface area increases		Alveolar surface area decreases	
		Combined changes	Increase residual volume
<b>Thoracic Cage</b>			
Thin chest wall	Increases compliance (i.e., retractions)	Ribs decalcify	Affects posture
Cartilaginous ribs	Increases compliance (i.e., retractions)	Costal cartilages calcify	Affects posture
Cartilaginous sternum	Increases compliance (i.e., retractions)	Costovertebral joints stiffen (arthritic changes)	Decreases height
Flattened position of diaphragm	Any impedance affects work of breathing	Dorsal kyphosis occurs	Increases anterior-posterior diameter (barrel shape)
		Combined changes	Decreases vital capacity, increases residual volume
<b>Pulmonary Vasculature</b>			
		Arteries enlarge and thicken (lose distensibility)	Decreases cardiac output during exercise/exertion
Mechanical Changes (Pediatric)	Result (Pediatric)	Mechanical Changes (Geriatric)	Result (Geriatric)
<b>Small Airways</b>			
Potential for premature closing	Grunting generates positive end-expiratory pressure (PEEP) and may prevent atelectasis	Premature closure	Air trapping/hyperinflation; impairs gas exchange and mucociliary clearance

(continued)

**TABLE 20.1** Effects of the Aging Process on the Pulmonary System (*continued*)

Mechanical Changes (Pediatric)	Result (Pediatric)	Mechanical Changes (Geriatric)	Result (Geriatric)
<b>Respiratory Musculature</b>			
Immature	Easily fatigued	Strength decreases; oxygen needs increase	Muscle fatigue; less reserve
<b>Lung Volumes, Capacities, Flow Rates</b>			
		Forced expiratory volume in 1 second decreases	Increases residual volume
		Forced vital capacity decreases	Increases residual volume
		Functional residual capacity increases	Increases work of breathing
		Diffusing capacity decreases	Impairs gas exchange

Source: McCaskey (2007); Sheahan & Musialowski (2001); Tan et al. (2009); Thompson (1996).

## ■ PEDIATRIC CONSIDERATIONS

Twelve thousand children are diagnosed with cancer each year and 1,300 die from the disease (American Cancer Society, 2013; Houlihan, Branowicki, Mack, Dinning, & McCabe, 2006), making cancer the leading cause of nonaccidental death in children ages 5 to 14 years (Wolfe et al., 2000). Among children ages 1 to 4 years, congenital anomalies account for the majority of nonaccidental deaths (CDC, 2009). In addition, nearly 400,000 children live with chronic life-limiting conditions and approximately 25,000 die from their disease annually (Jennings, 2005). To this end, three fourths of pediatric deaths occur in hospitals, primarily in the ICU (Davies et al., 2008). As many as 82% report dyspnea at the EOL, second only to loss of appetite (100%; Hongo et al., 2003) and fatigue (98%; Wolfe et al., 2000). Wolfe et al. (2000) asked parents to rate the degree of suffering their child experienced in the last month of life. Approximately 50% reported “a lot” or “a great deal of” suffering due to dyspnea. According to the parents, 65% of those children were treated for dyspnea, yet only 16% believed the treatment to be successful even though the symptom is generally considered responsive to treatment.

Palliation of dyspnea is complicated by several factors: the child’s ability to communicate the degrees of dyspnea and relief, the tension between curative and PC, and the desire to treat the child as part of the family unit (Robinson, 2012). Mack and Wolfe (2006) describe the tension between curative and PC as persisting until the EOL in pediatrics, whereas in adult care the focus moves more smoothly to palliation.

The respiratory system in children continues to grow and develop long after birth. Because respiratory function is immature in younger patients, deterioration can occur rapidly when disease is present (McCaskey, 2007). One exception is the neonate, who due to increased chest wall compliance may demonstrate abnormal breathing patterns that are actually adaptive for the condition (Robinson, 2012). Special attention should be given to the possibility of congenital anomalies (cardiac or respiratory) in this circumstance.

Observation, assessment, and a medical history are the tools to evaluate respiratory distress as the pediatric patient is not always able to communicate how he or she feels, especially if very young. However, in those who can describe their symptom(s), it is important to use pediatric age-appropriate tools, such as the Wong-Baker Faces or the Dalhousie Dyspnea Scale (Khan, Reddy, & Baptist, 2009; McGrath, Pianosi, Unruh, & Buckley, 2005; Pianosi, Smith, Almudevar, & McGrath, 2006). Once a baseline measurement has been obtained, the initial opioid dose is weight based and may range from 2.1 mg/kg/24 hr to 4.4 mg/kg/24 hr (Hewitt, Goldman, Collins, Childs, & Hain, 2008). A general rule of thumb is to start opioids at one fourth of that used for pain and increase as needed for good effect (Robinson, 2012). Children with solid tumors outside the central nervous system (CNS) may need increased doses of opioids or multiple different opioids to successfully manage their symptoms (Hewitt et al., 2008).

Complementary therapies may also assist with dyspnea management but have not been evaluated in children (Ladas, Post-White, Hawks, & Taromina, 2006). The scarcity of research in managing pediatric



dyspnea in the palliative setting means that many of the treatments are based more on practical wisdom than published evidence specific to pediatrics (Collins & Fitzgerald, 2006). Consequently, the majority of interventions are similar to those used with the adult population. One therapy not as common in adults is the use of airway clearance techniques to remove excess mucus production or to assist children with ineffective cough ability. The techniques range from postural drainage to the use of mechanical devices. One such option for children with chronic dyspnea is negative pressure ventilation using a cuirass (i.e., “turtle”) or a raincoat (poncho-like device, which surrounds the child; Robinson, 2012). Getting a good fit is essential and may prohibit use of the device.

It is not surprising that one of the greatest fears parents have for their dying child is that he or she will be uncomfortable during the last days of life (Widger & Wilkins, 2004). Yet barriers to quality EOL care such as prognostic uncertainties and discrepancies in treatment goals between staff and family members prevent dying children from being kept as comfortable as possible (Davies et al., 2008). Fewer than 1% of children who need hospice care actually receive it (Mellichamp, 2007). Consequently, health professionals in both Canada and the United States have advocated to improve the quality of EOL care provided to dying infants, children, adolescents, and their families through identification of key components (i.e., pain and symptom management) and an integrated PC approach (Widger & Wilkins, 2004). Seeking positive outcomes such as an overall improvement in patient/family/staff satisfaction with care, a decreased number of emergency department visits and hospitalizations, and an increased ability of the patient/family to make informed decisions and set realistic goals is within reach but not yet seen often enough (Jennings, 2005). Such an approach includes clarifying the objectives of treatment and frequently revisiting both the child’s and parent’s experiences while being sensitive to the burden of treatment and balancing it with the expected outcome for the child (Robinson, 2012).

## ■ TREATMENT AND INTERVENTIONS: NONPHARMACOLOGICAL

Because dyspnea is now recognized as a multidimensional symptom with psychosocial as well as physical components, pulmonary and PC experts are increasingly promoting the use of nonpharmacological interventions along with pharmacological therapies to improve the QOL for patients living with breathlessness (Booth, 2013; Rocker, 2011; Rocker, 2012). Booth (2013) concluded that **focused listening**

and acknowledgment of both patient’s and caregivers’ concerns is the most effective way of addressing the dyspneic patient’s needs. To assist with ongoing efforts to control the symptom, a classification system for nonpharmacological interventions grouped according to the component affected (i.e., breathing, thinking, and functioning) is under development (Booth, 2013).

### Cooling and Vibration

When stimulated, temperature and mechanical receptors of the trigeminal nerve in the cheek and nasopharynx alter feedback to the brain and modify the perception of dyspnea. The use of a fan set on low speed and directed toward the face will stimulate this response (Booth, Moosavi, & Higginson, 2008; Elia & Thomas, 2008). In a study of 50 patients with advanced disease who were not on oxygen, Galbraith et al. (2010) demonstrated a significant decrease in dyspnea when air from a handheld electric fan was directed toward the face for 5 minutes. In some patients, the effect continued even after discontinuation of the intervention. Cooling the body may have a beneficial effect as well. Simple techniques include applying cool damp cloths to the forehead or chest; offering a cool water sponge bath; or providing a clean, fresh pillow. Altering the environment by circulating cool air with either an air conditioning unit or a ceiling fan, or by placing the patient by an open window, may add an element of comfort (Williams, 2006).

Stimulation of the mechanical receptors in the respiratory muscles can alter the sensation of dyspnea, too. This accounts for why chest wall vibration is helpful in some patients (ATS, 1999). An electric massager can be purchased for this use, which also helps with relaxation and relief of pain. Another stimulatory modality, called acu-transcutaneous electrical nerve stimulation (TENS), is showing promise using TENS over acupoints. One randomized placebo-controlled study showed decreased dyspnea in ambulatory patients with COPD during a 45-minute acu-TENS session (Lau & Jones, 2008). Further investigation is warranted to evaluate the effects in a PC setting.

### Breathing Retraining

Diaphragmatic and pursed-lip breathing have been advocated to relieve dyspnea, especially in patients with COPD; however, relief is highly variable. Moreover, patients often resort to rapid, shallow breathing when unobserved. Despite these inconsistencies, both techniques offer an option that has no associated cost, is readily available, and can be easily learned. In some patients, breathing exercises

can promote effective lung function, feelings of relaxation, and stress reduction (Cairns, 2012). Families can play an active role in the patient's care by learning these techniques and coaching the patient during daily interactions.

## Positioning

Patients should be assisted to find a position of comfort. The leaning forward position has been reported to improve overall inspiratory muscle strength, increase diaphragmatic excursion, and decrease abdominal paradoxical breathing as well as reduce dyspnea in patients with COPD (ATS, 1999). While reducing participation of the chest wall and neck muscles overall, sitting and leaning forward with arms supported on a table facilitates a more focused effort on respiration rather than on maintenance of body posture and/or arm movement (Campbell, 1996; Spector et al., 2007).

Optimal comfort as well as ventilation and perfusion may be accomplished by placing the patient's good lung in a dependent position where gravity may assist in perfusing the healthiest area of lung tissue. In some patients, terminal dyspnea may only be relieved by an upright position where vital capacity is increased because of the lowered diaphragm. The clinician should accept the patient's position of choice, even if it belies traditional thinking.

## Energy Conservation

Activities of daily living strain dyspneic patients even if they are passive during the activity. Oxygen consumption is increased with any activity, so it is important to allow for an adequate recovery period. All care should be evaluated with regard to what the patient can tolerate and what is desired. In some cases, the activity or intervention can be modified to accommodate decreased tolerance. For example, a bath and linen change could be stretched out over the course of several hours, focused on face and hands only, or eliminated entirely. As noted earlier, a position of comfort is not only helpful but also critical to accommodating the patient's wants/needs with any required activities. However, if the care is more burdensome than beneficial, it should be reevaluated regarding the merit in continuing it (Ben-Aharon et al., 2008).

## ■ COGNITIVE-BEHAVIORAL APPROACHES/ COMPLEMENTARY THERAPIES

Distraction and relaxation strategies are important and useful adjuncts in the treatment of dyspnea. Distraction helps to focus the patient on something

other than breathing. Relaxation eases muscular tension, thereby allowing breathing to be less strenuous and more effective. One method, guided imagery, uses mental images to promote relaxation. Other therapeutic activities include mindfulness, stress-reduction techniques, massage, music therapy, Reiki, therapeutic touch, and aromatherapy. Yoga demonstrated a small improvement in dyspnea scores when taught to patients with COPD, though the difference was not statistically significant (Donesky-Cuenca, Nguyen, Paul, & Carrieri-Kohlman, 2009; Melendez et al., 2012). In any case, a wide range of alternatives evaluated in a systematic review of 11 randomized controlled trials (RCTs) and 2 controlled clinical trials failed to provide enough evidence to yield specific recommendations related to complementary therapies (Pan, Morrison, Ness, Fugh-Berman, & Leipzig, 2000).

Acupuncture and acupressure have emerged as possible options for relief of dyspnea. Acupuncture has already been integrated into PC settings in the United Kingdom (Suzuki et al., 2008). A review of the literature found 27 randomized controlled clinical trials with 23 reporting statistically significant results for symptoms such as dyspnea, pain, nausea, and vomiting (Standish, Kozak, & Congdon, 2008). However, the evidence remains low to moderate and the results for dyspnea are mixed. More research is needed to evaluate the potential benefits of this modality.

A number of essential oils (highly concentrated plant constituents) are thought to enhance respiration (Cooksley, 1996). These oils possess certain qualities such as expectorant, mucolytic, antiallergic, or immune stimulant; some also have antiviral and antibacterial benefits. Most of the essential oils useful in respiratory conditions come from the bark, leaves, berries, and branches of certain trees. Once properly diluted, essential oils can be applied directly to the skin (check for sensitivity first), in the form of massage, placed on pulse points, or inhaled through the use of a diffuser, aroma lamp, vaporizer, humidifier, or an absorbent material, such as a cotton ball. Oils are non-habit forming and excreted via the kidneys, skin, or lungs. Some recommended essential oils that can be used for dyspnea include eucalyptus, peppermint, ginger, hyssop, lavender, bergamot, basil, pine, sandalwood, and cypress. Blends of various oils are commonly used to achieve the maximum effect.

Education of the patient and family on management techniques and the basic rationale for each empowers them to take an active role in the treatment plan. Coaching both the patient and the family reinforces these interventions. Active listening and emotional support by the nurse encourages expression of thoughts and feelings and also helps with early identification of potential problems. Benefits have been achieved using a rehabilitative approach



that combined breathing retraining, psychosocial support, and help to develop adaptive strategies for breathlessness (Bredin et al., 1999; Corner, Plant, A'Hern, & Bailey, 1996; Hatley, Laurence, Scott, Baker, & Thomas, 2003; Solà, Thompson, Subirana, López, & Pascual, 2004). This was clearly found in a meta-analysis conducted by Salman, Mosier, Beasley, and Calkins (2003), where 20 RCTs showed strong evidence for pulmonary rehabilitation in the management of COPD. Support groups specifically for caregivers of patients with dyspnea can be a helpful intervention both in terms of the caregiver as well as for evaluation of management techniques (Moody, Webb, Cheung, & Lowell, 2004).

### ■ TRANSFUSION THERAPY

For patients with advanced cancer, blood transfusions are commonly used to alleviate symptoms such as dyspnea, fatigue, weakness, and tachycardia (Ripamonti, 1999). There is scarce evidence documenting symptom relief and improvement of the subjective sense of well-being after blood transfusions in anemic adults. With the potential risks of a transfusion reaction and adverse responses to blood transfusions, a safer, effective nontransfusion form of therapy might be considered, such as recombinant human erythropoietin (Williams, 2006). Disadvantages to this therapy include cost and the significant length of time required for an improvement in hemoglobin concentration, which is normally 4 to 6 weeks (Physicians' Desk Reference, 2009).

### ■ NONINVASIVE POSITIVE PRESSURE VENTILATION

Noninvasive positive pressure ventilation (NIV), often referred to as bilevel positive airway pressure (BiPAP), represents a controversial alternative method to treat dyspnea. While it is widely accepted as a curative intervention, no studies have yet been done on NIV as a comfort measure at the EOL, nor have any compared NIV with the use of pharmacological therapies such as morphine (Curtis et al., 2007). Nevertheless, NIV has found a place in PC for some patients with respiratory failure to either relieve symptoms or allow time for completion of life-closure tasks (Benditt, 2000).

For patients with advanced motor neuron diseases such as amyotrophic lateral sclerosis, NIV is considered the standard of care in the final phase of life (Tripodoro & De Vito, 2008). For patients who choose to forego endotracheal intubation in the presence of respiratory failure, the best candidates

for NIV are patients with COPD, cardiogenic pulmonary edema, and immunosuppression (Schettino, Altobelli, & Kacmarek, 2005) with mixed results for patients with advanced cancer (Cuomo et al., 2004). Alternatively, some have suggested it is inappropriate to use NIV for patients who choose comfort over life support because NIV is a form of life support itself; other drawbacks are poor outcomes or significant adverse events (Clarke, Vaughan, & Raffin, 1994; Delclaux et al., 2000). Therefore, the Society of Critical Care Medicine Task Force on the Palliative Use of NIV developed a framework for using NIV in patients with acute respiratory failure, especially for those patients who decline endotracheal intubation or who are receiving PC (Curtis et al., 2007). The proposed result is a categorical approach using an ethical framework based on the goals of care and informed patient and family preferences.

Frequent, ongoing, interprofessional patient and family communication is inherent in choosing or continuing NIV as an intervention. Clinical practice guidelines developed in Germany state that success of NIV for PC is measured by improvement of dyspnea without adverse effects and the ability to communicate with family (Schonhofer et al., 2008). NIV should be discontinued if it is not meeting these goals or causing unnecessary discomfort.

Advantages include a lack of adverse effects when compared to medications, continued patient participation, maintenance of communication, and relief of dyspnea and other symptoms related to hypoxia or hypercarbia. Disadvantages include the cost of equipment, hospice restrictions, lack of hypercarbic effect at the EOL (potential for increased suffering), the potential to decrease use of analgesics and anxiolytics prematurely, and the question of when/how to discontinue therapy (Booth et al., 2003; Williams, 2006). Adverse effects include facial irritation or discomfort, gastric distention, nasal/oral dryness or congestion, air leaks, failure to ventilate effectively, failure to tolerate, and, rarely, aspiration (Schettino et al., 2005).

As yet, many questions remain about the role of NIV at the EOL. However, if used in conjunction with traditional therapies, it may evolve into an effective tool for relieving dyspnea and improving QOL in terminal patients by reducing the demand on respiratory muscles. At this point, surveys indicate that physicians and respiratory therapists are using NIV in patients with "do not resuscitate" orders but are less inclined to use it for patients choosing comfort measures only (Sinuff et al., 2008). Other technological advances that may be of value for the dyspneic patient include laser therapy and the placement of endobronchial or tracheal stents to facilitate airway dilation, especially with tumor encroachment.

Another advancement is a minimally invasive alternative to the treatment of chronic or recurrent pleural effusion or malignant abdominal ascites, both of which cause dyspnea. This is an indwelling, cuffed, tunneled catheter placed percutaneously in an outpatient setting that facilitates patient-controlled drainage of either pleural or ascitic fluid without requiring hospitalization or office visits (Haas, 2007). Not only has this device shown substantial relief of dyspnea but it offers the patient a degree of control at the EOL as well (Arber, Clackson, & Dargan, 2013; Olden & Holloway, 2010).

## ■ PHARMACOLOGICAL THERAPIES

### Oxygen

Supplemental oxygen depresses the hypoxic drive, thereby reducing ventilation and subsequently relieving dyspnea. This physiologic response occurs at rest and during exertion in patients with a variety of lung diseases. Oxygen should be titrated to the individual's comfort level using the least restrictive device possible (e.g., nasal cannula does not interfere with eating and communication). Humidification is recommended for comfort and to prevent drying of mucous membranes at or above 4 L/minute. Continuous oxygen has been proven to be beneficial; however, some may prefer to use oxygen intermittently although assurance of the immediate availability of oxygen may be of greater importance (Currow, 2008; Elia & Thomas, 2008; Uronis & Abernethy, 2008).

High concentrations of oxygen can be problematic for those with COPD who are carbon dioxide retainers (i.e., their only drive to breathe is the hypoxic drive), but this should not be a major concern in the final hours of life because hypercarbia produces a sedating effect. Other potential adverse effects of oxygen include activity restriction, cumbersome apparatus, fire hazard, cost, psychological dependence, impaired communication, and difficult withdrawal.

It should be noted that the benefit of oxygen therapy for patients without hypoxemia remains controversial (Rousseau, 1997; Uronis & Abernethy, 2008; Zepetella, 1998). High-quality evidence (20/22 RCTs) shows that oxygen improves dyspnea during short-term exercise in COPD while the evidence for patients with COPD at rest, HF, and cancer (three small studies, one RCT) is weak (Brunnhuber, Nash, Meier, Weissman, & Woodcock, 2008). In fact, one review found oxygen equivalent to room air in patients with cancer (Booth et al., 2008). Clinical recommendations from the Association of Palliative Medicine emphasize tailored individual assessment and patient/family consultation with ongoing supervision to ensure that the goals of care are met (Booth et al., 2003).

Regardless of whether or not oxygen is indicated, it is frequently prescribed for long-term palliative use in patients with refractory dyspnea (Abernethy, Currow, & Frith, 2004; Stringer, McFarlane, & Hernandez, 2004). Currow et al. (2009) studied dyspnea scores on more than 400 patients (a majority had cancer) before and at 1 and 2 weeks after the introduction of palliative oxygen. The investigators found that only one third of the population ( $n = 150$ ) experienced an improvement in breathlessness. Predictive characteristics in the responders could not be identified. Overall, there was no clinically significant improvement with palliative oxygen in these subjects. The study authors suggested that, since oxygen is assumed to be beneficial, clinicians need to remember to conduct a reassessment after a week of therapy; if no benefit is perceived, discontinue the oxygen. Alternatively, there are patients as found in this study who may benefit from oxygen that does not meet standard (i.e., Medicare) criteria.

A double-blind, randomized, controlled trial of 239 patients with refractory dyspnea demonstrated no difference in breathlessness in either the delivery of oxygen or room air by nasal cannula (Abernethy et al., 2010). This group of investigators recommended that if oxygen is prescribed, appropriate patients should have dyspnea scores of 4 points or more on a 0 to 10 NRS; those with scores of greater than or equal to 7 points might be even more likely to experience benefit. The results of this study showed the most benefit in the first 24 hours of therapy and no additional benefit occurred after 3 days. Therefore, a therapeutic trial should last no longer than 72 hours. Clearly, more research is needed to determine which patients with dyspnea might achieve the most benefit from palliative oxygen.

Due to the decrease in airway resistance when helium is inhaled with oxygen, heliox gas mixtures for the relief of dyspnea have stimulated interest in this modality. Heliox reduces dynamic hyperinflation as well as decreases work of breathing in patients with COPD (Chiappa et al., 2009) and improves exercise tolerance in patients with lung cancer (Laude & Ahmedzai, 2007). Further investigation is needed to determine the best candidates and the potential for long-term benefits. Widespread use of heliox may be limited by cost, equipment logistics, geographical availability, and a lack of guidelines for patient selection (Kamal et al., 2010).

### Opioids

Opioids reduce dyspnea through a number of mechanisms. They act on the respiratory center by decreasing the ventilatory response to hypercapnia and hypoxia, reducing metabolic rate and oxygen



consumption, and altering the perception of breathlessness (Pinna, 2008). Furthermore, the cardiovascular effects of vasodilatation and decreased peripheral resistance help to improve oxygen supply and reduce lung congestion.

Despite concerns regarding the use of opioids, morphine therapy forms the basis for treatment of dyspnea at the EOL. One study found that improving the use of opioids is mostly a matter of improving communication and empathy between providers and patients (Bendiane et al., 2005). Opioids are very beneficial for many cardiopulmonary conditions, including lung cancer, CHF, COPD, and interstitial lung disease, as well as neuromuscular problems and others. The strongest evidence is for patients with COPD (12 RCTs), while the weakest is for patients with cancer (2 RCTs; Ben-Aharon et al., 2008; Brunnhuber et al., 2008; Lorenz et al., 2008). In chronic dyspnea, Currow et al. (2011) found 10 mg of sustained-release oral morphine once daily was safe and effective for 70% of patients ( $n = 58$ ), most of whom suffered from COPD. For the subjects who remained on opioids for the length of the study, benefit was maintained at 3 months.

There is no ceiling dose with opioids, so it is appropriate to titrate morphine to the desired effect, that is, dosing interval and quantity based on frequent symptom assessment and limited only by intolerable side effects. Commonly seen side effects include constipation, nausea and vomiting, urinary retention, altered mental status, and drowsiness; tolerance to all of these side effects, except constipation, usually occurs within a week. A bowel regimen should always be established when opioids are prescribed to prevent constipation. While the most feared opioid-related side effect is respiratory depression, titration for symptoms has not been shown to cause it (Estfan et al., 2007). In fact, respiratory depression appears primarily to be an effect of rapid escalation of the drug (Hallenbeck, 2012). Furthermore, Bengoechea et al. (2010) found a longer median survival time for patients with cancer who received at least twice their initial dose of opioids (22 days) than those who did not (9 days).

The oral route of morphine is preferred at the EOL because it is better tolerated, least invasive, and less costly. Other routes, such as sublingual, rectal, IV, subcutaneous, or aerosolized, can be utilized. Furthermore, a pilot study demonstrated relief of dyspnea in patients with advanced emphysema using epidural methadone without adverse effects (Juan et al., 2005). Opioid-naïve adults start with the morphine equivalent of 5 mg orally every 4 hours and, thereafter, increase dose 30% to 50% daily or more frequently until dyspnea is relieved or sedation or other adverse effects become problematic (Elia & Thomas, 2008; Rousseau, 1997). For those

already receiving morphine and experiencing dyspnea as a new symptom, the dose should be increased by 25% to 50% daily for mild to moderate dyspnea and 50% to 100% for moderate to severe dyspnea and then titrated accordingly (Elia & Thomas, 2008; Rousseau, 1997).

Since opioid receptors have been demonstrated to exist in the airways, nebulized morphine, hydromorphone, or fentanyl can be given in addition to systemic opioids or alone (Coyne, 2003; Shirk, Donahue, & Shirvani, 2006). Some patients experience relief of dyspnea with fewer side effects due to the lack of systemic concentration achieved by inhalation. However, morphine and hydromorphone can cause histamine release leading to bronchoconstriction, thus the preference by some for fentanyl. Regardless, this method of delivery remains controversial as studies have been conflicting, with nine RCTs demonstrating no symptomatic improvement (Ben-Aharon et al., 2008; Jennings, Davies, Higgins, & Broadley, 2001). Nevertheless, commonly used initial doses of preservative-free injectable solution are morphine 2.5 to 10 mg, hydromorphone 0.25 to 1 mg, and fentanyl 25 mg diluted in 2 mL of normal saline (Charles et al., 2008; Ferraresi, 2005).

One protocol recommends nebulized morphine only when intolerable side effects have occurred from systemic administration (Spector, Klein, & Rice-Wiley, 2000). This protocol begins at a conservative dose of 5 mg and titrates up to a maximum of 40 mg every 4 hours; the protocol includes frequent reevaluation of breathlessness. Dyspnea refractory to other routes of administration may justify a trial of nebulized opioids. However, further research is needed to determine what patients may achieve maximum benefit.

## Anxiolytics

Although not supported by RCT evidence for frontline therapy (Simon et al., 2011), an anxiolytic may help relieve dyspnea when morphine is not completely effective; anxiety is often one of the dimensions of dyspnea (Navigante, Cerchietti, Castro, Lutteral, & Cabalar, 2006; Reddy, Parsons, Elsayem, Palmer, & Bruera, 2009). Anxiolytics should be considered in combination with opioids and nonpharmacologic anxiety-reduction measures (Elia & Thomas, 2008). Low-dose benzodiazepines and phenothiazines are the categories of anxiolytics most commonly used in the management of dyspnea (Elia & Thomas, 2008). These drugs have hypnotic, sedative, anxiolytic, anti-convulsant, and muscle-relaxant actions, therefore achieving control of dyspnea via multiple mechanisms of action (Physicians' Desk Reference, 2009).

Benzodiazepines depress the hypoxic/hypercapnic ventilatory response as well as alter the emotional response to dyspnea (ATS, 1999; Spector & Klein, 2002). Specifically, they bind to a site on the gamma-aminobutyric acid (GABA) receptor and potentiate the action of GABA, which acts as an inhibitory neurotransmitter in the CNS (Physicians' Desk Reference, 2009).

Due to the long half-life of oral anxiolytics, some patients are unable to tolerate the side effects of prolonged sedation and cognitive impairment (Rousseau, 1997). Nevertheless, lorazepam 0.5 to 2.0 mg sublingual/oral every 4 to 6 hours as needed or around the clock (ATC) is frequently used (Dahlin, 2006). To break a severe anxiety–dyspnea cycle, the medication can be given as often as hourly until the patient is comfortable (Dahlin, 2006). Side effects include drowsiness, ataxia, reduced psychomotor performance, loss of appetite, and perceptual disturbances (Physicians' Desk Reference, 2009). Diazepam, alprazolam, clonazepam, buspirone, or chlorpromazine are considered alternative medications (Elia & Thomas, 2008; Spector et al., 2007).

Subcutaneous midazolam (5 mg every 4 hours) has been reported as a safe and effective adjunct to morphine in advanced cancer patients (Navigante et al., 2006). In this prospective, randomized, single-blind study, dyspneic cancer patients received either (a) ATC morphine with midazolam for breakthrough dyspnea, (b) ATC midazolam with morphine for breakthrough, or (c) ATC morphine plus midazolam with morphine for breakthrough. Dyspnea relief was achieved at the rates of 69%, 46%, and 92%, respectively. Midazolam may be better tolerated than other benzodiazepines due to a shorter half-life (less than 5 hours) and lack of active metabolites. More recently, a study of 63 ambulatory patients with cancer-related dyspnea were randomized to receive either oral morphine or oral midazolam (Navigante, Castro, & Cerchietti, 2010). Patients in both groups had a reduction of dyspnea by at least 50% during the initial phase of the study. For control of baseline and breakthrough dyspnea, midazolam was superior to morphine in the ambulatory phase of the study. The investigators concluded that oral midazolam could be considered as a first-line option for cancer-related dyspnea in ambulatory patients.

### Corticosteroids

Corticosteroids, while controversial in the treatment of dyspnea, may be of value because they reduce inflammation by suppressing the migration of polymorphonuclear leukocytes and reversing the increase in capillary permeability (Physicians' Desk Reference, 2009). Euphoria in the form of an overall feeling of

well-being and an increase in appetite exhibit a secondary response. In the lungs, corticosteroids decrease airway inflammation that may be experienced with COPD and radiation or drug-induced pneumonitis, reduce edema associated with tracheal or lung tumors, and increase vital capacity in interstitial disease.

Corticosteroids can improve airway obstruction in cases of carcinomatous lymphangitis or superior vena cava syndrome (Ripamonti, 1999; Williams, 2006). Dose and duration of therapy for dexamethasone and prednisone, two commonly used drugs, depend on the patient's condition and response (Physicians' Desk Reference, 2009). Starting doses are usually high, and then reduced to a lower maintenance dose. Adverse reactions (such as insomnia, nervousness, dizziness, indigestion, and hyperglycemia) are not unusual; the nurse should monitor the patient closely for any untoward outcomes (Physicians' Desk Reference, 2009). Corticosteroids can be given orally, subcutaneously, intramuscularly, intravenously, or by inhalation.

### Bronchodilators

With substantial evidence from RCTs, a trial of bronchodilator therapy is warranted to relieve dyspnea, especially with COPD, asthma, or other problems associated with reactive airways (ATS, 1999; Lorenz et al., 2008). Beta-2 agonists and anticholinergics cause smooth muscle dilation of the airways, thus removing any impedance to airflow (Spector & Klein, 2002). Specifically, bronchodilators exert synergistic action on cyclic 3 to 5 adenosine monophosphate (cyclic AMP; Physicians' Desk Reference, 2009). They also stabilize mast cells and stimulate the respiratory tract cilia to expel mucus. The preferred route is inhaled, either by metered dose inhaler or nebulizer, but the drug is also available in oral preparations (Ofir et al., 2008). Side effects such as tremors, agitation, and anxiety that may heighten the dyspnea are due to sympathetic stimulation. These potential systemic effects, however, are greater with the oral route. The patient's response should dictate the use of bronchodilators.

### Diuretics

Dyspnea may be associated with fluid volume excess, which can be treated with diuretics, such as furosemide, to mobilize edema, normalize blood volume, reduce vascular congestion, and reduce the workload of the heart (Oxberry & Johnson, 2008; Spector et al., 2007). Furosemide inhibits reabsorption of sodium and chloride in the ascending loop of Henle and distal renal tubule, interfering with the chloride-binding cotransport system, thus causing increased excretion



of water and electrolytes (Physicians' Desk Reference, 2009). Normal doses can be administered orally, subcutaneously, intramuscularly, intravenously, and by inhalation. For conditions where diuresis is urgently needed (e.g., HF or pulmonary edema), the IV form may be preferred (Kazanowski, 2001). Other disease states where diuretics may be helpful to relieve dyspnea include pulmonary hypertension and abdominal ascites (Selecky et al., 2005). For control of dyspnea refractory to standard treatments, inhaled furosemide has been tried. However, a few small trials in patients with COPD and advanced cancer thus far show mixed results and indicate a need for further investigation (Jensen, Amjadi, Harris-McAllister, Webb, & O'Donnell, 2008; Wilcock et al., 2008).

## Antibiotics

Antibiotics may be indicated when dyspnea occurs secondary to a respiratory infection (ATS, 1999; Ofir et al., 2008). Rather than pursue a traditional workup for infection, an empiric trial of antibiotics is appropriate when the patient is near death (Kazanowski, 2001). Antibiotics can provide symptom relief and facilitate comfort in the presence of a respiratory infection characterized by an elevated temperature, abnormal breath sounds, acute cough, and nasal/chest congestion (Selecky et al., 2005).

## Anticholinergics

The lack of ability to protect one's airway in the final hours of life contributes to the build-up of secretions that lead to what is commonly referred to as the "death rattle" (i.e., noisy breathing). While caregivers consider it to be a disturbing symptom for families and loved ones of the patient, recent studies have found that this is not necessarily the case (Wee, Coleman, Hillier, & Holgate, 2006). In contrast, it does have a negative impact on staff and volunteers working with dying patients, causing them to act without knowing which treatment is the most effective (Wee et al., 2006). The "death rattle" occurs in 25% to 92% of dying patients, occurs more commonly in men and patients with brain and lung neoplasms, and predicts most will die within 48 hours (Bennett, 1996; Plonk & Arnold, 2005; Wildiers & Menten, 2002). It is caused by the collection of secretions in the bronchi and, posterior oropharynx, a decreased ability to swallow, an absent cough reflex, and, in severe cases of cardiopulmonary failure, pulmonary edema (Bickel & Arnold, 2008; Picella, 1997).

Despite the lack of evidence-based guidelines, the standard of care has been to use anticholinergic drugs, namely, scopolamine, hyoscyamine, glycopyrrolate, and atropine (Bickel & Arnold, 2008). The

mechanism of action is the blockade of acetylcholine at parasympathetic sites in smooth muscle, secretory glands, and the CNS with the primary clinical effect of inhibition of salivary secretions (Physicians' Desk Reference, 2009). Side effects are generally not reported as the patient is unresponsive but may include dry mouth, urinary retention, visual disturbances, and less often confusion (Wee et al., 2006).

No controlled studies have determined if anticholinergics are the treatment of choice and, if so, which drug/dosage/route is best. Only glycopyrrolate crosses the blood-brain barrier, making it not only more potent but also more erratically and poorly absorbed (Bickel & Arnold, 2008). The scopolamine patch is convenient with the dosage being one to three patches every 3 days (Bickel & Arnold, 2008). Hyoscyamine offers the most flexibility as it comes in short-acting, sustained-released oral tablets and solution (Bickel & Arnold, 2008). Anecdotal reports from hospice nurses suggest the use of atropine eye drops sublingually as a reasonable alternative, as long as side effects are monitored (e.g., tachycardia). Nonpharmacologic interventions have not been studied either but include positioning (side-lying or semiprone), gentle oropharyngeal suctioning, postural drainage, and reduced fluid intake (Bickel & Arnold, 2008; Lawrey, 2005; Plonk & Arnold, 2005).

## Anesthetics

Recent reports in the literature suggest that ketamine may have a place in treating intractable symptoms, namely, pain, during a patient's final hours (Fine, 1999, 2003). Ketamine, an *N*-methyl-D-aspartate (NMDA) receptor antagonist, has strong analgesic, anxiolytic, and amnesiac properties that make it attractive as a treatment for uncontrollable dyspnea (Uslaner, Flick, Lee, Groover, & Hutson, 2012; Witte, 2002b). Anecdotal reports on a small number of patients with severe dyspnea unresponsive to usual therapy suggest that a conservative induction of ketamine can be successful (Witte, 2002a). Using trial and error, the following regime has safely facilitated control of severe dyspnea: initial IV bolus dose of 0.15 mg/kg (0.5 mg/kg SQ or IM); repeat every 10 to 15 minutes twice as needed (30–45 minutes for SQ or IM dosing; Fine, 2003; Witte, 2002a). If no effect is noted at this time, other options should be explored. If symptom(s) subside, a ketamine (IV or SQ) infusion can be started at a rate determined by dividing the relief-duration time into the total induction dose (Fine, 2003; Witte, 2002a; e.g., 50 kg person  $\times$  0.15 mg/kg = 7.5 mg IV bolus. Duration of relief is 3 hours. 7.5 mg divided by 3 hours = 2.5 mg/hr infusion). The patient may need to be rebolused at the start of the infusion.

Clinical signs and symptoms guide the number of boluses as well as the infusion rate of ketamine (Fine, 1999, 2003).

When using ketamine in subanesthetic doses, patients can respond and interact coherently and purposefully (Fine, 2003). Side effects such as vivid and disturbing dreams, hallucinations, and delirium common with anesthetic doses are rare but can be treated with a benzodiazepine or phenothiazine (Fine, 1999, 2003; Fitzgibbon & Viola, 2005). Opioids should be evaluated at the start of the ketamine infusion and reduced whenever possible to avoid opioid toxicity/tolerance (Fitzgibbon & Viola, 2005). Despite numerous reports of safety and efficacy, there may still be difficulty accessing this drug in PC due to lack of knowledge, professional bias, and financial constraints (Baumrucker, 2000). The success of using ketamine for pain control warrants further investigation regarding the role of ketamine in treating extreme dyspnea at the very EOL.

## ■ CONCLUSION

Dyspnea has long been recognized as a prevalent symptom near the EOL (Booth et al., 2003; Brunnhuber et al., 2008; Nauck, Klaschik, & Ostgathe, 2000; Williams, 2006). Similarly, noisy breathing (death rattle) is frequently observed in the last hours and days of life. Morita, Ichiki, and Tsunoda (1998) reported a mean of 57 hours till death once noisy breathing began. A retrospective chart review of 185 residents who died in a long-term care facility indicated that dyspnea was the most commonly recorded symptom (62%) and noisy breathing was the third (39%; Hall et al., 2002). However, in nearly a quarter of the patients with dyspnea, symptoms were not treated. Of those who did receive treatment, oxygen was the therapy most often utilized. Opioids accounted for 27% of the treatment and nonpharmacological

measures, 6%. About half of the cases with “noisy breathing” went untreated; those that did receive therapy were either suctioned or given hyoscine. The nurse was the only health care professional involved 40% of the time (Hall et al., 2002).

More recently, Currow et al. (2010) reported similar findings in a 4-year study of nearly 6,000 hospice patients in the last 3 months of life; one out of four experienced moderate-to-severe dyspnea despite treatment. The investigators questioned why such findings still exist when much has been done to improve our knowledge of effective interventions. Elmqvist et al. (2009) made comparable remarks after finding very little improvement in pain, dyspnea, fatigue, and anorexia scores in 116 patients with cancer in the last 3 months of life. In fact, the magnitude of the symptoms was consistently high and increased steadily as death approached.

Nearly a decade since the retrospective review done by Hall et al. (2002), 48% of patients in 230 long-term-care centers across four states experienced dyspnea during the last 30 days of life (Hall et al., 2002; Hasson et al., 2008). Interviews with over 1,000 staff and family caregivers rated the treatment very effective for only half. Furthermore, dyspnea assessment remains primarily observational even in hospice settings (Webb, Moody, & Mason, 2000). Lastly, while standard therapies have become more frequently employed, complementary alternatives are rarely utilized even though dyspnea is increasingly recognized as a multifaceted symptom affecting not only the patient but the family and caregivers as well (Abernethy, Wheeler, & Currow, 2010).

These and other similar findings continue to point to the tremendous need for EOL education and research, especially for dyspnea assessment and management. As the population ages and the symptoms of chronic diseases become even more prevalent, more people will suffer unnecessarily unless nurses advocate for quality EOL care.

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## CASE STUDY Conclusion

Despite all efforts to restore his health, Sam again developed pneumonia with respiratory failure that required mechanical ventilation. Acting as his health care proxy, his wife, within a few days, came to terms with the fact that he was not going to come home and made the decision to forego further life-sustaining therapies. He was moved to a room that offered more privacy and space. Prior to extubation, Sam was given IV morphine and then as needed for relief of breathlessness. Due to the severity of his pulmonary condition combined with the inflammatory effects of his rheumatoid arthritis, Sam required frequent doses of morphine that were difficult for the nursing staff to administer in a timely manner. It became clear that the morphine alone was not effectively managing his symptoms. However, with the addition of IV lorazepam, Sam became less dyspneic, less agitated, more alert, and required less frequent doses of morphine.



He was able to focus on his family for a few moments at a time. IV corticosteroids helped reduce the painful effects of the inflammation. During the course of his illness, Sam had become reassured by oxygen therapy, so it was offered by nasal cannula, the least restrictive device. A scopolamine patch was placed when his secretions became excessive. His family and a few close friends gathered at his bedside. They played his favorite country-western music, expressed their love for him, reminisced about the good times they had together, and told a few jokes. His priest came and offered the Sacrament of the Sick. His wife and son were encouraged to stay at the bedside as much as they wanted and were supported in their grief by friends, hospital staff, clergy, and the physicians involved in his care. Sam drifted in and out of consciousness until the last few hours of his life. He died peacefully with his family at his side.

## Evidence-Based Practice

Lindqvist, O., Lundquist, G., Dickman, A., Bükki, J., Lunder, U., Hagelin, C. L., Rasmussen, B. H.,...Fürost, C. J.; OPCARE9. (2013). Four essential drugs needed for quality care of the dying: A Delphi-study based international expert consensus opinion. *Journal of Palliative Medicine*, 16(1), 38–43.

### Purpose

The majority of dying patients do not have access to necessary drugs to alleviate their most common symptoms despite evidence of drug efficacy. Our aim was to explore the degree of consensus about appropriate pharmacological treatment for common symptoms in the last days of life for patients with cancer among physicians working in specialist PC.

### Material and Methods

Within OPCARE9, a European Union seventh framework project aiming to optimize EOL cancer care, we conducted a Delphi survey among 135 PC clinicians in nine countries. Physicians were initially asked about first and second choice of drugs to alleviate anxiety, dyspnea, nausea and vomiting, pain, respiratory tract secretions (RTS), and terminal restlessness.

### Results

Based on a list of 35 drugs mentioned at least twice in the first round ( $n = 93$ ), a second Delphi round was performed to determine less than or equal to five essential drugs for symptom alleviation in the last 48 hours of life that should be available even outside specialist PC. There was greater than or equal to 80% consensus among the participants ( $n = 90$ ) regarding morphine, midazolam, and haloperidol as essential drugs. For RTS, there was consensus about use of an antimuscarinic drug, with 9% to 27% of the physicians each choosing one of four different drugs.

### Conclusion

Based on this consensus opinion and other literature, we suggest four drugs that should be made available in all settings caring for dying patients with cancer, to decrease the gap between knowledge and practice: morphine (i.e., an opioid), midazolam (a benzodiazepine), haloperidol (a neuroleptic), and an antimuscarinic.

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# Anxiety, Depression, and Delirium

## KEY POINTS

- Anxiety, depression, and delirium are common symptoms during the dying process.
- Anxiety manifests itself in four ways: physical symptoms, affective symptoms, behavioral responses, and cognitive responses.
- The patient and his or her family should be reassured that the symptoms of depression are effectively treated the majority of the time.
- Effective treatment of anxiety, depression, and delirium necessitates a collaborative effort between the patient, family, and the health team.

## CASE STUDY

Ann is a 77-year-old retired woman who was a development officer of a local college. Her medical history is pertinent for breast cancer, low blood pressure, and depression. Her mother had depression and attempted suicide several times. She lives alone in the house she and her husband shared for 25 years. However, he died 20 years prior from cardiac disease. Ann has been fiercely active, traveling, participating in church activities, going to cultural events, and organizing book groups. Ann has three daughters; two live on the East and West coast, only one lives nearby. Until recently, Ann insisted she did not need much help.

In the last year, however, Ann has begun to get forgetful. Her appearance and her personal care have changed. Her house is in shambles. Ann seems more anxious and nervous and tries to avoid the neighbors. This is a distinct change from the past when she would stop and visit or invite them over. Her neighbors have noticed her behavior changes but they have not reported this to any of Ann's family.

Recently, Ann was involved in several car accidents. She appears more confused. After the last car accident, a neighbor found her walking home and called her daughter. Ann refused to let her daughter take her for evaluation for 1 week. She finally underwent imaging and was found to have bilateral acute on chronic subdural hematomas. She underwent surgery for the left hematomas. However, she decompensated and underwent emergent surgery for the right side.

Since her surgery, Ann is more confused with memory changes. She appears more anxious and angry about the changes in her functional status and her loss of independence. She is now in an assisted living facility, where she had considered moving into senior independent living. She is able to participate in activities and eat in the dining room. Recently, over the last few months, Ann has developed several bouts of urinary tract infections and pneumonia requiring hospital admission. With each of these admissions, Ann appears more depressed and anxious, with more periods of confusion. She has also become weaker, needing more assistance. She prefers to spend time in her room watching television. She has stopped reading, using the computer, or swimming; these were all things she loved.

The response to a serious, life-threatening, or progressive, chronic diagnosis results in various individuals' ways of coping. Often, a person may develop psychiatric symptoms including anxiety, depression, and delirium. There is a strong correlation among the diagnosis of anxiety, depression, and delirium in patients receiving palliative care for a life-limiting illness (Pasacrete, Minarik, & Nield-Anderson, 2010). As transient symptoms, anxiety, depression, and delirium may not cause long-term issues. In more chronic and severe diagnoses, however, these psychiatric issues may inhibit the ability to have meaningful communication with family and friends as part of life closure, cause suffering, and affect quality of life.

In palliative care, there is the expectation that clinicians will attend to psychiatric symptoms as well as physical symptoms. This is stated in the National Consensus Project for Quality Palliative Care, *Clinical Practice Guidelines*, under Domain 3, Psychological and Psychiatric Aspects of Care Guideline 3.1: "The interdisciplinary team assesses and addresses psychological and psychiatric aspects of care based upon the best available evidence to maximize patient and family coping and quality of life" (National Consensus Project, 2013). In doing so, with skills and training in the potential psychological and psychiatric impact of serious or life-threatening illness, on both the patient and family, including depression, anxiety, delirium, and cognitive impairment, the interprofessional team effectively treats psychiatric diagnoses, such as depression, suicidal ideation, anxiety, and delirium, whether as a consequence of the illness or among patients with comorbid psychiatric illness accompanying their serious or life-threatening illness (National Consensus Project, 2013). Moreover, this is done in partnership with the family and using interventions informed by evidence-based practice and may include pharmacological, non-pharmacological, and complementary therapies.

Anxiety, depression, and delirium commonly arise from fear of the disease, accompanying symptoms, and its progression. Specifically, patient fears include pain, loss of independence, functional alteration, cognitive changes, and the potential burden to others (Eliopoulos, 2010). However, anxiety, confusion,

or delirium may be the first sign of a medical problem, particularly in older adults (Rosen, Koretz, & Reuben, 2010). Moreover, these symptoms may be interwoven, making it difficult to differentiate among the three diagnoses. Anxiety may precede depression in the diagnosis of certain medical conditions such as myocardial infarction or dementia. Or often, anxiety and depression are seen together, perhaps in the setting of a diagnosis of a terminal illness. Delirium may cause anxiety stemming from the ensuing altered consciousness. This is particularly true if the delirium waxes and wanes and the patient has a sense of his or her cognitive impairment. Depression may result if a patient understands his or her cognitive deficits. Thus, diagnosis and treatment are even more challenging when the person tries to compensate for deficits.

The initial presentation of a medical condition may manifest itself as a psychiatric symptom, resulting in a misdiagnosis of anxiety, depression, or delirium. With the additional overlay of a life-threatening illness, diagnosis may be much more subtle and more complex. Cardinal signs of a disease may be hidden or diminished, such as decreased pain in a myocardial infarction or minimal fever in an infection. Other complex situations may include the presentation of delirium in a patient with a neurological process, depression in a patient who has underlying pancreatic cancer, or anxiety for underlying cardiac ailments (Rosen et al., 2010). In children, it may be difficult to distinguish anxiety and depression from sadness or grief. Historically, it was thought that children experience less psychosocial effects. However, this has been found to be a great underestimation. In addition, there are fewer available mental health specialists to treat children and pediatrics (Goldsmith, Ortiz-Rubio, Staveski, Chan, & Shaw, 2011; Pao & Weiner, 2011).

Once a diagnosis is made, treatment issues related to a specific patient must be considered. In particular, a clinician must take into account the patient's age. Older adults and young children may have more pronounced and adverse effects from medications. In addition, older adults may experience diminishing functional and physiological processes or possible



lack of social supports. The successful treatment of a patient includes pharmacological medications, complementary therapy, and mobilization of social support of the patient and family. This chapter addresses the holistic care necessary for effective diagnosis, assessment, and treatment of anxiety, depression, and delirium in the palliative care patient.

## ■ ANXIETY

### Definition

Anxiety is an expected state in life with some fluctuation. Anxiety is defined as feelings of distress, worry, and tension from a known or unknown stimulus. There are two categories: (a) acute anxiety comprising impressive cognitive, physiological, and behavioral manifestation; and (b) low-grade distress that interferes with psychosocial functioning due to restlessness or being on edge, difficulty in concentration, irritability, muscle tension, and sleep alterations (American Psychiatric Association [APA], 2013). However, in the recent *DSM-5*, the APA put forth a new diagnosis, “*Anxiety Disorder due to Another Medical Condition*,” which relates to a patient with a chronic, progressive, or serious life-threatening illness or injury. This diagnosis describes that the condition is related to the circumstances of the direct pathophysiological consequences of a medical condition, is not explained by a mental disorder, and affects the social and occupational situations of the patient as well as general functioning (APA, 2013).

Generalized anxiety disorder (GAD) is described as chronic uncontrollable nervousness, fearfulness, and sense of worry that lasts for 6 months or longer (APA, 2013). Patients may describe this as a sense of worry, fear, concern, or even foreboding. Although anxiety is a very subjective experience, it is often accompanied by somatic complaints such as tachycardia, fatigue, restlessness, difficulty concentrating, muscle tension, headaches, palpitations, sweating, abdominal discomfort, dizziness, urinary frequency, and sleep disturbances. Symptoms must be present for at least 6 months and should cause impairment in social or occupational functioning. In the older adults, there may be a sense of phobia where they may stay at home because they are fearful to leave, stop activities, and become more isolated (Katona, Livingston, & Cooper, 2010).

Anxiety in pediatric patients is a common occurrence. The challenge is twofold; the anxiety of the children as well as anxiety related to the stress of parents, family, and caregivers around them (Kane & Himelstein, 2007; Pao & Wiener, 2011). In addition, there is the burden of anxiety in long-term chronic illnesses. The symptoms that children experience are

related to behavioral issues and the change in their functional abilities; specifically irritability, resistance, and refusal of tests and procedures. Anxiety may affect their routines such as in school or other activities (APA, 2013). Younger children may have worries related to separation, strangers, injuries, and loud noises, while teens may have issues regarding personal appearance, self-worth, and competence (Kersun & Shemesh, 2007; Pao & Wiener, 2011). In addition, worries about being hospitalized, treatment sessions, or the side effects of these activities may occur as well.

### Incidence

Anxiety symptoms may develop in any individual diagnosed with a life-limiting illness. Increased anxiety has been associated with female gender, young age, and low socioeconomic status, as well as in lung cancer (Vodermaier, Linden, MacKenzie, Greig, & Marshall, 2011). However, as a life-threatening disease progresses and a person's physical status declines, anxiety may increase (Kolva, Rosenfeld, Pessin, Breibart, & Brescia, 2011). Cancer-related anxiety is a natural response to the crisis precipitated by such a diagnosis, the threat to life, and the future (Traeger, Greer, Fernandez-Robles, Temel, & Pirl, 2012). Within the pediatric population, there are no prevalent studies related to anxiety at the end of life.

### Etiology

Anxiety in patients with a life-limiting illness is common and may have a multitude of causes. It may be a component of adjustment disorder, a panic disorder, a GAD, phobia, or agitated depression (Kolva et al., 2011). The etiology of anxiety includes a multitude of medical conditions such as poorly managed pain, endocrine disorders including hypo- and hyperglycemia, hypo- and hyperthyroidism, Cushing's disease, and carcinoid syndrome. Cardiovascular conditions include myocardial infarctions, angina, congestive heart failure, mitral valve prolapse, and hypovolemia; respiratory conditions include asthma, chronic obstructive pulmonary disease (COPD), pneumonia, pulmonary edema, dyspnea, and hypoxia. Neoplasms and neurological conditions such as akathisia, encephalopathy, seizure disorder, and postconcussion disorders can also contribute to or exacerbate anxiety disorders (Fournier, 2013b; Pasacrete et al., 2010).

Stimulant substances may contribute to anxiety; these include caffeine present in coffee, tea, chocolate, and soda. Ephedrine present in cold products and stimulant-type drugs such as methylphenidate, and withdrawal from medications such as benzodiazepines, alcohol, and barbiturates, may cause anxiety.

Psychological distress such as worries about family relationships, family strife, and financial worries may all cause anxiety for patients with a life-limiting illness. These may be exacerbated by concern of being a burden to other family members. Lastly, a family history may be a component of anxiety that may become more pronounced in older patients as they lose physical functioning. See Table 21.1 for further summary of causative factors and Table 21.2 for emergent conditions disguised as anxiety.

## Cardinal Signs

Anxiety has four types of manifestations: physical symptoms, affective symptoms, behavioral responses, and cognitive responses (Pollack, Otto, Bernstein, &

Rosenbaum, 2010) outlined in Table 21.3. Generalized anxiety can be accompanied by symptoms of depression, panic, and phobias; however, in the elder patient, depression is the most common accompanying condition (Rosen et al., 2010). Patients may be observed with a tense posture and frequent sighing. Older adults are more likely to minimize emotions and feelings and report somatic complaints (Tabloski, 2010). In addition, they have many attributes of suicide vulnerability, which include pain and suffering, poor prognosis, depression, delirium, loss of control, and lack of social support (Breitbart, Chochinov, & Passik, 2012). In differentiating anxiety from fear, evaluation should explore the known presence of an external threat versus anxiety stemming from an unknown internal stimulus (Traeger et al., 2012). The new diagnosis of “Anxiety from Another Medical Condition” is helpful to consider as there are many “unknowns” in chronic progressive conditions or serious life-threatening

**TABLE 21.1 Anxiety-Associated Medical Conditions**

System/Condition	Examples
Cardiovascular conditions	Angina, congestive heart failure, hypovolemia, mitral valve prolapse, myocardial infarction, paroxysmal atrial tachycardia
Endocrine disorders	Carcinoid syndrome, Cushing's disease, hyperglycemia, hypoglycemia, hyperthyroidism, and hypothyroidism
Immune conditions	AIDS, infections
Metabolic conditions	Anemia, hyperkalemia, hyperthermia, hypoglycemia, and hyponatremia
Respiratory conditions	Asthma, chronic obstructive pulmonary disease, hypoxia, pneumonia, pulmonary edema, and pulmonary embolus
Neurological conditions	Akathisia, encephalopathy, brain lesion, seizure disorders, postconcussion syndrome, vertigo, cerebral vascular accident, and dementia
Cancer	Hormone producing tumors: pheochromocytoma
Medication and substances	Withdrawal of alcohol, benzodiazepines, nicotine, or sedatives. Use of steroids, stimulants, and neuroleptics such as metoclopramide or prochlorperazine
Uncontrolled pain	

Source: Adapted from Breitbart et al., 2010; Pasacrete et al., 2010; Fournier, 2013.

**TABLE 21.2 Emergent Conditions Disguised as Anxiety in Patients With Life-Threatening Illness**

■ Hypoxia
■ Sepsis
■ Uncontrolled pain
■ Pulmonary embolus
■ Impending cardiac or respiratory arrest
■ Electrolyte imbalance
■ Dehydration

Source: Adapted from Breitbart et al., 2010 and Fournier, 2013.

**TABLE 21.3 Four Types of Anxiety Manifestation**

Classification	Manifestations
Physical symptoms	Autonomic responses such as tachycardia, tachypnea, diaphoresis, lightheadedness, tremors
Affective symptoms	Nervous or restless behaviors such as pacing, picking, frequent movement
Behavioral responses	Avoidance, compulsions
Cognitive responses	Edginess, worry, panic, terror, apprehension, obsession, thoughts of physical or emotional damage to self

Source: Adapted from Pollack et al., 2010.



illnesses that cause anxiety: continued surveillance of the disease; the worry of test results; how fast the disease will progress; and when the disease will become advanced Table 21.2. All of these are areas of loss of control and major stressors.

## Severity

Anxiety, in its mildest form, assists any person to participate in general life activities; it serves as an impetus to perform various functions in learning, working, and adapting to the ongoing changes in life. Levels of anxiety are mild (which is considered normal), moderate, severe, and panic (Pasacrete et al., 2010). In its severest form, anxiety becomes panic, which prevents the patient from doing anything. The person may become paralyzed in fear and be confined to his or her immediate surroundings, such as his or her home or room. Table 21.4 outlines the characteristics of mild anxiety to panic.

## Assessment

Assessment requires vigilance for anxiety. A history and review of medical conditions for potential causes of anxiety are part of the initial evaluation. The evaluation of the serious illness and its symptom burden are important as well as other comorbid conditions. Other predisposing factors should be examined including previous history of anxiety or trauma, social isolation, and coping style (Traeger et al., 2012). A thorough discussion of psychosocial situations including living conditions, recent changes in the patient's life, and anticipated life changes is warranted. This conversation is most revealing if it includes both the patient and family or friends. An open discussion of fears and concerns of an uncertain illness trajectory may be helpful. This may help in determining whether the anxiety is a secondary response to the following: an organic factor, a primary psychiatric disorder, or reactive or situational-

related stress (Traeger et al., 2012). For children, a skilled assessment based on children's concerns and worries may help reveal both parent and child anxiety (Mullaney, 2011; Pao & Weiner, 2011).

## Physical Examination

A physical examination may reveal tachycardia, tachypnea, skin changes, tongue changes, rapid speech, restlessness, and tremors. Complete blood panels and metabolic screens can delineate imbalances. Further assessment includes ruling out associated conditions; for example, if the patient has tachycardia, a thyroid function panel can rule out hyperthyroidism or an electrocardiogram can rule out dysrhythmias. For patients feeling anxious, a glucose test can rule out hypoglycemia. If there is a sore tongue along with the anxiety, testing folate levels can rule out nutritional deficiencies. Pulmonary function tests and arterial blood gases can rule out hypoxia and pulmonary disease (Fournier, 2013a). Finally, there may be situations where drug toxicology screening is necessary to rule out for cocaine or amphetamine use.

## Assessment Tools

A tool for further assessing anxiety is the Anxiety Sensitivity Index (ASI). This is a 16-item self-report index in which responses are rated from 0 to 4. A mean score of 20 and below indicates no anxiety. A mean score in the 20s is common for those with GADs. A mean score of 35 and above indicates panic disorder (Reiss, Peterson, Gursky, & McNally, 1986). Another tool is the Hospital Anxiety and Depression Scale, which is a self-report measure of 10 questions (Emons, Sijtsma, & Pedersen, 2012). Other tools include the Visual Analog Scale or the Distress Inventory Scale (Sheldon, Swanson, Dolce, Marsh, & Summers, 2008).

For children, there are several tools to assess anxiety in well children; however, none have been tested in chronically ill or terminally ill children. Two self-report measures are the Spence Children's Anxiety Scale and the Screen for Child Anxiety Related Emotional Disorders. One interview that may help is the Anxiety Disorders International Schedule for Children (Kersun & Shemesh, 2007).

## Management

Treatment of anxiety is most successful when psychosocial and psychoeducational interventions are combined with pharmacological interventions (Blatt, 2012; Braun, Pirl, & Greenberg, 2010). Often a medication review may reveal substances that induce anxiety such as steroids or stimulants.

**TABLE 21.4 Mild to Severe Anxiety and Its Effects**

Mild	Awareness, alert attention for problem solving
Moderate	Perceptual field narrowed, decreased observation, and selective attention
Severe	Reduced perceptual field, scattered, escalated anxiety with inability to attend
Panic	Feelings of awe, dread, fear, panic; inability to focus; no perceptual field

Source: Adapted from Pasacrete et al., 2010.

**Pharmacological.** In a younger, healthier population, benzodiazepines are the drug of choice, along with possible tricyclic antidepressants (TCAs) and beta-adrenergic agents. However, in the geriatric population, benzodiazepines are the drug of choice with caution as tricyclics and beta-adrenergic agents are not well-tolerated. Even so, in the older adult, one should not use longer acting benzodiazepines as they may cause more confusion; use of shorter acting agents such as lorazepam, oxazepam, or temazepam may be more appropriate. Suggested doses are 0.25 to 5 mg TID of lorazepam or 10 to 15 mg TID of oxazepam. Selective serotonin reuptake inhibitors (SSRIs) may be worth a trial if benzodiazepines are not successful or for longer-term treatment. This could include fluoxetine 20 to 80 mg/day or sertraline 50 to 200 mg/day (Blatt, 2012). If insomnia is also an issue, temazepam 15 to 30 mg at bedtime may be helpful. Drug-induced anxiety may be caused by neuroleptic medications such as haloperidol. For patients with generalized anxiety and a history of substance abuse, buspirone may be useful. For patients with severe respiratory function, low-dose antihistamines may be helpful, as benzodiazepines may be too sedating and inhibit respiratory drive (Pasacreta et al., 2010). See Table 21.5 for drugs and dosages.

In children, benzodiazepines are the medication of choice. The short-acting agent lorazepam is helpful for procedures. Clonazepam or diazepam are helpful long-acting agents, although diazepam's half-life may affect other medications (Mullaney, 2011; Pao & Wiener, 2011). Dosing is based on weight (Mullaney, 2011; Pao & Wiener, 2011). Lorazepam is calculated at 0.025 mg/kg/24-hour dose with a maximum of 2 mg per dose. Diazepam is calculated at 0.01 to 0.02 mg/kg/24 hour with a maximum dose of about 10 mg/day. Clonazepam is 0.01/kg/24 hour.

**Nonpharmacological.** To manage anxiety, a range of psychosocial strategies are beneficial. It is helpful to work with the patients to allow them to acknowledge their fears and anxiety about their disease, treatment, symptoms, and future care. In particular, patients may have fears and concerns about dying and the dying process. Inquiring about such fears and addressing them in terms of future possible care plans are helpful to patients and families and provide them with the knowledge that the health care provider is proactive. Then interventions such as cognitive behavioral therapy, relaxation training, supportive counseling, or education may be helpful (Traeger et al., 2012). Providing structure and predictability can help to allay fears and can take place in the form of future appointments and symptom management (Bakitas, Dahlin, & Bishop, 2013).

TABLE 21.5 Medications to Treat Anxiety

Medication Class	Range
<b>Adults</b>	
<b>Benzodiazepines</b>	
Short acting:	
Lorazepam (Ativan)	0.25–5 mg tid-qid
Oxazepam (Serax)	10–15 mg tid-qid
Temazepam (Restoril)	15–30 mg at bedtime
<b>Neuroleptics</b>	
Haloperidol (Haldol)	0.5–2 mg q 2–12 hr
Olanzapine (Zyprexa, Zydys)	2.5–5 mg bid to tid
Chlorpromazine (Thorazine)	12.5–50 every 4–6 hr
<b>Antihistamines</b>	
Diphenhydramine (Benadryl)	25–75 mg bid
Hydroxyzine (Vistaril)	10–50 mg qid
<b>Azapirones</b>	
Buspirone (BuSpar)	5–20 mg tid
<b>Children</b>	
<b>Benzodiazepines</b>	
Lorazepam (Ativan) Maximum dose 2 mg per dose	Younger children, 0.025–0.05 mg/kg/dose every 4–6 hr
	Adolescents above 12 years: 1–2 mg every 8 hr
Diazepam (Valium)	Younger children: 0.08–0.12 mg/kg every 8–12 hr
	Adolescents above 12 years: 5 mg every 8 hr

Source: Adapted from Blatt, 2012; Mullaney, 2011; Pao & Wiener, 2011; Pasacreta et al., 2010.

Offering summary information about progress and future events is helpful to alleviate any surprises. Encouraging patient participation in care helps with a sense of control (Blatt, 2012). In severe anxiety and panic, medications are usually necessary; nonpharmacological or complementary therapy may help in mild to moderate anxiety.

There are other strategies for pediatric patients. Bibliotherapy, which is the use of literature and storytelling, allows children to tell their version of the situation. By using a book to stimulate thought or the



creation of a unique story, the child has assistance to review the situation, foster emotional responsiveness, discuss psychological reactions, and consider coping strategies (Pao & Wiener, 2011). Animal therapy is also quite effective in relieving stress as the animal reduces the threatening feelings by offering a social connection and unconditional love (Pao & Wiener, 2011).

Nonpharmacological treatment of anxiety includes modalities such as dietary intake, stress management, and psychotherapy. Nutritional assessment includes evaluating the diet for caffeine and alcohol (Blatt, 2012). Caffeine is an ingredient in tea, coffee, chocolate, and colas, as well as other products; sometimes, just decreasing the daily amount ingested is helpful. However, in many cases, the caffeine intake needs to be completely eliminated. If this is the case, weaning off the caffeine in a planned process helps avoid headache, nausea, and general malaise. High alcohol intake is common in anxious patients, although it does not actually help the anxiety, and it may worsen anxiety since it affects sleep and cognition. Alcohol may be commonly ingested as beer, wine, or hard liquors; alcohol may also be present in cough medicines. Reduction or elimination of alcohol intake may be helpful in the management of anxiety. Finally, nicotine may contribute to anxiety. Patients may desire smoking cessation programs or need smoking substitutes, such as nicotine patches and gums.

Stress management can include exercise programs, breathing exercises, relaxation techniques, massage, touch, distraction, music therapy, and visualization. Guided imagery and hypnosis may offer the patient more control (Plaskota et al., 2012). Some hospitals, health care systems, and even insurances offer exercise programs. Many Young Women's Christian Associations/Young Men's Christian Associations offer gentle exercise programs or special programs directed at keeping people of various ages healthy. Moreover, they offer discounts or subsidies for patients who need financial assistance. Shopping malls often offer patients the opportunity to walk in a safe, weather-friendly environment often at off hours to allow patients to avoid crowds. For patients in assisted living or skilled nursing facilities, physical therapists (PTs) can often help promote gentle exercise.

Massage therapy can be an effective method to help patients relax. However, as with any person, the patient must be assessed regarding his or her comfort of physical touch. Older adults may not have experience with formal massage and may be uncomfortable with such intimate touch. Often patients may receive modified massages from health care personnel in various settings, such as outpatient oncology settings, hospitals, skilled facilities, or day care centers.

Distraction occurs in many forms including having a television or radio to participating in arts and crafts, performing hobbies, and reading. It is

important to assess how the patient spends his or her time and what activities are distracting and helpful for him or her. Various volunteer organizations in the community can help with these sorts of activities. Music therapy has been shown to be effective in anxiety, as it can reduce pain, promote physical comfort, and induce relaxation (Horne-Thompson & Grocke, 2008).

Environmental manipulation may be very important, as patients are sometimes fearful of their living environment. PTs and occupational therapists (OTs) can assist with home-safety evaluations, social workers can assist with issues of personal safety. In the case of older adults, this may include situations of potential abuse and neglect, transportation, or nutrition. Helping the patient to maintain control of his or her daily schedule of activities may decrease anxiety. Too often, the patient loses control over the structure of his or her day, depending on his or her types of treatment. Facilitating the patients' ability to schedule when appointments, meals, and other activities occur can help them feel less anxious and out of control.

Psychotherapy may include counseling, spiritual care, and cognitive behavioral therapy. Counseling should include an acknowledgment of fears and specific conversations about fears. Spiritual care should focus on existential fears around death and dying (Borneman, 2012). Cognitive behavioral therapy focuses on restructuring the issues.

For children, stress and anxiety management may be developed into more structured programs. Children may need specially trained pediatric practitioners to assist with these areas. Nonetheless, anxiety can be managed with all sorts of therapy such as expressive therapy (art, music, and journaling), touch therapy, and talk therapy (Mullaney, 2011). Art and music therapy may promote a release in anxiety from tactile and intellectual stimulation. Other activities include sports, music, or, for younger children, play therapy activities with child life specialists. Adherence to routines and schedules helps reduce stress and normalize their illness. Of particular importance may be attendance at school and related activities since this plays a major role in the context of their daily routine and social networks (Mullaney, 2011). Parents may need to participate with the child so they may experience anxiety reduction together. This is important if the child reacts to the parent's anxiety.

## Dependent, Independent, and Collaborative Interventions

Treatment of anxiety for a patient with a life-threatening illness requires a collaborative approach by an interprofessional team. Specifically, the team needs to review the patient history and medications and then

determine symptom management together. Since treatment usually requires psychological support and medication management, clear delineation of roles should be clarified for the patient and his or her family. This provides consistent direction and support to the patient and family without provoking further anxiety. Usually a physician or an advanced practice nurse can diagnose and treat anxiety as well as provide medications and psychological support. A social worker can be quite effective in assessing the living conditions, the family dynamics that affect anxiety, as well as offering both counseling and stress management techniques. An OT or PT can assess in-home safety, and the pharmacist can examine a medication regimen for polypharmacy. A common observation for nurses working with patients is that they notice the anxiety can be easily absorbed. Therefore, anxious patients and families can make the nurse feel anxious or frustrated. Therefore, the nurse needs time and distance to dispense or relieve himself or herself of the anxiety of the patient and family.

### Family Concerns and Considerations

Education for the family and caregiver is important with regard to their understanding of anxiety and how it manifests itself. This enables early recognition and helps the patient utilize both medications and complementary strategies to manage symptoms. The patient and family should also understand that long-term use of medications to treat anxiety might be necessary. Moreover, these medications may cause some or all of the following side effects: daytime somnolence, confusion, unsteady stance or gait, paradoxical effects, memory disturbance, depression, withdrawal, abuse, dependence, and respiratory problems. Therefore, safety may be an issue, and how to prevent problems with medications should be discussed. The patient and family may need to discuss the risk–benefit ratio of interventions, particularly if medication side effects are debilitating and worse than the anxiety itself.

Medication information is imperative, as prescription medications as well as over-the-counter medications can cause anxiety. A careful review of each medication, its intent, and its dosage can help decrease confusion and help with compliance. A medication box prefilled by family or health care personnel with medications in the correct time slots can be tremendously helpful in ensuring correct medication dosage and timing. In addition, a patient or family member can keep a diary of medications, dosages, and time of administration. In creating medication schedules, it is best to work around previous rituals such as mealtime, and activities of daily living, with particular attention paid to sleep schedules.

Stress management techniques that can be utilized by both the patient and family should be offered. These interventions include promoting control for the older adults over their environment (e.g., simple planning of daily activities, toileting, mealtimes, and visiting times) and review of the symptoms including recognition, management, and prevention of anxiety. Encourage family or significant others to allow time for ventilation of feelings or concerns regarding their illness. Education is particularly important in terms of how to diffuse anxiety for the patient and suggestions for helpful behaviors or strategies that families can follow to de-escalate the patient's stress.

Care should be taken to simplify the day by not overbooking activities for the terminally ill patient. In addition, providing information to prepare the patient for any treatment, change in plans, or visitation by other medical personnel can greatly help decrease anxiety because the patient knows what to expect. Finally, all persons involved with the anxious patient need to be patient, speak calmly, and provide any direct care as gently as possible.

### ■ DEPRESSION

At the end of life, it is common for patients to experience psychological distress in response to their serious or life-threatening diagnosis. For many years, it was thought that grief and depression were normal coping mechanisms to accept a terminal illness (Block, 2000; Jacobsen, Zhang, Block, Maciejewski, & Prigerson, 2010); therefore, it was unnecessary to treat depression. The thought was that treatment would interfere with the natural dying process and the emotional work of dying. In fact, not treating depression may interfere with a patient's ability to bring closure to his or her end-of-life issues and concerns. Identifying depression in some patients is complicated by possible numerous comorbidities. These include cardiovascular conditions, neurological conditions, autoimmune diseases, endocrine disorders, and other conditions (Pasacreta et al., 2010). Specifically in cancer, depressive symptoms mimic those symptoms that caused the treatment including loss of appetite from chemotherapy, fatigue induced by the metabolic changes in cancer, and lack of sleep from compliance with continuous pain- and symptom-medication regimens (Breitbart et al., 2010).

Depression in children is complex to assess and manage due to the challenges of their developmental stage (APA, 2013). Moreover, they may exhibit more irritability and withdrawal due to the consequences of the illness. Their depression may often stem from the social issues such as being different from their friends and losing connection with their communities within and around school. It may also result from changes in the



routines of school and activities. Children may understand their illness through their continued repeated interactions within a health care system, rather than understanding the illness itself (Pao & Wiener, 2011). They may also pick up signals from their parents, so it is important to assess the family system (Pao & Wiener, 2011). However, no specific studies have been conducted on depression in dying children.

Depression in the older adult may be masked by the normal aging processes. Age-related changes include changes in the sleep–wake cycles, appetite, and the ability to continue previous pursuits in life conditions (Derby, 2012; Pasacreta et al., 2010). Specific to the elder patient, it is difficult to recognize depression secondary to the misperception that all elders become depressed as part of the aging process. Its features include changes in energy, sleep, and appetite, which are all common in the aging adult. Many older adults do not perceive they are depressed; they may also be of a generation that psychological problems were not discussed or admitted.

Further complicating the diagnosis and treatment of depression in the terminally ill adult or pediatric patient is inadequate health care provider knowledge regarding the treatment of depression (Pao & Wiener, 2011). A thorough assessment necessitates time to interview a patient more deeply than a cursory follow-up visit. Moreover, effective treatment and management require a time commitment that involves working on psychological issues, prescribing psychotropic agents, and monitoring the potential side effects of such agents. Under the time constraints of health care, the necessary time to perform a complete assessment may feel overwhelming to the novice clinician. Ageist attitudes on the part of the prescribing clinician can also affect treatment for older and younger patients.

Some clinicians express feelings of hopelessness around a life-limiting illness and feel depression cannot be well treated (Block, 2000). It is also still common that health care professionals, including nurses, believe that by asking about depression, they may add to the patient's psychological distress by further upsetting him or her. Furthermore, clinicians may feel unprepared and overwhelmed by the responsibility of caring for patients with life-threatening illnesses. Finally, there is the concern that once depression has been identified, it must be cured, rather than understand the complex interrelatedness of a life-threatening illness and its physical and psychosocial aspects.

## Definition

Depression is a mood disorder with both psychological (mood is low, inability to think or make decisions) and somatic symptoms (altered sleep, fatigue, slowed movements, decreased energy) that alter mood, affect,

and personality (APA, 2013). It is a compilation of signs and symptoms that are not usually a normal reaction to daily life occurrences. According to the *Diagnostic and Statistical Manual of Mental Disorders*, Fifth Edition (DSM-5 2013), it is defined as an episode of 2 weeks or longer where there is loss of interest or pleasure in nearly all activities (anhedonia). In addition, four or more symptoms are present from the following list: changes in appetite, sleep, weight, or psychomotor activity; decreased energy; feelings of worthlessness or guilt; difficulty thinking, concentrating, or making decisions; or recurrent thoughts of death, suicidal ideation, or attempts at such (APA, 2013). Depression can be persistent and last indefinitely if left untreated. Symptoms could include inconsistent memory or complaints of memory loss, increased speech latency, and an irritable affect (Cassano, Cassem, Papakostas, Fava, & Stern, 2010).

In the most recent DSM-5, the APA (2013) recognized a new aspect of depression, “*Depressive Disorder due to Another Medical Condition*,” which relates to the patient with a chronic, progressive, or serious life-threatening illness. This diagnosis is related to the circumstances of the direct pathophysiological consequences of a medical condition, it is not explained by a mental disorder, and it affects the social interaction of the patient (APA, 2013). This is helpful to consider for adults and children with chronic, progressive, or serious life-threatening illnesses or injuries in the context of life changes and adaptations resulting from these conditions that alter quality of life. The disease and treatment of side effects alone may result in many of the criteria in the depression profile (APA, 2013).

## Incidence

Depression is common in patients with cancer 10% to 25% of the time. This may increase with disease progression and particular types of cancer (e.g., pancreatic cancer; Breitbart et al., 2010). Depression is a major health problem and the most common psychiatric disorder secondary to the events that occur later in life (Kapo, Morrison, & Liao, 2007), but it may be overlooked and/or mistaken for dementia. Most studies on depression look at prevalence rather than incidence.

The incidence and prevalence of depression in children are less understood; there have been no large studies to evaluate these symptoms in children, since children have unique ways of coping depending on their age. More often than not, disruptions in routines, relationships, physical condition, and, for teenagers, loss of independence can be risk factors for depression, along with the adult reports of low self-esteem, guilt, hopelessness, and suicidal ideation (Kerson & Shemesh, 2007; Pao & Wiener, 2011).

## Etiology

The etiology of depression is multifactorial and falls into four categories: physical, psychological, social, and biological (Table 21.6). Physical factors encompass medical conditions, specific diseases, medication effects, and sensory deprivation from loss of vision or hearing. Many medical conditions can cause depression, including cardiovascular conditions such as congestive heart failure, myocardial infarction, and cardiac arrhythmias; neurological conditions such as cerebral vascular accidents, and cerebral anoxia; Huntington's, Parkinson's, and Alzheimer's diseases; HIV; dementia; epilepsy; multiple sclerosis; post-concussion periods; myasthenia gravis; narcolepsy; subarachnoid hemorrhage; autoimmune diseases such as rheumatoid arthritis or polyarteritis nodosa; endocrine disorders such as hypothyroidism, hyperparathyroidism, diabetes mellitus, folate deficiency, hypoadrenalism, Cushing's and Addison's diseases; and other conditions such as anemia, alcoholism, systemic lupus, Epstein Barr virus, hepatitis, malignancies, malnutrition, sexually transmitted diseases (STDs), and encephalitis. Medications that may generate depression include propranolol, reserpine, and metoclopramide (Pasacrete et al., 2010; Pollack et al., 2010). See Table 21.7 for a list of medical conditions associated with depression.

Psychological issues that may precipitate depression cover a wide spectrum including unresolved conflicts, memory loss, loss of independence, change in living situations, and possible financial consequences incurred from a life-limiting illness (Pasacrete et al., 2010). For children and adolescents, the loss of independence and the loss of school and related community can be difficult (Mullaney, 2011). Coping with the debilitating physical aspects of having a life-limiting illness may also cause depression. Pain and exhaustion often trigger depression in some patients. Other triggers include loss of routines and, more importantly, changes in body image. Older children may retreat from the embarrassment of disease and treatment-related change in their physical appearance (Mullaney, 2011).

Social issues include loss of family or friends, isolation, loss of job, and previous conflicted relationships (National Consensus Project, 2013). Even without dealing with terminal illness, older adults face loss as a consequence of the aging process. Close friends and family of similar age may predecease them; retirement results in multiple losses ranging from loss of social position as a working person, change in socioeconomic status, loss of friends and acquaintances, loss of routine, and a loss of purpose. Young children may have a loss of the school community including teachers, friends, sports, afterschool activities, and other social interactions.

**TABLE 21.6 Etiology of Depression for Adults and Children**

Category	Examples
Physical	Medical conditions including cardiac disease, cerebrovascular disease, autoimmune disease, and endocrine, liver, and renal failure; specific disease relationships; medication effects; symptom-related, such as pain or sleep disturbances; treatment effects, such as radiation sensory deprivation
Psychological	Memory loss, unresolved conflict, loss of independence, change in living situation, financial consequences from illness, poor coping and substance abuse
Social	Changes in body image, loss of independence, loss of family and friends, loss of community such as school-related activities, isolation, loss of employment, previous conflicted relationships
Biological	Family history, previous episodes of depression, neurotransmission deficiencies, central nervous effects of cytokine

Source: Adapted from Pasacrete et al., 2010.

**TABLE 21.7 Medical Conditions Associated With Depression**

Category/Basis	Examples
Endocrine disorders	Hypothyroidism, hyperparathyroidism, diabetes, Cushing's syndrome, Addison's syndrome
Cardiovascular conditions	Congestive heart failure, myocardial infarction, and cardiac arrhythmias
Neurological conditions	Cerebral vascular accident, anoxia, Huntington's disease, Alzheimer's disease, dementia, multiple sclerosis, postconcussion syndrome, myasthenia gravis, narcolepsy, subarachnoid hemorrhage
Immune disorders	HIV, rheumatoid arthritis, and polyarteritis nodosa
Cancer	Pancreatic, brain
Other	Pain, alcoholism, anemia, lupus

Source: Adapted from Derby, 2012; Fournier, 2013b; Pasacrete et al., 2010.



Biological factors of depression include family history of depression or other mental illness, prior episodes of depression, neurotransmission deficiencies, and central nervous effects of cytokines. It is postulated that depression may be caused by deficiencies in serotonin, norepinephrine, and prolactin, as well as abnormal cortisol and dopamine levels. Family history may increase the risk of depression by a factor of 1.5 to 3, and 50% of people with depression have recurrence. Other mental disorders may accompany depression, including somatoform disorders (Blatt, 2012).

## Cardinal Signs of Depression

There are several categories of depressive symptoms that include mood changes, vegetative signs, behavioral signs, and a person's perceptual disturbances of himself or herself, the environment, and the future. Depression may affect all aspects of a patient's life. This is because depression may play a role in other conditions, such as pain, confusion, agitation, anxiety, or irritability. Contrary to popular thought, depression is not a normal part of aging. Rather, the older adult may develop more physical symptoms rather than changes in emotional affect (Derby, 2012). For that reason alone, it is suggested that a clinician assess cognitive mood symptoms rather than neurovegetative symptoms (Breitbart et al., 2010).

Patients may present with a dysphoric mood or lack of pleasure. Other signs include poor personal hygiene and grooming; slow thought processes and speech; sadness, tearfulness, hopelessness, helplessness, worthlessness, and social withdrawal; changes in sleep patterns and appetite; fatigue; behavioral slowing; and complaints of diminished ability to think (Pasacrete et al., 2010). Signs of depression in children manifest as somatic complaints, periods of anger, and other behavior as well as sadness or melancholy (Pao & Wiener, 2011). For teenagers, it may be manifested by low self-esteem, guilt, and hopelessness (Pao & Wiener, 2011). Patients of all ages may express recurrent thoughts of worthlessness, excessive or inappropriate guilt, and a sense of being a burden (Derby, 2012; Pao & Wiener, 2011).

The elder with dementia manifests depression differently from the person whose cognitive function is intact. More peripheral symptoms in the elder with altered cognition, such as loss of interest and engagement with activities, isolation and social withdrawal, agitation, repetitive vocalization, apathy, insomnia, food refusal, or resisting care, may be present (Pattanayak & Sagar, 2011).

Depression in this population may lead to increased dependence in activities of daily living and decreased ability to engage in meaningful activities.

Most patients with a life-threatening illness fulfill several of the criteria for depression under *DSM-5* (APA, 2013). The challenge lies in differentiating depression from grief (Jacobsen et al., 2010). Grief is the normal response to a loss, injury, insult, illness deprivation, or disenfranchisement that is usually proportionate to the disruption caused by the loss (Jacobsen et al., 2010). To differentiate between grief and depression in the patient with a terminal illness, one must perform a more thorough interview that examines how the patient has coped with past crises to assess resiliency. Evaluation of the somatic distress the patient is experiencing includes hopelessness or helplessness, whether he or she still has the capacity for joy, and whether he or she looks to the future. If they still have joy and can look forward to the future with joy and the symptoms come in wavelike fashion, the patient probably has grief rather than depression (Block, 2000).

## Severity

Depression in its most severe form puts a person at a risk for suicide. The rate of suicide increases with age, with suicide being the third leading cause of death for older adults. One out of five suicides involves a person of 65 years or older (Stern, Cassem, Jellinek, & Rosenbaum). Suicidal behavior in the older adult differs from that of a younger person in that the elder is less likely to express suicidal ideation and more likely to utilize lethal methods. In children and teenagers, depression may be subtle.

In advanced illness, suicide has a higher incidence. Suicidal ideation should be considered a psychiatric emergency and assessed on an urgent basis. It is essential to assess for depression in any patient who verbalizes suicidal ideation because it plays a significant role. Lack of a previous suicide attempt may not be significant in assessing suicidal risk because the majority of older patients who commit suicide have no prior suicidal behaviors. Many elders who commit suicide have been found to have the most treatable types of depression; however, they have not received appropriate interventions (U.S. Preventive Services Task Force, 2009).

Risk for suicide in the general population includes prior psychiatric diagnosis including previous depression, family history of suicide, poor social support with isolation, delirium, fatigue, advanced illness with disfiguring disease or surgery, substance or alcohol abuse, poorly controlled pain, increasing age, and lack of control with hopelessness (Braun et al., 2010). There are no specific suicide assessments for children and teenagers, and they need to be screened as adults (Pao & Wiener, 2011). Therefore, assessment of the following areas is essential to the evaluation for suicide

potential: strong character; refusal of assistance—fear of becoming a burden on family; fear of dependence—fear of loss of control; fear of financial issues—cost of treatment and effect on siblings, retired or unemployed; unrelieved severe pain; poor functional status; poor health; poor/bad relationships with family; isolation from friends, school, and community; and previous psychiatric distress. Other factors include retirement, recent changes (such as a move), changes in health, history of poor interpersonal relationships, and a terminal diagnosis. For teenagers, the loss of social relationships with the school community, such as loss of relationships due to health care treatments, as well as an inability to attend school, activities, or sports, are of particular significance.

Once a patient has been identified as a suicide risk, this must be taken seriously. Using a nonjudgmental approach, the clinician must develop a rapport with the patient to evaluate the intent. This includes evaluating the presence of suicidal thoughts, details of a suicide plan, the seriousness of the intent, the risk ratio, the precipitants of such an intent, the patient's social supports, and the degree of the patient's impulsivity (APA, 2010). See Table 21.8 for a review of screening tools.

Suicidal ideation should be evaluated for its severity. There should be an examination of the suicide plan, specifically looking at the risk rescue ratio and the level of planning. Questions include the following:

- Do you find that death would come sooner rather than later?
- Have you thought about ending your life or killing yourself?
- Have you thought about what method you would use? (Blatt, 2012)

The patient's level of hopelessness should be examined. Further assessment of the possible precipitants should be determined as well as social supports. Specifically, a clinician should assess the history, determine the degree of intent, and the existence and quality of internal and external controls (Braun et al., 2010). This may include a safety assessment of the home to check for firearms, weapons, and alcohol. Finally, the issue of suicide ideation should be discussed with family and friends (Braun et al., 2010).

## Assessment

Assessment includes both cognitive and physical assessment. It is imperative that the palliative care clinician acknowledge the potential presence of depression in chronic progressive illness and life-threatening illness. Moreover, it is essential to screen

**TABLE 21.8 Depression Assessment Areas**

Areas of Psychosocial Assessment for the Patient	
Ability to engage in life	Boredom vs. inability to be active
Interest in world around them	Lack of interest vs. delight in shock, humor, etc.
Engagement in hobbies	Joy vs. lack of interest
Presence of anhedonia (capacity for pleasure)	Inability to anticipate anything with pleasure
View of life	Feelings of hopelessness vs. optimism and plans for the future
Self-worth	Worthfulness vs. worthlessness, any expressions of guilt or self-recrimination, expression of suicidal ideation

Source: Adapted from Block, 2000; Caplan et al., 2010.

**TABLE 21.9 Depression Scales**

Beck Depression Inventory
21-item questionnaires
Multiple choice
Scale of 11 or higher indicates depression 11–19: mild depression 20–30: moderate depression 31 or higher: severe depression
Geriatric Depression Scale
30-item scale
Yes/no format
Scale of 11 or more is positive for depression

for depression and evaluate risk factors, which include many of the aspects of disease progression. In particular, this includes past history of psychiatric disorders and substance abuse. Finally, the clinician should monitor for changes in life circumstances, function, medications, and comorbid conditions. In addition, a cultural assessment should be incorporated since there are racial, religious, and ethnic differences in the display of depression.

Assessment focuses on the cognitive process of the patient, including a mental status examination (Appendix 1). Other assessment areas are reviewed in Table 21.9 (Braun et al., 2010).



Assessment of depression in children is more complicated. The age and developmental level must be taken into account. Like adults, they may experience disease-related symptoms usually associated with depression such as fatigue, anorexia, insomnia, and agitation (Pao & Wiener, 2011). Parents are often experts on their child's behavior and may notice signs such as persistent sadness, tearfulness, irritability, withdrawal from previously enjoyed activities, changes in school performance or activity level, and general feelings of unwellness. In addition, parents must be evaluated for depression as this may affect the child patient as well (Pao & Wiener, 2011).

A thorough assessment of the patient includes laboratory tests to rule out other conditions. This may be appropriate if they do not present an undue burden on the patient and if there are plans to treat whatever deficiencies are found. Laboratory studies would include serum electrolytes to rule out dehydration; circulating blood count and hematocrit to rule out anemia; thyroid profile to rule out hypothyroidism; a venereal disease research laboratory (VDRL) screen to rule out an STD; vitamin B<sub>12</sub>/folate levels to rule out vitamin deficiencies; liver function tests (LFTs) to rule out liver failure; renal function tests to rule out renal failure; a urinalysis to rule out infections; and an EKG to rule out cardiac issues (Table 12.10 Dick, 2013).

Patients with preexisting neurovegetative conditions such as Alzheimer's disease or Parkinson's disease may be unable to respond to questioning; a cognitive assessment may be impossible or yield little helpful information. There is a high potential for depression in this population, which health care practitioners stress the importance of surveillance for behaviors that may indicate depression (U.S. National Library of Medicine, 2012). These behaviors include food refusal, angry affect, labile mood, agitation, repetitive movements, or increased withdrawal. Treatment of possible depression with medications serves as a diagnostic tool. The current standard is to initiate treatment and see if there is a response. Even without any outward clues to the presence of depression, medications may improve behavior and should be continued as long as the benefits outweigh the burdens of treatment.

Physical assessment includes general examination of the following areas: cardiopulmonary, gastrointestinal, genitourinary, and neurological. If pain develops, radiological studies and gastrointestinal studies are indicated to rule out fractures, ulcers, and neoplasms. Complaints of chest pain should be evaluated with an electrocardiogram, and noninvasive cardiovascular studies to rule out myocardial infarctions, congestive heart failure,

**TABLE 21.10** Types of Conditions and Treatment of Related Depression

Condition	Class of Medications
Cardiovascular disease	SSRIs: Sertraline, Paroxetine, Fluoxetine, Fluvoxamine, Citalopram
	Dopamine reuptake agents: Bupropion
	SNRIs: Venlafaxine
	5 HT antagonists: Nefazodone, Trazodone
Gastrointestinal disease	Tricyclics
	Dopamine reuptake agents: Bupropion
	5 HT antagonists: Nefazodone, Trazodone
Renal disease	Tricyclics
	SSRIs
	SNRIs: Venlafaxine
	Noradrenergic agonist: Mirtazapine
Hepatic disease	Tricyclics
	SSRIs
	SNRIs: Venlafaxine
	Noradrenergic agonist: Mirtazapine

Note: SSRIs, selective serotonin reuptake inhibitors; SNRIs, serotonin norepinephrine reuptake inhibitors.

Source: Adapted from Pasacrete et al., 2010.

and arrhythmias. Shortness of breath justifies chest films, pulmonary function test, pulse oximetry, and blood gases to rule out COPD, lung neoplasms, and other pulmonary conditions. The presence of constipation indicates occult blood test, barium enema, and thyroid function test to rule out neoplasms and ineffective thyroid. Neurological changes warrant an electroencephalogram with CT scan or MRI to rule out cerebrovascular accidents, tumors, or other brain conditions.

All too often, the symptom complaints of older adults are not taken seriously by their health care practitioners. The symptoms of depression can signal a medical condition, and a physical workup may be necessary to find the cause of problems. However, if the older adult is already known to have a terminal illness, the extent of a workup will depend on quality-of-life issues and how much a further workup would change an inevitable outcome. However, if a particular

diagnosis/condition is reversible and can have a positive effect on a patient, then at least a preliminary workup of depression may be appropriate. Evaluation of appropriate treatments need to occur on an individual basis where the health care team can examine the totality of the patient health condition and weigh the risks and benefits of workup and treatment.

## Assessment Tools

There are various depression assessment tools specific to screening for depression in the adult. However, there are no tools specific to children or teenagers. Two common screening tools are the Beck Depression Inventory (BDI) and the Geriatric Depression Scale (GDS). The BDI consists of 21 items with a 4-point scale, although there is a shorter 13-item version (Candilis, 1999). This self-report inventory investigates neurovegetative, cognitive, and mood symptoms. This scale is useful in examining psychological symptoms to develop a differential diagnosis of depression within its scoring of 10 (mild depression), 16 (mild to moderate depression), 20 (moderate to severe depression), and a score of 30 (severe depression; Candilis, 1999). The GDS (Appendix 2) was specifically developed for use with older adults. The long version is a 30-item questionnaire that has 30 questions and takes approximately 10 minutes. A score of 11 or more indicates depression. There is also a briefer 15-item geriatric depression screening scale in which the patient answers questions that are scored for specific answers (Yesavage et al., 1982). A new scale, known as the Terminally Ill Grief or Depression Scale (TIGDS), is a self-report measure that contains preparatory grief and depression subscales (Periyakoil et al., 2005). See Table 21.9 for a review of tools.

Often asking, “Are you depressed?” as suggested by Block (2000) will result in an honest assessment by an adult patient. However, this may not be as appropriate in the older adult population because there is a generational attitude of denying mental health issues. Many older people are not comfortable expressing emotions or directly answering a question. Rather than asking a single question, there is also a two-question screening assessment that includes the following questions: (a) Have you often been bothered by feeling down, depressed, or hopeless?; (b) Have you often been bothered by having little pleasure or interest in doing things? Another measure of depression is the mood of the health care provider after an encounter. If a health care provider feels down, hopeless, negative after an encounter, or has a desire to avoid the patient, there should be a high index of suspicion for depression and a rapid follow-up depression assessment (Lee, Back, Block, & Stewart, 2002). Of note, the U.S. Preventive Services Task Force (2009)

found little evidence to suggest one assessment tool was more effective than another. Instead, they state a simple assessment may be just as effective. They offer two simple screening questions that relate to mood and anhedonia. They are

1. “Over the past 2 weeks, have you felt down, depressed, or hopeless?”
2. Over the past 2 weeks, have you felt little interest or pleasure in doing things?”

Suicide assessment includes some specific questioning. One tool is the Suicidal Ideation Screening Questionnaire (SIS-Q), which is a four-item screening tool that examines sleep disturbances, mood disturbances, guilt, and hopelessness. A single positive response to a question correlates with 84% of patients with suicidal ideation and necessitates further assessment (Candilis, 1999).

The following questions have been offered within palliative care:

1. Often patients develop periods of feeling down; do you have any of those feelings?
2. Have you ever felt life is not worth living?
3. Have you thought about harming yourself? In what way?
4. Are you thinking about suicide or taking your own life?
5. Do you have a plan? What is it?
6. Have you ever attempted suicide?

Any question that receives a positive or “yes” answer warrants further questioning, assessment, and intervention with the patient and family.

## Management

Treatment of depression first includes management of pain and symptoms to ensure that optimal comfort is achieved since physical pain and discomfort in itself increases depression (Block, 2000). Some of the major pain and symptom areas include the use of medications: antiemetics for nausea and vomiting; narcotics for cancer pain, chest pain, and dyspnea; nonsteroidal medications for bone pain, arthritis-type pain, and various aches; and even low-dose antidepressant medications for nerve pain. In treating any one of these types of pain, the patient’s mood may improve. However, in this last category of treating nerve pain, the use of low-dose tricyclics may simultaneously treat the depression and the pain.

For the older adult who has altered metabolism, it is judicious to use the lowest dose of antidepressants possible. This dose range may particularly vary in elders who have had a stroke, Parkinson’s or



Alzheimer's, or other comorbidities and may need longer treatment. The underlying principle of medication management is to "start low and go slow." Practitioners should be careful not to stop therapy with a specific medication too soon because patients may need a longer time to respond or a higher dose of that medication.

For patients with a prognosis of 1 month or less, a psychostimulant, such as methylphenidate, may be very helpful. Psychostimulants typically work within 1 to 2 days. If the prognosis is longer than 1 month, one can start a psychostimulant to get an immediate effect and also start a longer-acting antidepressant medication (Candy, Jones, Williams, Tookman, & King, 2009). The effect a patient gets from the psychostimulant can help with predicting how he or she will respond to a longer-term medication; after a week on the psychostimulant, the dose can be decreased as the longer-acting antidepressant dose is increased (Candy et al., 2009).

Overall, there is no one antidepressant that is necessarily more effective than another (APA, 2010; Rayner, Price, Hotopf, & Higginson, 2011). Although the second-generation antidepressants seem to be better tolerated in the well population, it appears that mirtazapine, sertraline, and citalopram are better tolerated in terminally ill people (Li, Fitzgerald, & Rodin, 2012; Rayner et al., 2011; Watanabe et al., 2011). In elder patients, TCAs and SSRIs are roughly equivalent in efficacy (Derby, 2012). However, the older adult tends to tolerate SSRIs better than TCAs. Side effects of TCAs include sedation, confusion, orthostatic hypotension, cardiac arrhythmias, dry mouth, constipation, ataxia, and confusion (Blatt, 2012; Derby, 2012). SSRIs have fewer anticholinergic effects; other side effects of SSRIs include nausea, anorexia, diarrhea, and insomnia. Of note is that the use of herbal medications for treatment has shown no benefit over standard antidepressant therapy. More important is that these herbs (St. John's wort, kava, and valerian) may interfere with other medications and foods that may cause serious interactions (Blatt, 2012). See Table 21.11 for a review of medications used in treating depression.

There may be situations where electroconvulsive therapy (ECT) is warranted. These may include severe depression wherein antidepressant therapy has been unsuccessful. Or, it may include situations where there are psychotic features, severe suicidality (i.e., brain tumor with suicidality), severe malnutrition or dehydration in the setting of depression, catatonia, severe mania, or previous response to ECT (Blatt, 2012). The challenge is often whether the patient is ambulatory, has insurance, and has social supports.

The treatment of children is more complex. Use of nonpharmacological therapies is first, and then

medications. The use of antidepressants in children is not encouraged due to black box warnings from the Food and Drug Administration that they could lead to suicide or cause serotonin syndrome (Pao & Wiener, 2011). However, children are still prescribed SSRIs, serotonin noradrenaline reuptake inhibitors (SNRIs), and other medications with dosing considerations by height, weight, Tanner development, and severity of diagnosis. Citalopram and fluvoxamine have been used as well as TCAs. Although stimulants have been used in palliative adults and in children with attention deficit hyperactivity disorder, their use in the pediatric palliative patient has not been well studied. Therefore, it is necessary to collaborate with child psychiatry to help with medication use and psychotherapy in children with depression.

One of the challenges in treating terminally ill patients with severe depression and potential suicidality is the question of psychiatric hospitalization. This is a difficult decision, but necessary in extreme cases. Sometimes a patient may require hospitalization to manage depression and maximize quality of life. However, focused attention should be provided to the psychiatric unit to educate about symptoms seen at the end of life. Conversely, a patient may need to be on a medical floor with close psychiatric supervision to promote optimal management of other symptoms.

■ **Nonpharmacological.** In the last few years, it has been found that early intervention palliative care reduces depression and improves quality of life in cancer patients (Bakitas et al., 2009; Temel et al., 2010). This may be due to the interprofessional nature of palliative care. Current studies continue in other non-cancer conditions to see how early intervention palliative care affects depression and quality of life.

Generally, however, the mainstay of nonpharmacological interventions is psychotherapy. Psychological counseling may be even more important in older patients since they may not physically tolerate medications (Derby, 2012). The ability to express emotions and feelings may be a novel process to the older adult and may take some adjustment, but psychotherapy allows the reduction of emotional distress and attention to the individual's strengths and self-worth. Psychotherapy may focus on issues surrounding death and dying, including reminiscence and life review. In cognitive therapy, clinicians can help patients set realistic goals, provide compassionate listening, and validate the patients' feelings. In behavior therapy, clinicians can help patients develop structure for their day and activities (Pasacrete et al., 2010). This may allow a sense of making amends, identify accomplishments, improve interactions, and reduce fears of death. Cognitive therapy focuses on reframing and restructuring events.

TABLE 21.11 Medications to Treat Depression in Terminally Ill Patients

Adults		
Medication	Starting Dose	Daily Dose
Psychostimulants		
Dextroamphetamine	2.5–5 mg	10–20 mg 8 a.m./noon
Methylphenidate	2.5–5 mg	5–10 mg 8 a.m./noon
SSRIs with fewer side effects		
Citalopram	10 mg q am	10–40 mg
Sertraline	12.5–25 mg	50–100 mg
Fluoxetine	5–10 mg	20–40 mg
Paroxetine	5–10 mg	20–40 mg
Nefazodone		100–500 mg
Fluvoxamine		50–300 mg
SNRIs		
Venlafaxine	37.5 mg	37.5–225 mg
Tricyclics		
Amitriptyline	25–50 mg	25–125 mg
Imipramine	25–50 mg	25–125 mg
Desipramine	25–50 mg	25–125 mg
Nortriptyline	25–50 mg	25–125 mg
Bupropion		200–450 mg
Children		
Methylphenidate		0.1 mg/kg twice a day—may need to give in afternoons to teens who want to stay up late
Antidepressants		SSRIs—but should consult child psychiatry

Note: SSRIs, selective serotonin reuptake inhibitors; SNRIs, serotonin noradrenaline reuptake inhibitors.

Source: Compiled from Blatt, 2012; Candy et al., 2009; Pao & Wiener, 2011; Pasacreta et al., 2010.

Music and movement therapy may be helpful in stimulating interaction, providing sensory input, and increasing circulation. Other therapies may include pet therapy, group activities, and sensory stimulation. Music therapy allows a person to access his or her inner feelings because music can tap into emotions that words are unable to access (Maratos, Gold, Wang, & Crawford, 2008). Pet therapy enhances self-worth and fulfills a need to love and be loved in a safe environment while allowing tactile stimulation. Group activities and sensory stimulation increase contact and response to surroundings, stimulate thought and communication, and encourage interaction with other people.

### Dependent, Independent, and Collaborative Interventions

Interprofessional team members may interact with the patient in different ways due to their different functions. In staff conferences, vulnerable patients with a predisposition to depression can be identified. Reviewing specific patients in these team meetings can reveal subtle behavior changes that may indicate depression. Sometimes, certain behaviors alone may be difficult to evaluate, but discussing them in a more three-dimensional perspective may identify problems.



The effective management of depression requires a team approach. Physicians and advanced practice nurses may prescribe antidepressant medications. The social worker can provide counseling and assessment of social supports. In particular, the family caregiver should be assessed for stress and finances should be reviewed for potential burden. The chaplain can provide spiritual support (Borneman, 2012), volunteers can add to the web of social support, and rehabilitation therapists can help people function. Seeing the patient across the continuum and working within a collaborative approach may increase response to treatment.

### Family Concerns and Considerations

Education is very important in depression. Families should understand that depression is neither a necessity of life nor a sign of weakness or failure, but rather it is a medical illness. Families should receive information on the factors that make patients vulnerable (e.g., multiple health problems, untreated pain, discomfort, and multiple losses). A review of depressive symptoms can help the family to recognize depression and may help the patient, particularly the older adult, receive treatment sooner or alleviate suffering. In patients with severe depression, clinicians can assist the family in reviewing patient safety issues for potential suicide including access to weapons, leftover medications, ability to drive, using machinery, and extreme isolation.

Medical information is paramount. The patient and the family should understand that concurrent use of medications may cause depression or interfere with response to antidepressant medications. Discussion of treatment options comprises of discussion of side effects of medication: blurred vision, constipation, dry mouth, urinary retention, excessive perspiration, orthostatic hypotension, fatigue, weakness, drowsiness, tremors, twitching, and hallucinations. Family should understand these side effects further depress affect. With regard to medications and dosages, the family needs to understand that in the older adult population, lower medication doses are prescribed because of slower metabolism. The patient and family need to be reminded that it takes several weeks before the full effect of the medication is reached and may need encouragement to continue the medication for at least 6 weeks to receive the maximal effect of the medication. Medication education should also include continuing the medication when the patient feels better and thinks he or she can stop the medications.

Most important, the patient and his or her family should be reassured that the symptoms of depression are effectively treated the majority of the time. They should be reassured that the patient will not be

abandoned, and that a thoughtful treatment plan will be developed to improve quality of life. In the interim, education about severe depression should include information about support and obtaining emergency care if the depression worsens.

### ■ DELIRIUM

Delirium is defined as an acute disturbance of consciousness that affects cognition, arousal, and attention. It is also described as a confusional state resulting from a more global impairment in mental function and may also be referred to as confusion or agitation. This inconsistency in terminology makes management difficult. Alterations in thought processes are very common during the last weeks of life. Historically, this confusion was thought to be a normal part of the dying process and one of the stages of dying. Now it is recognized as a distressing symptom. It includes behaviors such as thrashing, agitation, muscle twitching, tossing or turning, moaning, and talking to the air; it also includes lethargy and listlessness in quiet forms.

Delirium should be considered an emergency situation. In the elder population, delirium may be associated with higher mortality rates, longer hospital admissions, increased costs of care, greater likelihood of being placed outside the home posthospitalization, and decreased functional ability (Breitbart & Alici, 2012). Moreover, patients may be terrified of fluctuating cognitive deficits, hallucinations, misperceptions, paranoid and psychomotor agitation, and changes in sleep–wake cycles (Breitbart et al., 2010). Families may become distressed by both the unusual behaviors and the sadness they feel from the premature loss of their loved one. If confusion is extreme, families may experience subsequent guilt or sadness at the necessity for physical or chemical restraint for fall prevention and safety. Delirium interferes with patient comfort and causes distress for family members. State of the art palliative care includes aggressive management and treatment of this symptom, promoting quality of life for patients at the end of their lives.

### Definition

According to the APA (2013), delirium is an alteration in attention that includes reduced ability to sustain, direct, focus, or shift attention and diminished awareness or orientation to environment. The key elements that determine delirium include changes in mental status in a short time, alternations in attention or consciousness, changes in cognition or memory, and a change in cognition from a direct physiological

consequence of a medical condition (APA, 2013). This disturbance cannot be better accounted for by a preexisting or evolving dementia.

## Incidence

Estimates of delirium range from 20% to 75% in cancer patients and up to 90% of all terminally ill patients (Breitbart et al., 2010). This symptom occurs frequently during perideath, particularly in the last days or hours. In elderly hospitalized patients, delirium is very common and its treatment adds costly hospital days.

## Etiology

The precise pathophysiology of delirium is not well understood. However, it is thought to involve neurotransmitters in the cortical and subcortical areas of the brain. These potential neurotransmitters, including increased dopamine, serotonin, gamma aminobutyric acid (GABA), beta-endorphins, and acetylcholine, are thought to play the most important roles (Braun et al., 2010; Breitbart & Alici, 2012; Goldsmith et al., 2011).

The etiology of delirium is multifactorial and includes medications, polypharmacy, brain metastases or other conditions, hypoxia, sepsis, hypercalcemia, hepatic and renal dysfunction, electrolyte imbalances, bowel obstruction, urinary tract infection, past psychiatric history, and medication withdrawal. Possible medications contributing to delirium include opioids, TCAs, diphenhydramine, antihistamines, H<sub>2</sub> blockers, analgesics, sedatives, and cardiovascular drugs (Derby, 2012).

Brain involvement may be secondary to metastases, primary cerebral disease, cancer, or cardiovascular accident. Systemic causes include organ failure, metabolic disturbances, infection, and toxic effects of substances (Breitbart & Alici, 2012; Caplan et al., 2010). In pediatric patients, infection appears to be a higher source of etiology than pharmaceutical agents (Goldsmith et al., 2011). Other factors specific to the older adult include preexisting dementia, a fracture, systemic infections, malnutrition, addition of three or more medications, simultaneous use of neuroleptics and narcotics, use of restraints, bladder catheters and iatrogenic events, and overall susceptibility due to lack of resilience (Derby, 2012). See Table 21.12 for a summary of conditions that cause delirium.

**TABLE 21.12 Causes of Delirium**

Category/Basis	Examples
Disease process	Primary brain tumor or secondary brain metastasis
Side effects of treatment	Chemotherapy, radiation to the brain
Pain and symptom medications	Corticosteroids, opioids, tricyclic antidepressants, H <sub>2</sub> blockers: cimetidine, ranitidine, anticholinergics, antiemetics—thioridazine, amitriptyline, diphenhydramine, over-the-counter antihistamines, benzodiazepines, sedatives: triazolam, acyclovir, cardiovascular drugs: digitalis, nifedipine, quinidine, beta-blockers
Medication withdrawal	Opioids, benzodiazepines, alcohol
Pain	Uncontrolled pain syndrome, urinary retention, constipation/impaction, obstruction
Metabolic fluctuations	Glucose-hypoglycemia, sodium-hyponatremia, potassium, calcium
Organ failure	Brain: stroke, seizure, cerebrovascular accidents Kidney: uremia Lungs: hypoxia Heart: hypoxia, CO <sub>2</sub> retention, MI, thyroid or adrenal gland
Infection	CNS: meningitis Urinary tract: urinary tract infection Respiratory tract: pneumonia, generalized sepsis, steroid-induced immunocompromise
Nutritional deficiencies	Thiamine, vitamin B <sub>12</sub> /folate
Miscellaneous	Sleep deprivation, urinary retention, sensory deprivation, change in environment, immobilization
Past psychiatric history	Depression

Source: Compiled from Blatt, 2012; Derby, 2012; Dick, 2013.



## Cardinal Signs

Delirium is a syndrome with many manifestations. Primarily, there are perceptual disturbances, which include misperceptions, illusions, and hallucinations. The cardinal signs of delirium include an acute onset, fluctuating course, presence of underlying organic cause, reduced sensorium, attention deficit, and cognitive or perceptual disturbances. Specific symptoms include insomnia during the night and somnolence during the day, nightmares, restlessness, hypersensitivity to light or noise, and emotional lability. Typical early signs of delirium include sundowning, withdrawal, irritability, new forgetfulness or befuddlement, and new onset of incontinence. Later signs include outbursts of anger, hostility, or abusive behavior. Confusion, agitation, or restlessness is usually worse at night and when a patient becomes disoriented to person, place, date, and time.

Either increased activity (hyperactive delirium) or passivity (hypoactive delirium) may delineate delirium. Hyperactive delirium or agitated delirium is characterized by agitation and hallucinations and the delirium or confusion is readily apparent and more easily recognized. Hypoactive delirium often goes unrecognized because the patient may be quiet and lethargic and may be mistaken for sedation from opioids, an obtunded state in the last days of life, or desired comfort, especially if symptom management has been difficult (Caplan et al., 2010). There may also be times when a patient experiences a mixed delirium, which means the patient alternates between a hypoactive and a hyperactive state.

## Severity

Delirium usually becomes more severe in the hyperactive form. If a patient becomes more agitated and delusional, then he or she may become a safety risk (e.g., falls). Behaviors can be aggressive, combative, or physically threatening, resulting in a tendency to place the patient in physical restraints to keep the patient from injuring himself or herself. However, it is best to avoid restraints because this can further exacerbate the problem if the patient were to fall. Physical restraints can cause further agitation because the patient cannot move and feels frustrated by this. Delirium is serious due to its symptoms such as delusions, hallucinations, confusion, and a risk of suicide. Restraints can further these symptoms.

The result of hypoactive delirium may be premature death. If pain and symptoms have been difficult to manage, the hypoactive patient will look sedated. The health care team may feel they have finally managed the symptoms because the patient is very quiet. In particular, the patient may be lethargic and unable to

communicate his or her confusion. Medications will continue and the vital functioning will be depressed; the result is premature death by weeks to months (Breitbart & Alici, 2012).

## Assessment

Evaluation of delirium includes several components: history, cognitive assessment, physical exam, and laboratory studies. As it can be confused with dementia or depression, the first step in diagnosing delirium is its identification. Challenges of assessment include absence of uniform classification (as seen by its several names), lack of knowledge regarding early signs, staff tolerance of confused behavior, and the assumption that, with age, most people inevitably become confused (Caplan et al., 2010). Caregivers and family may offer keen insight on subtle changes.

The APA (2013) *DSM-5* defining characteristics of delirium includes disturbance in consciousness with impaired ability to focus or shift attention; changes in cognition or the development of perceptual disturbance that is not better accounted for by a preexisting established or evolving dementia; the disturbance fluctuates over a short period of time; and evidence from the history, physical exam, or lab findings that the disturbance is caused by psychological consequences of a general medical condition. Diagnostic studies should be ordered if they are likely to change patient management (Bakitas et al., 2013). Other assessment tools to screen for delirium include the Delirium Rating Scale (DRS) and the Confusion Assessment Measure.

Assessment should first include a history and review of current medical conditions including disease side effects, such as a tumor; side effects of treatment, such as chemotherapy or radiation to the head; medications used to treat symptoms as well as corticosteroids, opioids, cimetidine, anticholinergics, antiemetics, benzodiazepines, and acyclovir; withdrawal of medications such as opioids, benzodiazepines, or alcohol; discomfort from uncontrolled pain, urinary retention, fecal impaction; metabolic fluctuations in glucose, sodium, potassium, or calcium; organ failure including the kidneys, liver, lungs, heart, brain, thyroid, or adrenal glands; infections of CNS, urinary tract, respiratory tract, generalized sepsis; and finally nutritional deficiencies from thiamine or folate/vitamin B<sub>12</sub> (Breitbart & Alici, 2012; Table 21.12). This is followed by a review of the patient's behavior and sleep cycles from the chart, followed by a review of the medication regimen.

A critical element of assessment includes the evaluation of mental status to develop a multidimensional clinical picture, functional performance status, and signs/symptoms. A mental status exam provides a

baseline for monitoring the course of cognition and is a source of documentation for reference and repeat evaluations. The key aspects of mental status assessment include general state and appearance, orientation, state of consciousness, short- and long-term memory, language, visuospatial functions, cognitive/executive functions (calculations, abstraction, spelling), insight and judgment, thought control, and mood and affect (Caplan et al., 2010; Folstein, Folstein, & McHugh, 1975; Nasreddine et al., 2005).

Physical exam is important to rule out possible treatable causes. Vital signs can give information regarding infection, hypoxemia, and hypoglycemia. Integument inspection may reveal sepsis or cardiac failure from

cold, clammy skin, or hot red skin from anticholinergic reactions. The head, eye, ears, neck, and throat exam may reveal signs of scleral icterus from liver failure, constricted pupils from opioids, or dilated pupils from anticholinergic toxicity. The oral exam reveals nutritional deficiencies, and the chest examinations check for rales of heart failure or dullness from pneumonia. The abdominal exam may reveal urinary retention, fecal slowing, extremities, Trousseau's sign, thiamine, and liver failure (Fournier, 2013b). Helpful lab data may include glucose level, electrolytes, bilirubin, lactate dehydrogenase, LFTs, urine culture, and oxygen saturation level. See Table 21.13 for a review of important elements to the physical exam for workup of delirium.

**TABLE 21.13** Physical Examination for Delirium

General	Skin	Cold clammy: cardiac failure, sepsis, hypoglycemia, hypocalcemia Warm, hot, red: anticholinergic
HE ENT	Head	
	Face	Chvostek's sign—hypocalcemia
	Eyes	
	Papilledema	Intracranial pressure
	Sclera	Icterus—liver failure
	Pupils	Constricted—opioid toxicity Dilated—anticholinergic toxicity
	Ears	
	Nose	
	Throat	
	Mouth	Smooth, shiny tongue—folate deficiency
Chest	Lungs	Rales—heart failure, dullness—pneumonia
Cor	S1 gallop	Heart failure
Abdominal	Palpable feces	Constipation or impaction, palpable bladder, urinary retention
Extremity	Trousseau's sign	Hypocalcemia
	Tender, swollen calves	Thiamine deficiency
	Asterixis	Liver failure
Neuro	Mental status examination	Evaluation of cognitive functioning
	Hemiplegia/hemiparesis	Stroke
	Proximal myopathy	Corticosteroid toxicity
	Ataxia, loss of vibration sense	Thiamine or vitamin B <sub>12</sub> deficiency
	Loss of position sense	

Note: ENT, ear, nose, and throat.

Source: Compiled from Fournier, 2013; Heidrich & English, 2010.



## Assessment Tools

There are several examinations available to assess mental status. In any mental status examination, several areas must be assessed: presentation, attention, visuospatial/executive function orientation, memory recall, calculation, abstraction, and language (Nasreddine et al., 2005). Until recently, the most frequently used was the Mini-Mental Status Examination (MMSE; Folstein, Folstein, & McHugh, 1975). The MMSE is a brief tool that measures cognitive impairment, specifically examining immediate memory, short-term memory, aphasia, apraxia, agnosia, and construction ability, along with concentration and spatial ability. The 30-item exam only requires approximately 10 minutes to complete. Out of possible 30 points, scores below 20 indicate possible organic brain disorders; a score of 23 is sensitive to thought disorders and mood (Candilis, 1999). However, a new tool called the Montreal Cognitive Assessment (MoCA), a one-page 30-item test that is administered by a clinician, is free to use as long as credit is given. It measures the areas of cognitive function and is available in many languages ([www.moca-test.org/pdf\\_files/test/MoCA-Test-English\\_7\\_1.pdf](http://www.moca-test.org/pdf_files/test/MoCA-Test-English_7_1.pdf)).

There are three delirium assessment tools used specifically for patients with life-limiting illnesses. All have been used with the older adult and are outlined in Table 21.14. These are the Confusion Assessment Method Diagnostic Algorithm (CAM), the DRS, and the Memorial Delirium Assessment Scale (MDAS). The CAM and the DRS have pediatric versions (Goldsmith et al., 2011).

The CAM assesses nine domains of cognitive functioning: acute changes in mental status with fluctuating course including inattention (e.g., digit span, months backward), or observation; disorganized thinking (e.g., rambling, incoherent speech); and altered level of consciousness (e.g., sleepy, stuporous, hypervigilant); disorientation (e.g., not cognizant of location or time); memory impairment (e.g., inability to remember events or instructions); perceptual disturbances (e.g., hallucinations or illusions); psychomotor agitation or retardation (e.g., restlessness or sluggishness); altered sleep-wake cycle (e.g., excessive daytime sleepiness with insomnia at night). The presence of at least the first three elements suggests a diagnosis of delirium.

The DRS (Appendix 3) is a 10-item structured interview, with each answer rated on a 0 to 3 scale. It is the most widely used assessment of delirium with the longest history of use in the psychiatric setting. It measures mood, onset of perceptual disturbances (including hallucinations and delusions), and behavior (Heidrich & English, 2010). The MDAS (Appendix 4) is a 10-item assessment tool measuring

**TABLE 21.14 Delirium Assessment Scales**

<b>Delirium Rating Scale (DRS)</b>
10-item scale
4-point clinician rated scale
Assesses:
Temporal onset
Perceptual disturbance
Delusions
Psychomotor activity
Cognitive status
Sleep-wake disturbance
Mood lability
Symptom variability
Score of 12 or above from range of 0–32 indicates presence of delirium
<b>Memorial Delirium Assessment Scale (MDAS)</b>
10-item scale
4-point clinician rated scale
Assesses:
Disturbance in arousal
Level of consciousness
Cognitive functions
Psychomotor activity
Score of 13 or above from range of 0–30 indicates presence of delirium
<b>Diagnostic Instruments</b>
<b>Confusion Assessment Method (CAM)</b>
10-item scale
Clinician rated scale
Assesses nine domains from <i>DSM-III r</i>
Level of consciousness
Thought clarity
Perceptual disturbances
Psychomotor activity
Presence of first three of four items indicates presence of delirium

Source: Compiled from Derby, 2012; Dick, 2013; Heidrich & English, 2010.

awareness and cognitive impairment with attention to memory, and psychomotor responses. Each response is rated from 0 to 3; a score of 13 or higher is diagnostic of delirium (Breitbart & Strout, 2000).

## Management

To treat the delirium, it is first necessary to establish the goals of care. Specifically, it must be determined if (a) the patient is close to death, and (b) whether the delirium is reversible. A stepwise approach is taken regarding treatment. Predisposing, precipitating, and environmental factors should be determined (Goldsmith et al., 2011). Predisposing factors of visual and audio impairments should be attended to with glasses and hearing aids. Postsurgical considerations should be evaluated. The precipitating factors of constipation and urinary retention should be assessed and treated. An infectious process should be ruled out as well as metabolic imbalances.

The medication review is imperative. The clinician should initiate the discontinuation of problematic medications one by one to determine the causative agent. If complete discontinuation of the offending medication is not appropriate, then decreasing the dose may be helpful. Some patients may be sensitive to medications needed for pain and symptom management; therefore, discussion is critical regarding the benefits and burdens of pain and symptom management. Alcohol or benzodiazepine withdrawal should be considered.

Any treatments (respiratory care, wound care, or medications) should be provided with promotion of appropriate pacing and time to promote rest and sleep. Metabolic fluctuations should be corrected, including hydration (if appropriate), within the patient's entire clinical picture. Lastly, it may be appropriate to do further workup with particular importance to discern delirium from dementia or possible depression. Table 21.15 compares the differences between depression, delirium, and dementia.

**TABLE 21.15** Comparison of Depression, Delirium, and Dementia

	Depression	Delirium	Dementia
Onset	Coincides without major life changes	Acute/abrupt	Insidious—chronic
Course	Diurnal effects—worse in a.m.; usually situational fluctuations	Short diurnal fluctuations worse at night	Long—no diurnal effects Progressive
Progression	Variable—rapid or slow	Slow—uneven	Abrupt
Duration	Persistent—at least 2 wk	Days to hours—less than 1 mo	Months to years
Awareness	Clear	Clear	Reduced
Alertness	Normal	Fluctuates	Generally normal
Attention	Minimal impairment	Impaired	Generally normal
Orientation	Selective orientation	Generally impaired	Possibly impaired
Memory	Selective or patchy impairment	Recent and immediate impairment	Recent memory worse, remote impairment
Thinking	Intact without hopelessness, helplessness	Disorganized, distorted, fragmented, incoherent	Difficulty without abstraction, word finding
Perception	Intact except severe cases	Distorted, illusions, hallucinations	Misperceptions, usually absent
Psychomotor behavior	Variable—retardation or agitation	Variable—hypokinetic or hyperkinetic	Normal with apraxia
Sleep–wake cycle	Disturbed early A.M. waking	Cycle reversed	Fragmented
Affect	Depressed/irritable	Labile mood swings	Variable
Family history	May be positive	Noncontributory	May be positive for dementia of Alzheimer type

Source: Compiled from Derby, 2012; Heidrich & English, 2010; Kazer, 2011; Pasacreta et al., 2010.



In palliative care, the treatment of delirium must first consider the prognosis, the goals of care, and etiology. Then the clinician must determine whether it is a hypoactive or hyperactive delirium. If the delirium is hypoactive, then reversible causes should be ruled out. Assessment includes evaluating for causative factors, abnormal lab exams, metastatic processes, sepsis, and opioid review. Hydration and an opioid rotation may be necessary. Reassessment should occur to determine if the delirium is reversible. If the delirium is hyperactive, then the patient is started on haloperidol. If delirium continues in spite of high doses of haloperidol, then the patient could receive a trial of methotrimeprazine. If this medication has no effect, a benzodiazepine drip may be appropriate. Midazolam, diazepam, or lorazepam may be appropriate. Throughout the treatment of delirium, counseling and education is offered to the patient, his or her family, and support staff, with continual reassessment focusing on determining any other causes of the delirium.

■ **Pharmacological Interventions.** Pharmacological interventions will depend upon the suspected etiology. For undetermined causes, neuroleptics are the drug of choice. Haloperidol (a potent dopamine blocker) and Olanzapine are the preferred medications (Blatt, 2012). Haloperidol is safely used in children (Goldsmith et al., 2011). The initial adult dose of haloperidol is 1 mg three times a day and the dose of olanzapine is 2.5 to 5 mg two to three times a day. In children, depending on age and weight, dosing is 0.1 to 0.4 mg/kg. Historically, chlorpromazine has been used, but it is much more sedating. Benzodiazepines may be helpful, but caution should be used as they may not be tolerated in older adults. Short-acting ones are better tolerated, making lorazepam the preferred drug. Doses can range from 0.5 to 1 mg every 4 hours. For brain metastases, a trial of steroids may help. The dose of dexamethasone ranges from 16 to 36 mg, every morning. Patients who had Parkinson's disease may receive relief from risperidone.

If delirium is intractable, further action is necessary. The clinician should consult pain service, psychiatry, and other disease specific specialists to ensure there are no further options. If the treatment is successful, palliative sedation may be necessary. Palliative sedation is the use of nonopioids to place patients in an unconscious state. It necessitates team collaboration and discussion and an ethics consult. Patients, as appropriate, and families will need discussion of the benefits and burdens of treatment to obtain informed consent. There are a variety of agents used for palliative sedation in the patient with terminal delirium. Table 21.16 offers suggestions for medications and dosages in the treatment of delirium.

TABLE 21.16 Treatment of Delirium

Adults	Oral Dose
<b>Neuroleptics</b>	
Haloperidol	0.5–5 mg every 2–12 hr
Thioridazine	10–75 mg every 4–8 hr
Chlorpromazine	12.5–50 mg every 4–12 hr
Methotrimeprazine	12.5–50 mg every 4–8 hr
Olanzapine	2.5–5 mg every 8–12 hr
<b>Benzodiazepines</b>	
Lorazepam	0.5–2.0 mg every 1–4 hr
Midazolam	1.0–4.0 mg every 1–4 hr
<b>Anesthetics</b>	
Propofol	10 mg bolus with 10–20 mg/hr
Children	Oral Dose
<b>Benzodiazepines</b>	
Midazolam	0.2–0.75 mg/kg every 6 hr
Lorazepam	0.025–0.05 mg/kg up to 2 mg every 4–6 hr, adolescents above 12 yr: 1–2 mg every 8 hr
Diazepam	0.12–0.8 mg/kg every 6–12 hr, adolescent older than 12 yr: 5 mg q 8 hr
<b>Neuroleptics</b>	
Haloperidol	0.01–0.03 mg/kg up to 6 mg/day every 8 hr
Olanzapine	1.25 mg–2.5 per day
Thioridazine	0.5–3 mg/kg every 8–12 hr
Chlorpromazine	0.5–1 mg/kg every 4–6 hr
Risperidone	0.0125–0.25 mg/kg every 6–12 hr
<b>Barbiturates</b>	
Phenobarbital	2 mg/kg q 8 hr

Source: Heidrich & English, 2010; Mullaney, 2011; Pao & Wiener, 2011.

■ **Nonpharmacological.** Nonpharmacological treatments focus on the management of the environment, which includes creating a safe environment, reducing stimuli, and providing reassurance. A basic, but often ignored, intervention is to make sure patients have access to their hearing aids and vision correcting glasses. Other strategies focus on the patient's

room and climate, such as soft lighting that does not cause harsh images or shadows to prevent misinterpretation of the environment that can result in hallucinations. Cognitive devices (e.g., calendars or clocks) can cue orientation to time and date. Familiar sounds, smells, and touch may help promote calmness. Personal effects (e.g., lotions, perfumes, foods), as well as family and friends, can provide reorientation and reassurance.

Consistent nurses caring for the patient may also be of benefit. To avoid using restraints, family or health care providers may need to provide “sitters.” Confused patients may unintentionally harm themselves by trying to undo restraints or slipping out of bed. Sitters can help with reorientation, respond to the patient’s fear, and watch the patient to prevent falls. However, they may need to be reassured and coached about how much interaction to have with the patient, if interaction stimulates agitation.

Sleep deprivation may cause further confusion; therefore, the elimination of both visual and sensory stimuli is paramount. Scheduling medications without constant interruption of sleep during the night can decrease sleep loss. Reduction and elimination of noise pollution such as radios, television, or overhead announcements can also increase rest and promote sleep. Indeed, it may be appropriate to close the patient’s door to induce a restful environment. Good nursing care such as gentle massage and warm drinks can promote sleep.

## Family Concerns and Considerations

Education of the family is a cornerstone of management of the prevention and treatment of delirium. Families need to understand predisposing risk factors that can lead to delirium including pressure sores, poor nutrition, incontinence, sleep disturbances, and decreased functional ability including vision and hearing (Breitbart & Alici, 2012). Other preventive measures include the use of cognitive assistive devices such as glasses and hearing aids, avoiding restraints for confusion, judicious use of urinary catheters, removal of unnecessary tubes, prevention of skin ulcers, and maximal psychosocial support and education to family caregivers. Assessment of the home environment can be quite revealing, particularly whether the patient has the basic necessities such as food, finances, and medications. Family should be educated regarding the importance of skin care, the use of glasses, hearing aids, and assistive devices; and the importance of a well-balanced diet and hydration, as long as these interventions are not a burden or source of distress to the patient.

When a patient becomes delirious at the end of life, ongoing support of the family is important.

Delirium may be irreversible due to the various medical conditions the patient is experiencing as well as the dying process. In deciding treatment, an informed discussion of the realistic options should occur in the context of life expectancy and the risk versus benefit of any treatment. Families often welcome this clear discussion of all the current issues, including possible dying scenarios and what to expect so that they can become prepared for anticipated events.

Health care providers should be the role model of the art of “presence” or being with a patient. The patient’s family should be encouraged to provide ongoing, soothing communication, reassuring the elder patient that he or she is safe, while not confronting the patient about what he or she sees or hears. Gentle reorientation should be provided and perhaps, if appropriate, gentle reassurance that they may be intermittently confused.

Often, in the search to find an explanation for delirium, the very fact that the patient is actively dying is overlooked. Therefore, families may need education that delirium may be a signal that their loved one is nearing the end of his or her life. The other signs and symptoms of the dying process should be reviewed in the larger context of the terminal illness. Family should be encouraged to talk to the older adult even when death is imminent. They should also be reassured that pain and symptoms will be managed.

■ **Gerontological Consideration.** There are many developmental tasks of late adulthood, including role changes related to retirement, widowhood, or caring for a spouse. In addition, there are normal biological changes in physical appearance and function that may result in loss of health and independence. Indeed, the older adult may have a keen sense of his or her mortality and limited life span. In response to such events, individuals cope in many ways. Sometimes, individuals develop psychiatric symptoms including anxiety, depression, and delirium.

Older adults may be frail, have altered mental status, and be unable to make decisions. Many patients experience delirium; in the older adult population, this confusion is even more prevalent. The aging process makes the elder more susceptible to delirium because of decreased kidney function, causing inability to eliminate toxic substances from the body, decreased ability to metabolize medications, and decreased fluid balance mechanisms. This is a serious prognostic marker for older adults (Kapo et al., 2007).

Depressive symptoms are more common in the elderly because of the effects from comorbidities and the adjustment to loss of health and independent living situations. This includes grief and loss, fatigue, changing in appetite that may cause metabolic imbalances, weight changes, changes in energy, changes in



sleep, and changes in concentration. However, once the depression has been identified, treatment is usually effective. Treatment focuses on the use of antidepressants within the SSRI class because TCAs may cause orthostatic hypotension and be too sedating.

Anxiety is not well understood in the geriatric population due to lack of research. However, it can be stressed that loss of control and overall sense of vulnerability may increase the risk of anxiety. The challenge for treating anxiety in elders is that they may have a paradoxical effect to the use of benzodiazepines, which are commonly used in anxiety. Therefore, this class of medication should be used with caution. As it helps with sleep and appetite as well as depression, mirtazepine may help, as well as trazodone.

■ **Pediatric Considerations.** Anxiety, depression, and delirium present differently in the younger population of patients. Indeed, it may be hard to differentiate among sadness, anxiety, depression, and panic. These symptoms are typically unrecognized and underestimated, necessitating more research into the pediatric population.

Anxiety in terminally ill children may include separation anxiety. In older children and teens, anxiety may exhibit itself as posttraumatic distress disorder over treatment, social phobia over the results of treatment effects, and general anxiety in terms of the unknown future for living with a life-threatening illness. There are no specific tools for assessing pediatric anxiety; pediatric dosages of benzodiazepines are the first line of short-term therapy (Pao & Wiener, 2011).

Depression manifests itself in younger patients similar to its onset among older patients: changes in appetite and sleep, as well as psychomotor retardation with less energy. Grief in children is self-limited and can be improved with reassurance. Depression can result from self-blaming and decreased self-worth (Pao & Wiener, 2011). Similarly, there is limited experience in treating depression in children, SSRIs have been found to lead to a suicidal risk in the healthy child, and no further research has been done in children with life-limiting illnesses. Optimal treatment is best achieved in consultation of a pediatric psychiatrist, who can also help with medication utilization and psychotherapy.

Delirium is difficult to determine in children. Like adults, it can be seen as agitation with loud, angry speech; irritability; and crying with nonpurposeful activity (Goldsmith et al., 2011). However, its frequency and prevalence, like many other issues in pediatrics, has not been studied. The usual diagnosis algorithm for delirium is followed in children. First, there is identification of symptoms and considerations of possible causes. Identification of symptoms

includes changes in sleep, impaired attention, mood lability, and confusion. An initial review of medications includes recent changes and side effects of medications. Further assessment includes pain, bladder fullness, positioning, and external stressors. The child should then be evaluated for medical issues such as increased intracranial pressure, hypoxia, and hypercapnia, along with kidney and liver failure. Additionally, infection should be considered (Goldsmith et al., 2011).

Treatment for agitation and delirium includes soothing touch and voice. Familiarity also provides calmness, so bringing objects from home such as pillows, pictures, and blankets may help by their touch and smell. It is important to limit television that is stimulating and perhaps providing more calming music on radios, MP3 players, video players, and cell phones. Pharmacological treatment again focuses on sedatives and benzodiazepines, though there is a paucity of research in this area (Goldsmith et al., 2011). Neuroleptics are very controversial at this point due to their potent side effects. Specialist pediatric palliative care providers should be consulted for pediatric delirium.

## ■ CONCLUSION

The goal of palliative care is a holistic approach that improves physical, psychological, spiritual, and emotional well-being. A chronic progressive or serious life-threatening illness is a life crisis. Patients may develop psychiatric symptoms in response to such a diagnosis such as anxiety, depression, and delirium. Anxiety, depression, and delirium can be difficult disorders to recognize and treat. Yet, these conditions cause suffering by reducing both daily functioning and quality of life. In addition, these symptoms may herald a serious illness. It is incumbent upon clinicians to be vigilant for the presence of these disorders. Therefore, a thorough assessment, which requires skill, time, and patience, is essential to consider management.

Psychosocial effects of simultaneous patient and family reactions must be considered in evaluation and management of anxiety, depression, and delirium. Social issues such as isolation and lack of family supports may affect anxiety, depression, and delirium and their treatment. Many older patients may not want to burden relatives with their daily struggle. Many children and teenagers worry about burdening siblings, parents, and grandparents or other relatives assisting in care. Other adults worry about the impact of a chronic progressive or serious life-threatening illness on work, finances, insurance, and the future.

The result may be unnecessary placement outside the home, causing increased stress and guilt for family caregivers.

Effective treatment of anxiety, depression, and delirium necessitates a collaborative approach between the patient, family, and health team. The patient may perceive something is wrong but cannot articulate the problem; the family may perceive something is wrong but feels it is part of the disease process. The health care provider may not account for the biologic or developmental differences in the child or elder in evaluating the problem. These factors make communication and vigilance necessary components to care. Anxiety, depression, and delirium can be effectively treated; however, treatment considerations are affected by biological processes in all patients. For elders, these issues include slower metabolism, a higher side effect profile for many medications, and

a lower threshold for any imbalances. For children, lower weight and developing organ systems affect medication and dosages as well. Moreover, there are many medications inappropriate for pediatric use due to either potential dangerous side effects or no research to support their use.

A collaborative partnership of the circle of care (the patient, the family, and caregivers) supports a patient's integrity, independence, and dignity. Moreover, a comprehensive interprofessional approach offers a myriad of interventions and strategies to support the patient and family, offering the most effective management. It is important for nurses to normalize these symptoms and emphasize that management of them improves quality of life.

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### CASE STUDY *Conclusion*

Given Ann's continuing functional and cognitive decline, she was a perfect candidate for palliative care. The palliative care team evaluated her and decided to treat her depression and anxiety. To treat her depression, Ann was started on sertraline 12.5 mg a day. The effect of this was seen within several weeks. For her anxiety, Ann was placed on a scheduled dose of a short-acting benzodiazepine, lorazepam 0.5 mg every 6 hours for her anxiety. This smaller dose was chosen because Ann had lost so much weight and weighed about 90 pounds. The lorazepam helped decrease her anxiety, which in turn helped with her confusion and her short-term memory. In addition, a family meeting was held to determine her advance care planning. It was decided that Ann should not be further hospitalized for any further infections because this caused more confusion and agitation. Instead, the goal would be palliative measures to manage symptoms of infection. This would include oral antibiotics, as Ann was able to take them, and antipyretics for fever control for either urinary tract infections or pneumonia. Should Ann develop labored breathing, a plan was made for the use of sublingual morphine elixir 0.5 to 1.0 mg every 6 hours to ease labored breathing. A referral to hospice care was also made since Ann met several criteria for decline from dementia: frequent hospitalizations, continued weakness, continued weight loss of 10% of her body weight, an inability to perform independent self-care, and assistance needed for feeding.

Within 1 month, Ann was calmer, less anxious, and more engaged. In fact, she felt so much better she asked to stop her medications. However, with coaxing, Ann allowed these medications to continue.

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### Evidence-Based Practice

Gagnon, P., Allard, P., Gagnon, B., Merette, C., & Tardif, F. (2012). Delirium prevention in terminal cancer: Assessment of a multicomponent intervention. *Psycho-Oncology*, 21, 187–194.

#### Research Problem

Delirium is a highly prevalent and detrimental symptom in terminally ill cancer patients. The challenge has been both in preventing its occurrence and effectively managing when it arises.



## Methodology

The researchers conducted a nonrandomized clinical trial to establish a lower incidence in delirium for terminally ill patients by using a multifaceted intervention strategy. Patients were assessed and excluded if they were delirious at admission, within 48 hours of admission, hospitalized shorter than 48 hours or longer than 90 days, or still alive at discharge. Trained bedside nurses administered the Confusion Rating Scale (CRS) at the end of each shift. Patients who scored a 2 or higher underwent the Confusion Assessment Method (CAM).

## Findings

The study accrued 2,515 patients over 3 years. Of these, 20% (507 patients) were ineligible because they were delirious on admission or became delirious within 48 hours. Another 177 patients were excluded because they died within 48 hours of admission and 222 patients were alive at discharge. Finally, 62 patients were excluded because they lived more than 90 days. This left 1,516 patients, of whom 674 were in the intervention group. The intervention included family psychoeducation, patient assessment, and clinician screening.

## Limitations

This study was not randomized. In addition, there may have been contamination of the interventions from the study group to the usual care as clinicians became familiar with the assessment tools and interventions. However, the nurse was not consistent in rating delirium since stupor or pharmacologic sedation can appear as delirium. Finally, the CAM intervention was only able to be performed on 39% of the study patients due to the burden of the examination.

## Implications

Delirium is a major symptom in terminally ill cancer patients, occurring in 50% of patients. Past history of delirium appears to be the strongest risk factor. This study had lower rates of delirium than previously reported. The question is how results differ in other populations of patients such as those with noncancer diagnoses, younger patients, or specific cancers. More research is needed in pharmacological interventions and their effect on delirium prevention and severity, as well as quality of life.

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## ■ APPENDIX 1

**MONTREAL COGNITIVE ASSESSMENT (MOCA)**  
 Version 7.1 Original Version

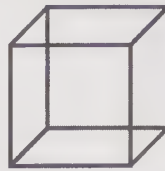
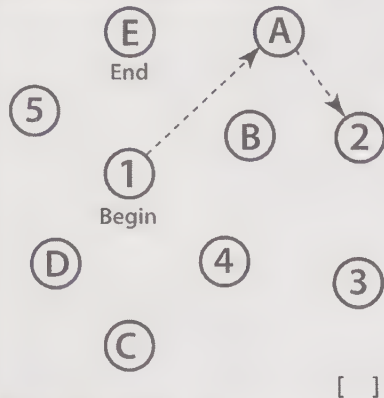
NAME :

Education :

Sex :

Date of birth :

DATE :

**VISUOSPATIAL / EXECUTIVE**Copy  
cubeDraw CLOCK (Ten past eleven)  
(3 points)

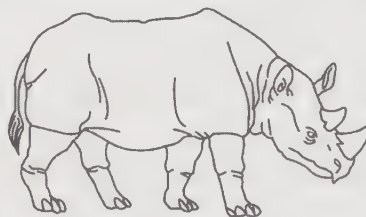
POINTS

☐ ☐ ☐  
 Contour Numbers Hands

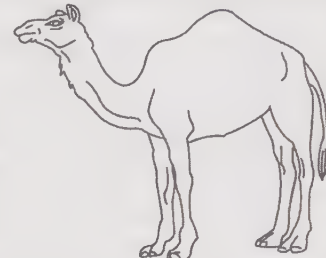
\_\_\_/5

**NAMING**

[ ]



[ ]



[ ]

\_\_\_/3

**MEMORY**

Read list of words, subject must repeat them. Do 2 trials, even if 1st trial is successful. Do a recall after 5 minutes.

	FACE	VELVET	CHURCH	DAISY	RED
1st trial					
2nd trial					

No  
points**ATTENTION**

Read list of digits (1 digit/ sec.).

Subject has to repeat them in the forward order

[ ] 2 1 8 5 4

Subject has to repeat them in the backward order

[ ] 7 4 2

\_\_\_/2

Read list of letters. The subject must tap with his hand at each letter A. No points if  $\geq 2$  errors

[ ] FBACMNAAJKLBAFAKDEAAAJAMOFAAB

\_\_\_/1

Serial 7 subtraction starting at 100

[ ] 93

[ ] 86

[ ] 79

[ ] 72

[ ] 65

4 or 5 correct subtractions: 3 pts, 2 or 3 correct: 2 pts, 1 correct: 1 pt, 0 correct: 0 pt

\_\_\_/3

**LANGUAGE**

Repeat : I only know that John is the one to help today. [ ]

The cat always hid under the couch when dogs were in the room. [ ]

\_\_\_/2

Fluency / Name maximum number of words in one minute that begin with the letter F

[ ] \_\_\_\_\_ (N  $\geq$  11 words)

\_\_\_/1

**ABSTRACTION**

Similarity between e.g. banana - orange = fruit [ ] train - bicycle [ ] watch - ruler

\_\_\_/2

**DELAYED RECALL**

Has to recall words

WITH NO CUE

FACE

[ ]

VELVET

[ ]

CHURCH

[ ]

DAISY

[ ]

RED

[ ]

Points for  
UNCUED  
recall only

\_\_\_/5

**Optional**

Category cue

Multiple choice cue

**ORIENTATION**

[ ] Date

[ ] Month

[ ] Year

[ ] Day

[ ] Place

[ ] City

\_\_\_/6

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www.mocatest.org

Normal  $\geq 26$  / 30

TOTAL

\_\_\_/30

Administered by: \_\_\_\_\_

Add 1 point if  $\leq 12$  yr edu



## ■ APPENDIX 2

## GERIATRIC DEPRESSION SCALE

Choose the best answer for how you felt over the past week.

1. Are you basically satisfied with your life?  
YES NO
2. Have you dropped many of your activities and interests? YES NO
3. Do you feel that your life is empty?  
YES NO
4. Do you often get board? YES NO
5. Are you hopeful about the future? YES NO
6. Are you bothered by thoughts you can't get out of your head? YES NO
7. Are you in good spirits most of the time?  
YES NO
8. Are you afraid that something bad is going to happen to you? YES NO
9. Do you feel happy most of the time?\*
- YES NO
10. Do you often feel helpless? YES NO
11. Do you often get restless and fidgety?  
YES NO
12. Do you prefer to stay at home, rather than going out and doing things? YES NO
13. Do you frequently worry about the future?  
YES NO
14. Do you feel you have more problems with memory than most? YES NO
15. Do you think it is wonderful to be alive now?\*
- YES NO
16. Do you often feel downhearted and blue?  
YES NO

17. Do you feel pretty worthless the way you are now? YES NO
18. Do you worry a lot about the past?  
YES NO
19. Do you find life very exciting?\* YES NO
20. Is it hard for you to get started on new projects? YES NO
21. Do you feel full of energy?\* YES NO
22. Do you feel that your situation is helpless?  
YES NO
23. Do you think that most people are better off than you are? YES NO
24. Do you frequently get upset over little things?  
YES NO
25. Do you frequently feel like crying? YES NO
26. Do you have trouble concentrating?  
YES NO
27. Do you enjoy getting up in the morning?\*
- YES NO
28. Do you prefer to avoid social gatherings?  
YES NO
29. Is it easy for you to make decisions?\*
- YES NO
30. Is your mind as clear as it used to be?\*
- YES NO

---

Score:

\*Nondepressed answers = yes, all others = no

**Norms**

Normal  $5 \pm 4$

Mildly depressed  $15 \pm 6$

Very depressed  $13 \pm$

Source: Yesavage J., Brink, T. L., Rose, T. L., Lum, O., Huang, V., Adey, M., & Leirer, V. O. (1982). Development and validation of a geriatric screening scale: A preliminary report. *Journal of Psychiatric Research*, 17, 37-49. (Reprinted with permission from Pergamon Press PLC, Headington Hill Hall, Oxford OX3 OBW, UK.)

## ■ APPENDIX 3

### THE DELIRIUM RATING SCALE

#### Item 1: Temporal Onset of Symptoms

This item addresses the time course over which symptoms appear; the maximum rating is for the most abrupt onset of symptoms, a common pattern for delirium. Dementia is usually more gradual in onset. Other psychiatric disorders, such as affective disorders, might be scored with 1 or 2 points on this item. Sometimes delirium can be chronic (e.g., in geriatric nursing home patients), and unfortunately only 1 or 2 points would be assessed in that situation.

0. No significant change from long-standing behavior, essentially a chronic or chronic-recurrent disorder
1. Gradual onset of symptoms, occurring within a six-month period
2. Acute change in behavior or personality occurring over a month
3. Abrupt changes in behavior, usually occurring over a one- to three-day period

#### Item 2: Perceptual Disturbances

This item rates most highly the extreme inability to perceive differences between internal and external reality, while intermittent misperceptions such as illusions are given 2 points. Depersonalization and derealization can be seen in other organic mental disorders such as temporal lobe epilepsy, in severe depression, and in borderline personality disorder and thus are given only 1 point.

0. None evident by history or observation
1. Feelings of depersonalization or derealization
2. Visual illusions or misperceptions including macropsia, micropsia; for example, may urinate in wastebasket or mistake bedclothes for something else
3. Evidence that the patient is markedly confused about external reality; for example, not discriminating between dreams and reality

#### Item 3: Hallucination Type

The presence of any type of hallucination is rated. Auditory hallucinations alone are rated with less weight because of their common occurrence in primary psychiatric disorders. Visual hallucinations are generally associated with organic mental syndromes, although not exclusively, and are given 2 points. Tactile hallucinations are classically described in delirium, particularly due to anticholinergic toxicity and are given the most points.

0. Hallucinations not present

1. Auditory hallucinations only
2. Visual hallucinations present by patient's history or inferred by observation, with or without auditory hallucinations
3. Tactile, olfactory, or gustatory hallucinations present with or without visual or auditory hallucinations

#### Item 4: Delusions

Delusions can be present in many different psychiatric disorders, but tend to be better organized and more fixed in nondelirious disorders and thus are given less weight. Chronic fixed delusions are probably most prevalent in schizophrenic disorders. New delusions may indicate affective and schizophrenic disorders, dementia, or substance intoxication but should also alert the clinician to possible delirium and are given 2 points. Poorly formed delusions, often of a paranoid nature, are typical of delirium.

0. Not present
1. Delusions are systematized, that is, well organized and persistent
2. Delusions are new and not part of a preexisting primary psychiatric disorder
3. Delusions are not well circumscribed; are transient, poorly organized, and mostly in response to misperceived environmental cues; for example, are paranoid and involve persons who are in reality caregivers, loved ones, hospital staff, and so on.

#### Item 5: Psychomotor Behavior

This item describes degrees of severity of altered psychomotor behavior. Maximum points can be given for severe agitation or severe withdrawal to reflect either the hyperactive or the hypoactive variant in delirium

0. No significant retardation or agitation
1. Mild restlessness, tremulousness, or anxiety evident by observation and a change from patient's usual behavior
2. Moderate agitation with pacing, removing IVs, and so on.
3. Severe agitation, needs to be restrained, may be combative; or has significant withdrawal from the environment, but not due to major depression or schizophrenic catatonia

#### Item 6: Cognitive Status During Formal Testing

Information from the cognitive portion of a routine mental status examination is needed to rate this item. The maximum rating of 4 points is given for severe



cognitive deficits while only 1 point is given for mild inattention, which could be attributed to pain and fatigue seen in medically ill persons. Two points are given for a relatively isolated cognitive deficit, such as memory impairment, which could be due to dementia or organic amnesic syndrome as well as to early delirium.

0. No cognitive deficits, or deficits that can be alternatively explained by lack of education or prior mental retardation
1. Very mild cognitive deficits that might be attributed to inattention due to acute pain, fatigue, depression, or anxiety associated with having a medical illness
2. Cognitive deficit largely in one major area tested, for example, memory, but otherwise intact
3. Significant cognitive deficits that are diffused, that is, affecting many different areas tested; most include periods of disorientation to time or place at least once each 24-hour period; registration and/or recall are abnormal; concentration is reduced.
4. Severe cognitive deficits, including motor or verbal perseveration, confabulations, disorientation to person, remote and recent memory deficits, and inability to cooperate with formal mental status testing

### Item 7: Physical Disorder

Maximum points are given when a specific lesion or physiological disturbance can be temporally associated with the altered behavior. Dementias are often not found to have a specific underlying medical cause, while delirium usually has at least one identifiable physical cause.

0. None present or active
1. Presence of any physical disorder that might affect mental state
2. Specific drug, infection, metabolic, central nervous system lesion, or other medical problem that can be temporally implicated in causing the altered behavior or mental status

### Item 8: Sleep–Wake Cycle Disturbance

Disruption of the sleep–wake cycle is typical in delirium, with demented persons generally having significant sleep disturbances much later in their course. Severe delirium is on a continuum with stupor and coma, and persons with a resolving coma are likely to be delirious temporarily.

0. Not present; awake and alert during the day, and sleeps without significant disruption at night
1. Occasional drowsiness during day and mild sleep continuity disturbance at night; may have

nightmares, but can readily distinguish from reality

2. Frequent napping and unable to sleep at night, constituting a significant disruption of or a reversal of the usual sleep–wake cycle
3. Drowsiness prominent, difficulty staying alert during interview, loss of self-control over alertness, and somnolence.
4. Drifts into stuporous or comatose periods.

### Item 9: Lability of Mood

Rapid shifts in mood can occur in various organic mental syndromes, perhaps due to a disinhibition of one's normal control. The patient may be aware of this lack of emotional control and may behave inappropriately relative to the situation or to his or her thinking state; for example, crying for no apparent reason. Delirious patients may score points on any of these items depending upon the severity of the delirium and upon how their underlying psychological state “colors” their delirious presentation. Patients with borderline personality disorder might score 1 or 2 points on this item.

0. Not present; mood stable
1. Affect/mood somewhat altered and changes over the course of hours; patient states that mood changes are not under self-control

#### Item 1-Reduced Level of Consciousness (Awareness)

Rate the patient's current awareness of an interaction with the environment (interviewer, other people/objects in the room, for example, ask patients to describe the surroundings)

- 0: none Patient spontaneously fully aware of environment and interacts appropriately  
Patient is unaware of some elements in the environment, or not spontaneously interacting appropriately with the interviewer: becomes fully aware and appropriately interactive when prodded strongly; interview is prolonged but not seriously disrupted
- 2: moderate Patient is unaware of some or all elements in the environment, or not spontaneously interacting with the interviewer: becomes incompletely aware and inappropriately interactive when prodded strongly; interview is prolonged but not seriously disrupted  
Patient is unaware of all elements in the environment with no spontaneous interaction or awareness of the interviewer, so that the interview is

difficult or next to impossible, even with maximal prodding

2. Significant mood changes that are inappropriate to situation, including fear, anger, or tearfulness; rapid shifts of emotion, even over several minutes
3. Severe disinhibition of emotions, including temper outbursts, uncontrolled inappropriate laughter, or crying

### Item 10: Variability of Symptoms

The hallmark of delirium is the waxing and waning of symptoms, which is given 4 points on this item.

Demented as well as delirious patients, who become more confused at night when environmental cues have decreased, could score 2 points.

0. Symptoms stable and mostly present during daytime
  2. Symptoms worsen at night
  4. Fluctuating intensity of symptoms, such that they wax and wane during a 24-hour period
- Total Score

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*Source:* From "A Symptom Rating Scale for Delirium," by P. T. Trzepacz, R. W. Baker, and J. Greenhouse, 1988, *Psychiatry Research*, 23, pp. 89–97. Copyright 1988. Reprinted with permission.



■ **APPENDIX 4****MEMORIAL DELIRIUM ASSESSMENT SCALE**

**INSTRUCTIONS:** Rate the severity of the following symptoms of delirium based on current interaction with the subject or assessment of his or her behavior or experience over the past several hours (as indicated in each time).

**Item 1: Reduced Level of Consciousness (Awareness)**

Rate patient's current awareness of and interaction with the environment (interviewer, other people/objects; for example, ask patients to describe their surroundings).

- 0: none Patient is spontaneously fully aware of the environment and interacts appropriately
- 1: mild Patient is unaware of some elements in the environment, or not spontaneously interacting appropriately with the interviewer; becomes fully aware and appropriately interactive when prodded strongly; interview is prolonged but not seriously disrupted
- 2: moderate Patient is unaware of some or all elements in the environment, or not spontaneously interacting with the interviewer; becomes incompletely aware and inappropriately interactive when prodded strongly; interview is prolonged but not seriously disrupted
- 3: severe Patient is unaware of all elements in the environment, with no spontaneous interaction or awareness of the interviewer, so that the interview is difficult to impossible, even with maximal prodding.

**Item 2: Disorientation**

Rate current state by asking the following 10 orientation items: date, month, day, year, season, floor, name of hospital, city, state, and country.

- 0: none Patient knows 9 to 10 items
- 1: mild Patient knows 7 to 8 items
- 2: moderate Patient knows 5 to 6 items
- 3: severe Patient knows no more than 4 items

**Item 3: Short-Term Memory Impairment**

Rate current state by using repetition and delayed recall of three words (patient must immediately repeat and recall words five minutes later) after an intervening task. Use alternate sets of three words for successive evaluation (e.g., apple, table, tomorrow, sky, cigar, and justice).

- 0: none All three words repeated and recalled
- 1: mild All three repeated, patient fails to recall one
- 2: moderate All three repeated, patient fails to recall two
- 3: severe Patient fails to repeat one or more words

**Item 4: Impaired Digit Span**

Rate current performance by asking subjects to repeat first three, four, then five digits forward and then three, then four backward: continue to the next step only if patient succeeds at the previous one.

- 0: none Patient can do at least five numbers forward and four backward
- 1: mild Patient can do at least five numbers forward, three backward
- 2: moderate Patient can do four to five numbers forward, cannot do three backward
- 3: severe Patient can do no more than three numbers forward

**Item 5: Reduced Ability to Maintain and Shift Attention**

As indicated during the interview by questions needing to be rephrased and/or repeated because patient's attention wanders, patient loses track, patient is distracted by outside stimuli, or patient is over-absorbed in a task.

- 0: none None of the above: patient maintains and shifts attention normally
- 1: mild Above attention problems occur once or twice without prolonging the interview
- 2: moderate Above attention problems occur often, prolonging the interview without seriously disrupting it

Above attention problems occur constantly, disrupting and making the interview difficult to impossible

### Item 6: Disorganized Thinking

Disorganized thinking is indicated during the interview by rambling, irrelevant, or incoherent speech, or by tangential, circumstantial, or faulty reasoning. Ask patient a somewhat complex question (e.g., "Describe your current medical condition.").

- 0: none Patient's speech is coherent and goal directed
- 1: mild Patient's speech is slightly difficult to follow; responses to questions are slightly off target but not so much as to prolong the interview. Disorganized thoughts or speech are clearly present, such that interview is prolonged but not disrupted
- 3: severe Examination is very difficult or impossible due to disorganized thinking or speech

### Item 7: Perceptual Disturbance

Misperceptions, illusions, hallucinations inferred from inappropriate behavior during the interview or admitted by subject as well as those elicited from nurse/family/chart accounts of the past several hours or of the time since last examination.

- 0: none No misperceptions, illusions, or hallucinations
- 1: mild Misperceptions or illusions related to sleep, fleeting hallucinations on one or two occasions without inappropriate behavior
- 2: moderate Hallucinations or frequent illusions on several occasions with minimal inappropriate behavior that does not disrupt the interview
- 3: severe Frequent or intense illusions or hallucinations with persistent inappropriate behavior that disrupts the interview or interferes with medical care

### Item 8: Delusions

Rate delusions inferred from inappropriate behavior during the interview or admitted by the patient as well as delusions elicited from nurse/family/chart accounts of the past several hours or of the time since the previous examination.

- 0: none No evidence of misinterpretations or delusions
- 1: mild Misinterpretations or suspiciousness without clear delusional ideas or inappropriate behavior

- 2: moderate Delusions admitted by the patient or evidenced by his/her behavior that do not or only marginally disrupt the interview or interfere with medical care
- 3: severe Persistent and/or intense delusions resulting in inappropriate behavior, disrupting the interview or seriously interfering with medical care.

### Item 9: Decreased or Increased Psychomotor Activity

Rate activity over past several hours as well as activity during interview.

- 0: none Normal psychomotor activity
- 1: mild Hypoactivity is barely noticeable, expressed as slight slowing of movement. Hyperactivity is barely noticeable or appears as simple restlessness
- 2: moderate Hypoactivity is undeniable with marked reduction in number of movements or marked slowness of movement: subject rarely spontaneously moves or speaks. Hyperactivity is undeniable: subject moves almost constantly. In both cases, examination is prolonged as a consequence
- 3: severe Hypoactivity is severe, patient does not move or speak without prodding or is catatonic. Hyperactivity is severe; patient is constantly moving, overreacts to stimuli, and requires surveillance and/or restraint. Getting through the exam is difficult or impossible

### Item 10: Sleep–Wake Cycle Disturbance (Disorder of Arousal)

Rate patient's ability to either sleep or stay awake at the appropriate times. Utilize direct observation during the interview as well as reports from nurses, family, patient, or charts describing sleep–wake cycle disturbance over the past several hours or since last examination. Use observations of the previous night for morning evaluations only.

- 0: none At night, sleeps well. During the day, has no trouble staying awake
- 1: mild Mild deviation from appropriate sleepfulness and wakefulness states at night, difficulty falling asleep or transient night awakenings, needs medication to sleep well: during the



- day, reports periods of drowsiness, or during the interview, is drowsy but can easily fully awaken himself or herself
- 2: moderate Moderate deviations from appropriate sleepfulness and wakefulness states at night, repeated and prolonged night awakening; during the day, reports of frequent and prolonged napping, or, during the interview, can only be roused to complete wakefulness by strong stimuli
- 3: severe Severe deviations from appropriate sleepfulness and wakefulness states at night, sleeplessness; during the day, patient spends most of the time sleeping, or, during the interview, cannot be roused to full wakefulness by any stimuli

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Source: Reprinted with permission from Breitbart, W., Rosenfeld, B., Roth, A., Smith, M. J., Cohen, K., & Passik, S. (1997). The Memorial Delirium Assessment Scale. *Journal of Pain and Symptom Management*, 13(3), 128-137, by the U.S. Cancer Pain Relief Committee.





# Posttraumatic Stress Disorder and End-of-Life Care

## CHAPTER

### KEY POINTS

- There is a high likelihood that anyone who is receiving palliative care has been exposed to a traumatic event during his or her life that may place him or her at risk of post-traumatic stress disorder (PTSD).
- PTSD can negatively impact patient-provider communication and lead to increased psychological distress at end of life.
- Although evidence-based research is limited, there are a number of approaches to address PTSD at end of life that bring comfort to both the individual receiving palliative care and his or her family.

### CASE STUDY

#### Palliative Care Case

A 64-year-old American Indian, Vietnam-era veteran was brought to the Veterans Administration Medical Center by ambulance for low back pain and was reporting an increase in pain over the last 4 months. Prior medical history included stroke, HIV/AIDS, previous L1 to 3 compression fracture, and history of mental health treatment. He completed 16 weeks of vancomycin for epidural abscesses as well as methicillin-resistant *Staphylococcus aureus* (MRSA) bacteremia. MRI on admission showed an acute compression fracture of L5 vertebral body and stable compression fractures of L 1 to 4. He was found to have *Clostridium difficile* (*C. diff*) and started on vancomycin. During the admission, he became septic and progressed into respiratory failure and was taken to the ICU. He was found to have bilateral consolidations in lungs and placed on an antibiotic regimen, and then he developed persistent diarrhea. By the end of the month, he was short of breath and his hemoglobin had dropped. Medical compliance was inconsistent. A palliative care consult was placed.

What details of this case are suggestive of PTSD? What assessment approaches should be used with this patient? What interventions would be appropriate to consider?

The likelihood of being exposed to a traumatic event, such as a natural disaster, child sexual or physical abuse, serious accident, sexual or physical assault, terrorist attack, or combat, increases across a life span. By the time an individual reaches his or her early 20s, there is a high chance that the individual has already experienced a trauma, with prevalence rates as high as 84% among nonclinical college samples (Vrana & Lauterbach, 1994). After experiencing a traumatic event, most people experience stress-related reactions such as fear, sadness, guilt, anger, or sleep problems. For many, stress-related reactions resolve over time, but about 7% of individuals who experience a traumatic event will continue to have difficulty coping with symptoms associated with the event and develop post-traumatic stress disorder (PTSD; Gradus, 2007).

Given the high likelihood that an individual receiving palliative care has experienced a traumatic event during his or her life, it is important to be familiar with how PTSD may impact end-of-life (EOL) care. Treatment of PTSD at the EOL is directly relevant to the recommended competencies and curricular guidelines for EOL nursing care put forth by the American Association of Colleges of Nursing (AACN; *Nursing*, 2013). Specifically, this chapter will address AACN competencies related to communication, interprofessional care, and use of evidence-based practices, as well as highlight the importance of assessing for specific mental health disorders such as PTSD in order to allow both the individual and his or her family to receive state-of-the-art EOL care.

The main objectives of this chapter are to provide the reader with an overview of PTSD and evidence-based treatments within a palliative care setting. The criteria for PTSD will be outlined along with a description of appropriate approaches to assessment. Currently available evidence-based treatments are described and illustrated with case examples. The importance of addressing PTSD in EOL care for both the individual as well as his or her family is highlighted.

## ■ DIAGNOSTIC CRITERIA FOR POSTTRAUMATIC STRESS DISORDER

According to the *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition, (DSM-5; American Psychiatric Association [APA], 2013), a diagnosis of PTSD must involve the “exposure to actual or threatened death, serious injury, or sexual violence.” The exposure itself does not always need to be the direct experience of a traumatic event. According to DSM-5 criteria (APA, 2013), an individual can also develop PTSD by witnessing a traumatic event in person, learning that the traumatic events occurred to a close family member or friend, or experiencing repeated

or extreme exposure to aversive details of the traumatic event. Medical conditions would only qualify as traumatic events if the incidents involved sudden, catastrophic events, such as waking during surgery or anaphylactic shock (APA, 2013). Emotional reactions to the traumatic event, such as fear or helplessness, are no longer part of the diagnostic criteria with the release of DSM-5 (APA, 2013).

Following the exposure, the individual must experience one or more symptoms in each of the following symptom clusters (APA, 2013): (a) Reexperiencing (e.g., recurrent distressing memories or dreams); (b) avoidance (e.g., evasion of memories or cues related to traumatic event); (c) negative alterations in cognitions or mood (e.g., inability to remember details related to traumatic event, increased negative beliefs, persistent negative mood state); and (d) changes in arousal and reactivity (e.g., irritability, hypervigilance, poor sleep). The reexperiencing and avoidance symptom clusters require a minimum of one symptom in each cluster, while the other symptom clusters require two or more symptoms to be present to meet diagnostic criteria (APA, 2013). The duration of the symptoms must be for a month or longer, cause clinically significant impairment, and cannot be due to substances or another medical condition (APA, 2013). The above criteria are for children older than 6 years, adolescents, and adults. The DSM-5 has modified PTSD criteria for children 6 years and younger (APA, 2013).

## Prevalence

Compared to 8% in the general population, PTSD occurs at a significantly higher rate among individuals receiving care in a medical setting for potentially life-threatening illnesses. The prevalence of PTSD among patients treated in an ICU, regardless of diagnosis, was found to be as high as 64% depending upon the method of assessment (Griffiths, Fortune, Barber, & Young, 2007). Similar findings are noted in pediatric patients treated in a pediatric intensive care unit (PICU; Stuber & Shemesh, 2006). Rees, Gledhill, Garralda, & Nadel (2004) found 21% of PICU-discharged children developed PTSD in comparison to a control group of children receiving care on a general pediatric ward. PTSD symptoms also are more prevalent among medical diagnoses that are potentially life limiting. For example, in comparison to community samples, prevalence rates have been shown to be higher for individuals with cancer (Alter et al., 1996; Amir & Ramati, 2002).

## Impact of Posttraumatic Stress Disorder on End-of-Life Care

The very nature of the symptoms, including hyperarousal and avoidance, may complicate EOL care.



The simple distress associated with being confronted with a life-threatening illness may exacerbate PTSD symptoms and provoke similar responses to the original trauma. Normal life review is an important part of the dying process in order to resolve unfinished business (Feldman & Periyakoil, 2006), but it may also result in symptoms such as intense anxiety, anger, guilt, or sadness due to traumatic memories. As a result, individuals with PTSD may avoid traumatic memories and may be unable to come to terms with unresolved life events.

Avoidance symptoms may also interfere with processes, such as communication with medical providers, which are paramount to successful EOL care. PTSD symptoms can impede the ability for the health care practitioner to engage in direct, problem-focused communication regarding the patient's care (Feldman & Periyakoil, 2006). Refusal of care or excessive questioning of providers' actions or distrust of authority may result (Feldman & Periyakoil, 2006). It has been documented that people with PTSD diagnoses tend to have poor medical adherence (Shemesh et al., 2004). In addition, individuals with PTSD may experience decreased social support or a lack of caregivers as a result of social isolation and avoidance.

■ **Impact of Posttraumatic Stress Disorder on the Family.** PTSD can negatively impact interpersonal relationships. The National Center for PTSD's website documents that family members themselves may have a number of reactions to their family member having PTSD, including sympathy, negative feelings, avoidance, depression, anger, guilt, or health problems. Research has documented that spouses of veterans have higher rates of caregiver burden and mental health problems themselves (Carlson & Ruzek, 2013). Among the veteran population, those with PTSD are more likely to report marital difficulties and have higher rates of divorce and interpersonal violence. As a result, individuals with severe PTSD in palliative care settings may have very limited social support networks and existing family relations may be strained.

Family members of critically ill individuals are also susceptible to developing PTSD. Prevalence studies of family members of critically ill patients in France suggest rates may be as high as 33% (Azoulay et al., 2005); Lautrette et al. (2007) documented a reduction in depression, anxiety, and PTSD symptoms through the implementation of family conferences and psychoeducation on grief and bereavement in a French population. Curtis et al. (2012) is evaluating an interprofessional communication intervention to improve family outcomes in the United States with qualitative data suggesting positive outcomes.

## ■ ASSESSMENT OF POSTTRAUMATIC STRESS DISORDER AT END OF LIFE

Accurately assessing symptoms, providing appropriate treatment, monitoring symptom change, communicating, and evaluating the effectiveness of an intervention are all crucial. Assessing for PTSD can pose several daunting challenges. First, the criteria for the diagnoses of PTSD are changing as the field learns more about this syndrome and the numerous ways it can present. This section identifies age-related issues that may impact how PTSD is manifested across the life span, how EOL issues may affect the presentation of PTSD, and the approaches and measures utilized to assess PTSD.

When determining the most appropriate measure to utilize in assessing PTSD at the EOL, there are several factors that are important to consider. First, due to the varied nature of life-threatening or life-limiting illnesses, the amount of time required to administer the measure is a critical factor. There are numerous measures that vary in the amount of time required to administer, ranging from 5 to 120 minutes. Second, not all measures are written at the same comprehension level; therefore, the reading level of the patient is an important consideration. Third, the clinician needs to be able to evaluate for a single or multiple traumatic events. Another important consideration when assessing patients for PTSD is whether the assessment focuses on determining the specific diagnosis of PTSD or if the objective is to identify PTSD symptoms. Finally, the level of training and competency of the clinician administering and interpreting the results will impact the validity of the findings.

### Key Components to Assess

When assessing for PTSD at the EOL, an evaluation of past traumatic events (e.g., combat, sexual assault, natural disasters, and accidents) is critical. Once the traumatic event(s) are identified, the meaning the patient has attributed to them and how they have coped with these symptoms provides useful information for treatment. Averill and Beck (2000) suggest that the meaning a person attributes to the event and his or her related coping style can influence the severity of the disorder. Also, assessing the influence of various psychosocial factors (e.g., social support, health status, employment status, and activity level) and their effect on PTSD symptoms should be considered. Patients may not offer this information freely, possibly because they may not consider the information relevant to their current circumstances, may not want to discuss the event, or may not remember many aspects of the event (in the case of childhood trauma or dementia).

A thorough assessment should focus on age of onset, duration, severity, and course of symptoms.

There are numerous approaches to assessment of PTSD or symptoms of PTSD that include chart review, screening measures, interviews, self-report measures, and trauma exposure measures. A comprehensive chart review can be an invaluable tool in assessing a patient for PTSD. The patient's medical illness may inhibit him or her from being able to share his or her mental health history with you. Also, given that avoidance is a core symptom of PTSD, the patient may not readily share this information, even when asked if he or she has a mental health history. A comprehensive chart review can be conducted by evaluating the following: history of a preexisting mental health diagnosis, use of prescribed psychotropic medication (past/present), and any documentation pertaining to the patient's mental health. Once the patient's chart has been reviewed, a brief note including the findings from the chart review and a discussion of the clinical implications for EOL care should be documented. After reviewing the mental health history in the medical record, the next phase of assessment is to talk with the patient to discuss his or her symptoms and background to fill in missing data from the chart review. Any of the remaining approaches (screening, interview, self-report, and trauma exposure measure) can be utilized after the chart review has been conducted.

Screening measures are designed to identify people who are at a higher risk for PTSD. A screening measure is useful particularly when there is ease of administration and minimal administration time. A positive

screen indicates that further evaluation is warranted in order to determine if a patient's symptoms meet the criteria for a diagnosis of PTSD. When utilizing screening measures, it is important to understand the unique needs of the person who is being assessed. A vital assessment factor is the history of a traumatic event. For example, when working with veterans it is important to ask, "Did you see combat?" and "Is there anything about your military service that still bothers you?" The most effective way to screen for PTSD is to ask about current symptoms and past experiences (primary care-PTSD screen; Feldman & Periyakoil, 2006).

A clinical interview is considered to be the most comprehensive assessment of PTSD. However, this assessment requires more time and training of the interviewer. The PTSD interview varies in the breadth and depth of information regarding symptom severity and frequency that can be gathered. A table of assessment measures for PTSD is provided in Table 22.1; with the Clinician-Administered PTSD Scale (CAPS; Blake et al., 1995; Elhai, Gray, Kashdan, & Franklin, 2005) considered the "gold standard" in assessing PTSD due to its quality of psychometric properties and flexibility (Weathers, Keane, & Davidson, 2001). Some of the interview scales designed for assessing PTSD are the Clinician Administered PTSD Scale (CAPS; Blake et al., 1995); PTSD Symptom Scale-Interview Version (PSS-I; Foa & Tolin, 2000); Structured Clinical Interview for DSM-IV PTSD Module (SCID; First, Spitzer, Gibbon, & Williams, 1996); and the Structured Interview for PTSD (SI-PTSD; Davidson, Kudler, & Smith, 1990). When a patient's trauma history is unknown, a trauma

**TABLE 22.1** Assessment Measures for PTSD

Measure	Time Required (min)	Type
Clinician-Administered PTSD Scale (CAPS)	45	Interview
Structured Interview for PTSD (SI-PTSD)	20–30	Interview
Structured Clinical Interview for <i>DSM-IV</i> PTSD Module (SCID)	20–30	Interview
PTSD Symptom Scale-Interview Version (PSS-I)	20–30	Interview
Primary Care PTSD Screen (PC-PTSD)	2–3	Screen
Trauma Screening Questionnaire (TSQ)	2–3	Screen
Short Posttraumatic Stress Disorder Rating Interview (SPRINT)	5	Self-report
Late-Onset Stress Symptomology (LOSS)	20–30	Self-report
PTSD Checklist (PCL)	5	Self-report
Impact of Event Scale (IES)	5	Self-report
Minnesota Multiphasic Personality Inventory (MMPI)	60–120	Self-report



exposure measure may be helpful in assessing what traumatic events he or she may have experienced during his or her lifetime. Trauma exposure measures vary with regard to length, types of trauma assessed, and the amount of information gathered about each event. The purpose of the assessment will determine what type of measure is needed.

Finally, self-report measures play a vital role in the assessment of PTSD. As with the previously mentioned assessment measures, self-report measures vary in length and amount of detailed information that is gathered regarding symptoms and their severity. The commonly utilized self-report measures are PTSD Checklist (Weathers, Litz, Herman, Huska, & Keane, 1993) three versions: military, civilian, and specific version (i.e., PCL-M, PCL-C, and PCL-S); SPRINT (Connor & Davidson, 2001); Trauma Screening Questionnaire (Brewin et al., 2002), and Late-Onset Stress Symptomology (Davison et al., 2006).

■ **Life Span Considerations for Pediatric Assessments.** According to the National Child Trauma Stress Network (NCTSN), child traumatic stress occurs when children and adolescents are exposed to traumatic events or traumatic situations that overwhelm their ability to cope. Symptom presentation will be influenced by age and developmental level. There are a number of reliable and valid assessment measures by trauma type to assess for PTSD in children and adolescents. For a complete listing, please refer to National Center for PTSD and the National Child Trauma Stress Network's websites in the resource section at the end of this chapter.

■ **Older Adults Assessment.** Due to the dearth of literature pertaining to the assessment of PTSD at the EOL, assessment strategies that are focused on assessing PTSD in older adults may be lacking a vital first step. The patient's ability to contribute to the assessment process, as well as decisions regarding treatment and medication regimens, can be more accurately planned once the patient's cognitive status has been determined (Kaiser et al., 2013). If warning signs suggest a cognitive impairment is present, a Mental Status Examination can help determine if the patient needs to be referred for a neurological examination in the case of suspected dementia or for a medication evaluation if delirium or a medication interaction is suspected (Kaiser et al., 2013).

Comorbid medical and mental health problems also should be evaluated. Older adults are more likely to report physical health symptoms (e.g., pain, sleep issues, gastrointestinal distress, or cognitive difficulties) rather than emotional difficulties (i.e., anxiety or depression). Furthermore, substance use, abuse, and dependence, as well as suicidal and para-suicidal behaviors, should be evaluated. Finally, a patient's medication adherence and tolerance needs to be determined because avoidance is one factor considered for

diagnosing PTSD (Kaiser et al., 2013). Therefore, patients who experience PTSD may struggle with treatment adherence. Another important consideration regarding the use of medication is if the patient is taking medication to treat some of his or her PTSD symptoms. If they are currently managing with these symptoms pharmacologically, they may not be evident during the clinical assessment. This is important to be aware of when determining the diagnosis.

## ■ OVERVIEW OF EVIDENCE-BASED TREATMENTS FOR POSTTRAUMATIC STRESS DISORDER

There are a number of effective treatments for PTSD; clinical practice guidelines by the Institute of Medicine (2007) and Veterans Administration/Department of Defense (2010; Department of Veterans Affairs, 2010) both conclude that cognitive behavioral therapies are the most effective treatment for PTSD. Cognitive behavioral therapies involve a multifaceted approach including psycho-education, anxiety management, exposure, and cognitive restructuring. Cognitive Processing Therapy (CPT) and Prolonged Exposure (PE) are the two subtypes of cognitive behavioral therapies with the most evidence-based research (Hamblen, Schnurr, Rosenberger, & Eftekhari, 2013). Eye movement desensitization and reprocessing (EMDR) has also been recommended by some guidelines. All of these treatment approaches are explained in detail on the website for the national center for PTSD, but the four main components of each approach are identified in Table 22.2.

The practitioner who treats individuals with PTSD should be trained in a specific approach such as CPT or PE. When this is not possible, therapy should be conducted by a mental health professional who has received training in cognitive behavioral techniques. Therapists can always utilize peer consultation and supervision to augment their competency level. In general, treatment is administered in a weekly or bi-weekly basis. Average number of sessions required to complete the treatment is between 8 and 15 sessions with each session lasting between 60 and 90 minutes (National Center for Posttraumatic Stress Disorder [NCPTSD], 2009b, 2009c). In addition to therapy sessions, the individual should engage in practice assignments outside of the session. Although treatment may be considered time intensive, cognitive behavioral therapies are very effective in helping individuals to manage their reactions to stressful memories (NCPTSD, 2007).

The most effective classes of medication to treat PTSD symptoms are selective serotonin reuptake inhibitors (SSRIs), which increase the level of serotonin

**TABLE 22.2 Four Main Components of Each of the Cognitive Behavioral Treatments Recommended for PTSD**

Individual Therapy Components	Cognitive Processing Therapy	Prolonged Exposure Therapy	Eye Movement Desensitization and Reprocessing
Component 1	Learning PTSD symptoms and how treatment can help	Education to learn about symptoms and how treatment can help	Identification of a target memory, image, and belief about the trauma
Component 2	Becoming aware of your thoughts and feelings	Breathing retraining to help you relax and manage distress	Desensitization and reprocessing which involves focusing on mental images while doing eye movements that the therapist has taught the individual receiving therapy
Component 3	Learning skills to challenge your thoughts and feelings (cognitive restructuring)	Real world practice (in vivo exposure) to reduce distress in safe situations that have been avoided	Installing positive thoughts and images, once the negative images are no longer distressing
Component 4	Understanding the common changes in beliefs that occur after going through trauma	Talking through the trauma (imaginal exposure) to get control of thoughts and feelings related to the trauma	Body scan to focus on tension or unusual sensations in the body to identify any additional issues you may need to address in later sessions

PTSD, posttraumatic stress disorder.

in the brain (NCPTSD, 2007). Low levels of serotonin are correlated with poorer mood states. Both sertraline (Zoloft) and paroxetine (Paxil) are approved by the FDA for the treatment of PTSD (NCPTSD, 2009a). The three most common side effects of these medications are nausea, decreased libido, and feeling drowsy, tired, or sleeping too much (NCPTSD, 2009a).

### Treatment Approaches for Posttraumatic Stress Disorder in Palliative Care

Although there are several effective evidence based treatments for PTSD, there are several problems with these standard psychological treatments in a palliative care setting. First, these approaches often are too demanding for individuals receiving palliative care. The manualized treatments require anywhere from 12–18 sessions with each session lasting 60–90 minutes. The life expectancy for many individuals receiving hospice care may not be sufficient enough to complete treatment and the length of sessions may require too much stamina. This may present a problem for the clinician who is considering initial therapy because completion of treatment is paramount given that the interventions may lead to short-term distress with an increase in symptoms prior to full relief of symptoms (Feldman, 2011).

Second, the current evidence-based treatments that are available are designed for traumas that have ended (Feldman, 2011). If an individual's PTSD is related

to his or her medical diagnosis, the trauma is ongoing and requires a different approach to care. Third, existing PTSD treatments do not address EOL issues. Incorporating traumatic events into the life review process is an important aspect of EOL care, particularly if the trauma has not been previously processed. As discussed earlier, PTSD also can have a significant impact on family members. There is little role for family members in existing PTSD treatments. Lastly, for some older adults with cognitive deficits, PTSD treatments may need to be adapted based on the individual's specific neurocognitive deficits (Kaiser et al., 2013).

■ **A Palliative Approach to Posttraumatic Stress Disorder at the End of Life.** As a result of these shortcomings related to standard evidence-based treatments for PTSD, a new approach needed to be developed for a palliative care setting. Feldman (2011) proposed a staged, patient-centered model for treating PTSD symptoms at the EOL. Movement from one stage to the other is dictated completely by the individual's palliative care needs with particular attention to life expectancy as well as the nature and acuity of symptoms. Stages of the model are highlighted in Table 22.3 and each stage is described in detail below (Feldman, 2011).

Stage I of the model is designed to palliate immediate discomfort and provide social support. This stage is best suited for palliative care patients who are unable to tolerate time-intensive interventions either because of a short life expectancy or fatigue.



**TABLE 22.3 A Staged Model for Treating PTSD at the EOL**

Stage I: Palliate immediate discomfort and provide social supports
Stage II: Provide psycho-education and enhance coping skills
Stage III: Treat specific trauma issues

EOL, end of life; PTSD, posttraumatic stress disorder.

Immediate distress is alleviated through emotional support and environmental adaptations, such as the presence of supportive family and other caregivers as well as creating safe and comforting surroundings. Communication techniques that are used during this stage include active listening, reassurance, and mediating discussions with medical providers or family members. Direct assistance with problem solving (such as finding a notary or notifying a family member) and working with health care providers and family about how to avoid triggering PTSD symptoms also are important aspects of Stage I (Feldman, 2011).

Providing psycho-education regarding PTSD and enhancing coping strategies is the goal of Stage II. Consistent with a palliative care approach, Stage II is designed to enhance the quality of life (QOL) by helping the individual better manage PTSD symptoms. Education and training on the symptoms of PTSD are given to the patient, family, and interprofessional treatment team members. Evidence-based cognitive-behavioral therapy (OBT) coping strategies, such as relaxation (Goldfried & Davison, 1994), cognitive restructuring (Beck, 1995), and acceptance-based techniques (Hayes, Strosahl, & Wilson, 2003), are taught to the patient. A mental health provider can help match a CBT technique to a particular CBT symptom. For example, relaxation and breathing techniques can help to reduce somatic symptoms of anxiety and cognitive restructuring assists with distorted thinking regarding either the medical condition or trauma (Feldman et al., 2013). Problem-solving and communication skills are also often taught during Stage II. A mental health provider often initially teaches the patient these coping skills and then the use of these skills are encouraged by care partners, including family and interprofessional treatment team members.

Stage III involves the treatment of specific trauma issues. The application of specific evidence-based treatment approaches (e.g., CBT) only occurs after consideration is given to the patient's preference, prognosis, energy level, and life expectancy. As part of a palliative care approach to PTSD, a life review based exposure approach conducted by a mental health practitioner is recommended (Feldman, 2011).

A safe environment is established that would allow the individual to share traumatic memories. The patient dictates the pace of the life review sessions, with sessions typically occurring more frequently and for a shorter duration than other previously discussed approaches. During the life review, the therapist places an emphasis on reframing and meaning making in a semistructured format through the use of a set of planned questions that promote life review dictated by the pace and content choice of the patient (Feldman, 2011).

### ■ Role of Interprofessional Treatment Providers.

Nurses and other interprofessional treatment team members play a vital role in the successful implementation of a palliative care approach to manage PTSD symptoms. Prior to the development of the stage-based model to manage PTSD symptoms at the EOL, Feldman and Periyakoil (2006) outlined general considerations for the psychosocial management of PTSD, which included adopting a patient-centered approach, educating the staff, educating the patient, and developing a set of PTSD resources. These recommendations included a focus on communication skills (i.e., active listening, empathy, and respecting the individual's autonomy and staff education; emphasizing how PTSD symptoms influence nursing care). According to the authors of this chapter, these general approaches to the psychosocial management of PTSD at the EOL should be followed by all disciplines regardless of the degree of mental health resources available.

Interprofessional treatment providers can also directly implement portions of the stage-based model to manage PTSD symptoms (Feldman, 2011). For example, in Stages I and II, practitioners outside of mental health should be able to assist in the identification of PTSD symptoms and implement effective environmental interventions. In order to facilitate this, both active and passive approaches to staff education need to be implemented in palliative care settings. An active approach to staff education is to require general training on PTSD symptoms by palliative care staff. Free, online educational resources (see *Resources* section for listing) are accessible to the general public. Interprofessional treatment practitioners with some expertise in the management of PTSD can educate staff during interprofessional treatment team meetings and even through their charting notes. For example, when a chart review reveals a potential or confirmed diagnosis of PTSD, the provider can alert others to possible symptoms of PTSD and their impact on patient care. An example of this documentation is as follows:

Clinical literature has documented that veterans with PTSD may have an increase in symptoms when dealing with issues related to palliative care, even if symptoms were well controlled

prior to the change in health status. Common PTSD symptoms related to palliative care include: intense anxiety, anger, guilt, or sadness; poor medical adherence; difficulty engaging in direct problem focused communication regarding care; refusal of care or excessive questioning of providers actions or distrust of authority.

Staff education is the essential component to the implementation of successful interventions to manage PTSD at the EOL.

■ **Pharmacologic Approaches to Treat Posttraumatic Stress Disorder at End of Life.** Pharmacological approaches to the treatment of PTSD are important to consider in conjunction with psychosocial approaches, particularly when life expectancy is limited (Feldman, 2011). Patient preference regardless of life expectancy may also dictate the use of pharmacological approaches. Therefore, interprofessional practitioners should know that there are two major classes of medications that have been shown to be effective for alleviating symptoms of PTSD. The first major class of drugs is the selective serotonin reuptake inhibitors (SSRIs), which have been found to alleviate the avoidance and numbing symptoms associated with PTSD (NCPTSD, 2009a). The second class of medications are tricyclic antidepressants (TCAs), which have been shown to alleviate intrusive symptoms, anxiety and depressed affect (NCPTSD, 2009a).

In conjunction with SSRIs or TCAs, practitioners may also choose to prescribe other medications such as benzodiazepines. Benzodiazepines can be prescribed in combination with SSRIs in order to alleviate anxiety, panic, and hyperarousal symptoms (NCPTSD, 2009a). It is important to note that benzodiazepines are not recommended for long-term treatment of PTSD because they have not been found to treat the core symptoms of PTSD and have

additive properties, although they can be effective for EOL care. Although there is a paucity of research on medication to treat PTSD at the EOL, a more detailed review of pharmacotherapy for PTSD can be found on the National Center for PTSD website.

## ■ FUTURE DIRECTIONS

The need for additional research on the impact of PTSD and EOL care was recommended more than two decades ago during the National Cancer Institute of Canada Workshop on Symptom Control and Supportive Care in Patients with Advanced Cancer (Breitbart, Bruera, Chochinov, & Lynch, 1995). During this workshop, the panelists recommended the need for prevalence and intervention studies on PTSD among advanced cancer patients. Despite the apparent need, there continue to be very limited data on the prevalence of PTSD and effectiveness of evidence-based interventions to address PTSD in palliative care patients. For example, PTSD symptoms often influence the perception and experience of pain at the EOL (Chang et al., 2007). Informative and evidence-based websites regarding PTSD symptoms across the life span exist; however, none of them to date include recommendations regarding EOL care. To provide quality palliative care, educating the treatment team members on the management of PTSD at the EOL needs to form a core component of palliative care training. However, with the exception of the End-of-Life Nursing Education Consortium for veterans, PTSD is not even addressed. Regardless of whether or not an individual meets criteria for a PTSD diagnosis or has PTSD-like symptoms as the result of an acute medical procedure, his or her symptoms will need to be palliated. Education and research in the area of PTSD and EOL is in need of development.

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## CASE STUDY Conclusion

Prior to reviewing a chart for mental health issues or directly working with the patient, there are often clues that might suggest a diagnosis of PTSD. In this case, key aspects included basic patient demographics (e.g., Vietnam-era veteran, American Indian), mistrust of the medical system, and poor medical compliance. Appropriate assessment approaches might include a chart review, intake interview that would include evaluation of past traumatic events, the meaning of those traumas, and screening measures to identify symptoms in need of intervention. A structured clinical interview is less often used when life expectancy is limited. The goal of the assessment in palliative care is to identify which symptoms of PTSD are currently distressing to the patient and to determine how



to best manage these symptoms to improve the individual's QOL. Appropriate interventions include making sure the interprofessional treatment team is aware of any mental health diagnoses, such as PTSD. Effective communication skills and developing a strong rapport with the individual is vital to build a trusting relationship. Environmental adaptations such as knocking on the door before entering and not abruptly waking patients will help to prevent symptoms related to an exaggerated startle response. Psycho-education and techniques for enhancing coping strategies shall be based on life expectancy and their level of fatigue.

## Evidence-Based Practice

Alici, Y., Smith, D., Lu, H., Bailey, A., Shreve, S., Rosenfeld, K., &...Casarett, D. (2010). Families' perceptions of veterans' distress due to posttraumatic stress disorder-related symptoms at the end of life. *Journal of Pain & Symptom Management*, 39(3), 507–514. doi:10.1016/j.jpainsymman.2009.07.011

### Objectives

To define the frequency of posttraumatic stress disorder (PTSD)-related symptoms among veterans who are near the end of life and to describe the impact that these symptoms have on patients and their families.

### Methods

Patients had received inpatient or outpatient care from a participating VA facility in the last month of life, and one family member per patient was selected using pre-defined eligibility criteria. Family members then completed a telephone survey, The Family Assessment of Treatment at End-of-Life, which assessed their perceptions of the quality of the care that the patients and they themselves received during the patients' last month of life.

### Results

Seventeen percent of the patients (89 of 524) were reported to have had PTSD-related symptoms in the last month of life. PTSD-related symptoms caused discomfort less often than pain did (mean frequency score 1.79 vs. 1.93; Wilcoxon sign rank test,  $p < .001$ ) but more often than dyspnea did (mean severity score 1.79 vs. 1.73; Wilcoxon sign rank test,  $p < .001$ ). Family members of patients with PTSD-related symptoms reported less satisfaction overall with the care the patient received (mean score 48 vs. 62; rank sum test,  $p < .001$ ). Patients who received a palliative care consult ( $n = 49$ ) had lower ratings of discomfort attributed to PTSD-related symptoms (mean 1.55 vs. 2.07; rank sum test,  $p = .007$ ).

### Conclusions

PTSD-related symptoms may be common and severe among veterans near the end of life and may have a negative effect on families' perceptions of the quality of care that the veteran received.

## RESOURCES

National Center for PTSD—[www.ptsd.va.gov](http://www.ptsd.va.gov)

National Center for Child Traumatic Stress Network—[www.nctsn.org](http://www.nctsn.org)

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# Gastrointestinal Symptoms

## CHAPTER

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**KEY POINTS**

- Gastrointestinal (GI) symptomatology is common in patients receiving palliative care; however, research to support evidence-based interventions in this population specifically is insufficient.
  - Assessment of GI symptoms in patients in palliative care should begin with identification of the underlying cause that may be related to the pathology and/or treatment.
  - The evidence to support treatment of nausea and vomiting (N&V) in palliative care is mostly drawn from chemotherapy-induced nausea and vomiting (CINV); however, the mechanisms and pathophysiology of CINV and the N&V of the palliative care population may be very different.
  - The diagnosis and treatment of dysphagia is based on the patient's prognosis. With a longer prognosis, medically assisted feeding and hydration may be attempted. With a shorter prognosis, the treatment may be different.
  - Multiple medications, although primarily opioids, are a principal cause of constipation in the palliative care population.
  - Laxatives may be used either as a preventive measure, or as treatment for constipation.
  - Signs and symptoms of bowel obstruction are based on the site of the obstruction. In older adults, the signs and symptoms of obstruction may be less apparent than in the younger population.
  - The most common cause of diarrhea in palliative care is inappropriate laxative therapy.
- 

**CASE STUDY**

Three months ago, Mrs. Adams was diagnosed with pancreatic cancer with metastasis to her stomach, liver, and intestines, resulting in a poor prognosis. Mrs. Adams is 65 years of age with a history of tobacco and alcohol use on a regular basis. There is no family history of cancer, and Mrs. Adams had no significant health history until this diagnosis. With the involvement of other organs, she made the decision not to have surgery. She is admitted to the medical unit today for severe abdominal pain, constipation, nausea, and vomiting.

The nurse completed the admission assessment and finds that she is jaundiced and has a bruit located in the left upper quadrant. A nasogastric tube has been inserted and is connected to low suction. Breath sounds reveal fine crackles in the bases bilaterally. Mrs. Adams states that her appetite has been poor, and she has not been taking the Viokase as prescribed because of her vomiting. Her last stool was 2 days ago, consistent with diarrhea. She states that she has been taking morphine sulfate subcutaneously at home and an antiemetic that she cannot remember the name of. Mrs. Adams's daughter is with her today and is concerned that her mother waited too long to come to the hospital for treatment of her symptoms. Lab results include total bilirubin of 4 mg/dL, amylase 2,500 IU/dL, AST 30 units/L, Hgb 4.0 g/dL and Hct 13%, Na 133, and K<sup>+</sup> 3.4 mEq/L. Arterial blood gas results demonstrate pH of 7.33, PaCO<sub>2</sub> 34, and HCO<sub>3</sub> 21. The chest x-ray shows bilateral pleural effusions.

In most countries of the world, sharing meals with others is a social activity. The primary purpose of the meal may be consumption of food; however, the socialization with others while eating may be even more important. Communities, organizations, and churches often have potluck suppers where individuals gather to share a meal. If an individual is unable to share a meal with others due to gastrointestinal (GI) symptomatology, the effect on the emotional health of the individual from being socially isolated and unable to participate in such activities may be greater than the physical effects of the symptoms.

While the full scope of the problem is uncertain, it is well established that both adult and pediatric patients at the end of life suffer from GI symptoms. For those with cancer, nausea and vomiting (N&V) occurs in nearly 50% of patients (Dean, Harris, Regnard, & Hockley, 2006). Individuals with chronic kidney disease often suffer from numerous GI symptoms due to uremia. In particular, they are prone to development of upper GI symptoms including erosive gastritis, ulcerative esophagitis, and duodenitis (Thomas et al., 2013). GI symptomatology is also common in AIDS patients and end stage heart failure (Dean et al., 2006). Patients suffering from continuous nausea, vomiting, or diarrhea may be precluded from leaving their care setting, whether it is home, assisted living, or a long-term care facility, and may affect their quality of life and the ability to function normally.

The incidence of GI symptoms in children who die of non-cancer-related illness is unknown; however, GI symptomatology in pediatric cancer patients at the end of life is significant. Common GI symptoms include pain, constipation, and N&V. These may be a result of the disease process itself or treatments such as chemotherapeutic agents. In addition, treatment of symptoms with medications such as narcotics can contribute to constipation and N&V. Decreased PO intake, poor hydration, and decreased activity all can contribute to the GI symptoms as well (Klick & Hauer, 2010). This chapter focuses on the cluster of GI symptoms that occur in the patient who is under palliative care.

There are multiple ways of assessing and diagnosing the symptomatology that a patient may develop from the side effects of treatment and/or comfort measures. A mnemonic, developed by Esper and Heidrich (2005), gives the caregiver a resource in assessing and managing the multiple symptoms that may be experienced by the patient (Esper & Heidrich, 2005, p. 20):

- R—Review the situation
- E—Explore findings
- S—Strategize a plan of action
- C—Carry out the plan
- U—Umbrella resources
- E—Evaluate and modify as needed

## ■ NAUSEA AND VOMITING

N&V are unpleasant GI symptoms that often are described by patients as more severe and disabling than pain (Chilton & Faull, 2005). Although nausea may occur without vomiting on occasion, they commonly occur together and are discussed in tandem in this chapter. Nausea is a nonobservable subjective symptom involving an unpleasant sensation experienced in the back of the throat and the epigastrium that precedes but may or may not result in vomiting (Rhodes & McDaniel, 2001). Patients will state that they feel as though they are about to vomit or use other descriptors including “sick to the stomach” or “queasy.” Vomiting is the forceful expulsion of gastric contents through the oral or nasal cavity, which typically is preceded by nausea (Rhodes & McDaniel, 2001).

Although N&V are primarily associated with chemotherapy in cancer treatment, these symptoms occur in 40% to 70% of all patients in palliative care settings (Dalal, Del Fabbro, & Bruera, 2006). While chemotherapy is also used as a palliative measure in the oncology population, patients with AIDS, heart, renal, and hepatic failure often have nausea during the disease process and at the end of life as well (Barnes et al., 2006; Mannix, 2005).



Most of the literature regarding management and treatment is derived from studying chemotherapy-induced nausea and vomiting (CINV). As this type of N&V differs both in mechanism and in pathophysiology from N&V due to advanced disease, it is important to note that these findings may not be completely applicable to the palliative care setting (Tyler, 2000). Unfortunately, little progress has been made in understanding the mechanism and determining optimal treatment of multicausal N&V or non-chemotherapy-related N&V (King, 2006).

## Etiology of Nausea and Vomiting

N&V involve activity at multiple levels of the nervous system. Two distinct sites in the medulla are critical for the control of emesis: the vomiting center (VC) and the chemoreceptor trigger zone (CTZ; Dalal et al., 2006). The VC is not a discrete anatomical structure but represents an interrelated neural network including the nucleus tractus solitarius (NTS) and the dorsal motor nucleus of the vagus (DMV). The NTS is where numerous afferent neuronal pathways from these sources converge. Once the NTS receives signals from the various afferent sources, this information is processed and the DMV emits an appropriate

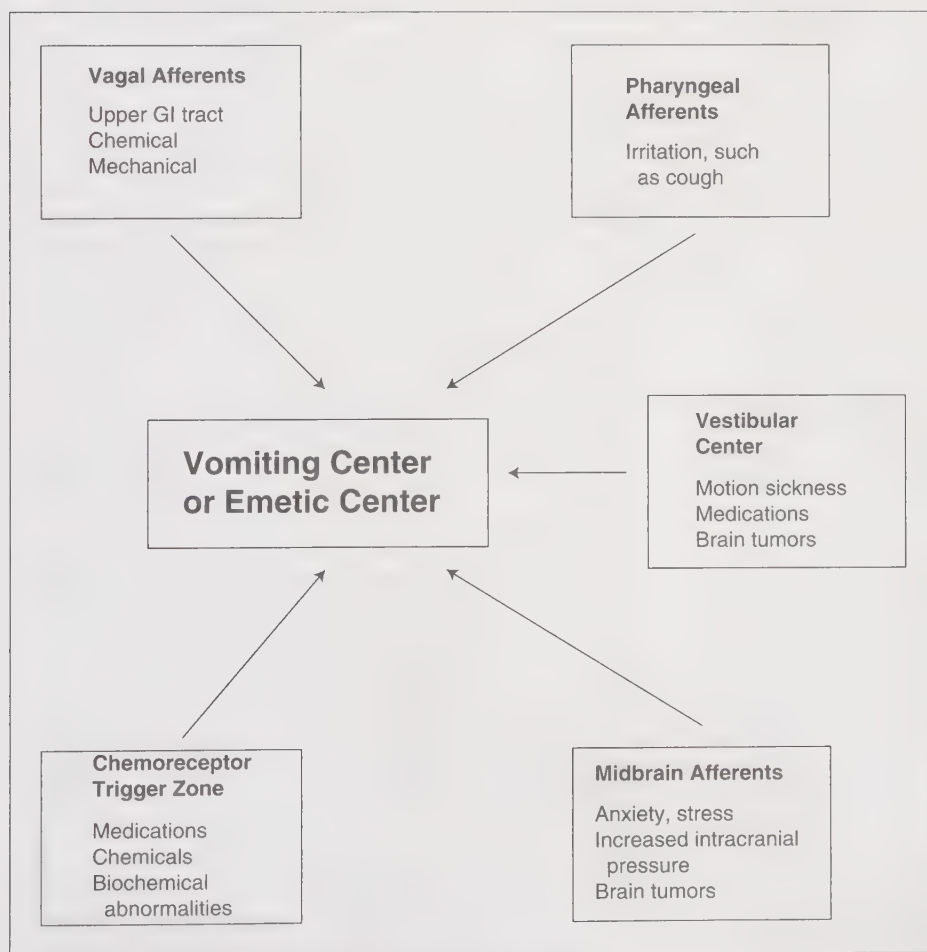
vasomotor response (respiratory, salivary, gut, diaphragm, and abdominal muscles), including nausea, retching, or vomiting, depending on the intensity of the signals (Dalal et al., 2006).

Multiple pathways stimulate the VC. Understanding the pathways is necessary to determine the cause and appropriate treatment (King, 2006). The various pathways include (King, 2006):

- Peripheral pathways
  - Vagal afferents
  - Pharyngeal afferents
  - Vestibular system
- Central pathways
  - Midbrain afferents
  - Chemoreceptor trigger zone (CTZ)

Figure 23.1 demonstrates the various pathways and potential factors that may contribute to each.

Table 23.1 lists potential causes and conditions associated with N&V that may occur in patients receiving palliative care. It should be emphasized that if comorbidities exist, the etiology of N&V may be difficult to ascertain. This is particularly an issue in the older adult who may have more than one disease process present. As with the case of chemotherapy, the



**FIGURE 23.1** Physiological symptoms of nausea and vomiting. (Source: Adapted from King, 2006.)

**TABLE 23.1 Causes of Nausea and Vomiting in Palliative Care**

Chemoreceptor trigger zone-mediated
■ Medications
– Opioids
– Antibiotics
– Chemotherapy
– Corticosteroids
– Digoxin
– Nonsteroidal anti-inflammatory drugs (NSAIDs)
– Iron
■ Metabolic
– Hypercalcemia
– Hyponatremia
– Uremia
Midbrain afferents
■ Emotional factors
– Anxiety
– Fear
– Pain
■ Increased intracranial pressure
■ Primary or metastatic brain tumors
■ Meningitis
Vagal afferents
■ Gastrointestinal distention, stasis, or obstruction
■ Constipation
■ Gastritis
■ External pressure (“squashed stomach syndrome”)
Pharyngeal afferents
■ Thick sputum
■ Oral infection
■ Chronic cough
■ Unpleasant tastes
Vestibular apparatus
■ Motion sickness
■ Brain tumors
■ Opioids

Source: Adapted from Gullatte et al., 2005, p. 230.

treatment itself often contributes to the symptoms as well. Without a clear appreciation of the cause, successful treatment may become even more challenging.

## Signs and Symptoms

A sign is the objective evidence of what is occurring with the patient; in this case, the presence of vomitus in any amount is objective evidence. Nausea, however, is a subjective symptom that the patient experiences, and it is not measurable to the caregiver. Although it is not objective, nausea may produce significant distress for the patient, and affect activities of daily living and quality of life.

N&V may have accompanying signs and symptoms. With nausea, there may be evidence of increased salivation and swallowing, perspiration, and tachycardia.

In patients with N&V triggered by GI tract stasis, there may be accompanying epigastric discomfort, fullness, early satiety, flatulence, acid reflux, hiccups, and large volume vomitus (possibly projectile). In patients with N&V associated with increased intracranial pressure (ICP), headache and nausea, both diurnal in nature, may occur. Other neurological signs may or may not be present with increased ICP.

## Assessment of Nausea and Vomiting

There are a number of factors to consider when assessing the N&V of a patient. Some data can be obtained from self-report or from family caregivers, while other information may be objective. Assessment of N&V includes frequency and duration of symptoms, color, amount and consistency of vomitus, contributing factors to the N&V, pattern of the N&V, presence of abdominal pain, presence of other abdominal symptoms, and disruption to the patient (e.g., can the patient continue activities of daily living and other “normal” activities with N&V present?).

Patients should be questioned about the frequency of their bowel movements because in the palliative care population, as with the elderly, chronic constipation is frequently present and may contribute to nausea. In patients with cancer, it is important to obtain details of the sites of the tumor involvement as well. Intra-abdominal cancer involvement may lead to nausea with or without vomiting and can often be caused by liver metastasis, bowel obstruction by the tumor, or peritoneal carcinomatosis (Dalal et al., 2006). Unrelieved pain is also another common cause of N&V. Pain originating from the GI tract, whether related to luminal disruption or visceral sensitivity, often exacerbates N&V (Kenny, 2007). Narcotics, commonly used in the treatment of pain, are well established as a cause of N&V as well (Buenaventura, Adlaka, & Sehgal, 2008).

A large number of medications are associated with nausea; thus, a detailed medication history is necessary. Nausea often accompanies the use of opioids, nonsteroidal anti-inflammatories, anticholinergics, and antibiotics. Many of these are commonly used in treatment and symptom management of the patient in palliative care. Patients with HIV often have nausea as a side effect of all of the highly active antiretroviral therapy (HAART) drugs. Physiological changes such as decreased renal function, variations in body fat distribution, and alterations in hepatic metabolism can lead to higher levels of medications and a greater susceptibility to adverse effects in the geriatric patient (Bishop & Morrison, 2007; Gullatte, Kaplow, & Heidrich, 2005, p. 229). Alterations or discontinuation of corticosteroids or high-dose progesterone therapy can also lead to N&V due to adrenal insufficiency (Morrow, Hickok, Andrews, & Stern, 2002). Assessing for



hypercalcemia, hyponatremia, and SIADH (syndrome of insufficient and diuretic hormone), particularly in cancer patients, is important. High levels of serum calcium and low sodium stimulate the CTZ and may incite N&V (Gullatte et al., 2005).

History should be directed to understand possible causes of the symptoms. Glare, Miller, Nikolova, and Tickoo (2011) offer six such questions and suggested etiology: (a) Intermittent nausea associated with early satiety and postprandial fullness or bloating. It is relieved by vomiting that is usually small volume, occasionally forceful, and may contain food. This suggests impaired gastric emptying and is the cause in 35% to 45% of cases. (b) Persistent nausea, aggravated by the sight and smell of food, unrelieved by vomiting. This suggests chemical causes, activating the CTZ. It is found in 30% to 40% of cases. (c) Intermittent nausea associated with abdominal cramping and altered bowel habits. It is relieved by vomiting that may be large in volume and bilious or feculent. This suggests a bowel obstruction and is the cause in 10% to 30% of cases. (d) Early morning symptoms associated with headache that suggest raised ICP. (e) Nausea aggravated by movement, including motion sickness or even just turning the head. This indicates a vestibular component. (f) N&V associated with anxiety, suggesting a cortical component. The final three occur in less than 15% of patients (Glare et al., 2011).

Assessing the young child for causes of N&V is often more challenging. Although the above-mentioned assessment guide can be used, very young children may have difficulty differentiating between nausea and pain (Santucci & Mack, 2007). Even older children may have confusion in understanding and describing the difference between nausea, GI reflux symptoms, and pain.

As part of the assessment, it is essential to understand if the patient considers the N&V to affect his or her quality of life or if it is seen merely as a nuisance. To have a clearer understanding of the patient's N&V, an instrument with known reliability and validity should be utilized.

■ **Instruments.** Accurate assessment of signs and symptoms can better determine the pattern of occurrence, if there is one, and the effect of interventions. There are both self-report and observer-report tools, although there is a debate as to which type of tool is best (Saxby, Ackroyd, Callin, Mayland, & Kite, 2007). Some see self-report as essential to determine effective interventions, while others believe that the antiemetic medications given can cause sedation, mood alteration, disorientation, or memory loss, and thus accurate self-report may be affected (Saxby et al., 2007). Many of the specific tools have been validated

in chemotherapy outpatient settings, although none have been extensively validated for assessment of emesis in a palliative care population specifically (Saxby et al., 2007).

Rhodes (1997) suggests the following points when using an instrument to measure N&V: (a) use self-report tools; (b) determine and describe the symptoms; (c) consider the clarity, cultural sensitivity, and understandability of the tool; (d) consider reliability and validity of the tool; (e) use an instrument in an easy-to-read format; (f) consider the purpose of the tool and for what population of patients; and (g) consider the type of scoring and the ease of scoring.

The tools mentioned in this chapter have limited reliability and validity, specifically to the palliative care setting. Much of the focus regarding assessment of N&V has been directed toward the oncology population and the effects of CINV. The Index of Nausea, Vomiting, and Retching–Revised (INVR-R) instrument measures nausea, vomiting, retching, and the associated perceived patient distress. The tool is an 8-item 5-point Likert-type self-report tool with “check the box inserts.” Although it was originally developed for the adult oncology population, it has been demonstrated to have use with other populations also (Rhodes & McDaniel, 1997; Saxby et al., 2007). Of the multiple assessment tools for nausea, vomiting, and retching, the INVR has been shown to be the most reliable (Wood, Chapman, & Eilers, 2011).

A number of other instruments are more global in nature and include examining all symptomatology present. These include the Visual Analog Scale (VAS), Verbal Categorical Scale (VCS), Adapted Symptom Distress Scale (SDS-2), and the Edmonton Symptom Assessment Scale (ESAS; Saxby et al., 2007). The use of reliable and valid instruments is necessary to develop evidence-based interventions to assist patients with these symptoms.

## Management of Nausea and Vomiting

A thorough evaluation to determine both the etiology of the symptoms and the pathophysiological mechanism by which they are triggered allows directed interventions to begin. Therapy should not only include antiemetics, but also measures to alleviate the cause of the symptoms. Interventions should take into account the symptoms and the central emetogenic pathways involved (Mannix, 2005). There remains a gap in the evidence regarding high-quality studies in the management of N&V in chronic advanced disease other than related to cancer and its treatment (Brunnhuber, Nash, Meier, Weissman, & Woodcock, 2008).

■ **Pharmacological Interventions of Nausea and Vomiting.** Although progress has been made in

identifying antiemetic agents that alleviate CINV, little work has been accomplished to establish drugs that alleviate the N&V experienced at the end of life specifically. Benze, Geyer, Alt-Epping, and Nauck (2012) reviewed 75 studies to analyze the current evidence for antiemetic treatment with 5-HT<sub>3</sub> receptor antagonists, steroids, antihistamines, anticholinergics, somatostatin analogs, benzodiazepines, and cannabinoids in palliative care patients with far advanced cancer not receiving chemotherapy or radiotherapy, AIDS, chronic obstructive pulmonary disease (COPD), progressive heart failure, amyotrophic lateral sclerosis (ALS), or multiple sclerosis (MS). And while the overall strength of evidence is low and they acknowledge that well-designed studies in palliative care patients are needed to provide evidence-based therapy, there is evidence that several different treatments, often in combination, do offer some beneficial symptom relief (Benze et al., 2012).

Having an understanding of the potential causes of N&V in the palliative care patient is essential in directing the correct therapy toward symptom relief.

Different antiemetics act on different parts of the N&V process; therefore, when antiemetics are not prescribed correctly, optimal results will not occur. These sites hold receptors for one or more neurotransmitters, including dopamine type 2 (D<sub>2</sub>), serotonin types 2 to 4 (5HT<sub>2-4</sub>), histamine type 1 (H<sub>1</sub>), and acetylcholine (muscarinic receptors type 1 to 5, M1–5). Other receptors such as substance P, cannabinoid type 1 (CB1), and the endogenous opioids may also be involved (Glare et al., 2011). Table 23.2 lists examples of drugs, site of action, receptors, and comments that may be useful in determining the appropriate antiemetic choice.

Mannix (2005) recommends seven steps in choosing the appropriate antiemetic: (a) identify the cause of the N&V, (b) identify the pathway triggering the vomiting reflex, (c) identify the neurotransmitter receptor involved in the pathway, (d) choose the most potent antagonist to the receptor identified, (e) choose a route of administration that ensures optimal action, (f) titrate the dosage, and (g) if symptoms persist, review the cause (pp. 459–460).

**TABLE 23.2 Receptor-Specific Antiemetics for Use in Palliative Care**

Drug	Site	Receptor	Comments
Haloperidol	CTZ	Dopamine antagonist	Use in opioid-induced nausea and chemical and mechanical nausea; use when anxiety symptoms aggravate N&V; may have additive effects with other CNS depressants.
Metoclopramide Cisapride	CTZ GIT	Metoclopramide is a dopamine antagonist at low doses; at doses greater than 120 mg/24 hr, it becomes a 5-HT <sub>3</sub> antagonist	Use in gastric stasis, ileus, and chemotherapy; use diphenhydramine to decrease extrapyramidal symptoms; cisapride has potentially fatal cardiac arrhythmias
Phenothiazines (prochlorperazine, chlorpromazine, levomepromazine, thiethylperazine)	CTZ GIT VC	Predominantly as dopamine antagonists	Use in intestinal obstruction, peritoneal irritation, vestibular causes, raised ICP, and nausea of unknown etiology; extrapyramidal effects; not recommended for routine use
Scopolamine	VC	Anticholinergic	Use in intestinal obstruction, increased ICP, and peritoneal irritation; useful if N&V exists with colic
5-HT <sub>3</sub> receptor antagonists (ondansetron, granisetron, tropisetron, palonosetron)	CTZ VC GIT	Serotonin antagonist	Use in chemotherapy, abdominal radiation, and postop N&V; safe for children and older adults; effectiveness increased by combining with dexamethasone
Antihistamines (cinnarizine, cyclizine, diphenhydramine, promethazine)	VC	H <sub>1</sub> receptor	Use in intestinal obstruction, increased ICP, vestibular causes and peritoneal irritation; cyclizine is the least sedative

CNS, central nervous system; CTZ, chemoreceptor trigger zone; GIT, gastrointestinal tract; ICP, intracranial pressure; N&V, nausea and vomiting; VC, vomiting center.

Sources: Adapted from Dalal et al. 2006; Gullatte et al., 2005; King, 2001; Mannix, 2005.



Some antiemetics are not well tolerated in older adults, often as a result of impaired renal or hepatic clearance. Metoclopramide, for example, must be used with caution in older adults as decreased hepatic function increases drug toxicity and increases the incidence of extrapyramidal effects such as tardive dyskinesia (Gridelli, 2004). Although typically the dosage guidelines of the most common 5-HT<sub>3</sub> receptor antagonists do not differ, these drugs do vary in terms of receptor selectivity, duration of action, and metabolism (Gridelli, 2004). These differences may have potential clinical implications in older adults and should be considered. As an example, granisetron has a duration of action of 24 hours, while ondansetron's action is 9 hours. Additionally, three of these drugs, dolasetron, palonosetron, and tropisetron, have cardiovascular effects and should not be prescribed to patients of any age with a cardiovascular history (Gridelli, 2004). Regardless of the antiemetic agent, it is imperative to have an understanding of the drug and its properties to ensure a positive effect and prevent potential adverse outcomes.

Drugs from other classifications may be used in palliative care as well. These include corticosteroids, octreotide, cannabinoids, and benzodiazepines. Corticosteroids have intrinsic antiemetic properties and have been known to enhance the effects of other antiemetics (Mannix, 2005). They should be considered cautiously, however, given the potential negative effects of prolonged therapy including adrenal suppression, increased risk for development of infection, psychosis, and altered glucose control. There is also evidence that cannabinoids may reduce N&V in CINV. Studies assessing its use in individuals with advanced disease are lacking and its use is indicated only in patients with symptoms refractory to conventional treatment. Benzodiazepines have been used in combination with other antiemetics in chemotherapy. Although they have little antiemetic potency on their own, in combination, they may also reduce anxiety and akathisia (Mannix, 2005). While the research is ongoing, it seems that treatment of N&V utilizing multiple therapies is more effective than any one agent alone (Slatkin, 2007).

The National Comprehensive Cancer Network (NCCN) has published guidelines for treatment of N&V in the palliative care patient. From a treatment perspective, it outlines an approach that titrates and adds therapy based on the patient's symptom response. The algorithm starts with titrating and maximizing oral dopamine receptor antagonists (e.g., prochlorperazine, haloperidol, metochloperamide), then adding 5-HT<sub>3</sub> blockers (e.g., ondansetron) as well as possibly anticholinergics (e.g., scopolamine), antihistamines (e.g., meclizine), and cannabinoids. If symptoms persist then the addition of corticosteroids (e.g., dexamethasone) may be beneficial. With continued symptoms,

it is recommended that the previous therapy be tried by infusion or the subcutaneous injection route. With severe protracted symptoms, adding alternative therapy (e.g., acupuncture, hypnosis, cognitive behavior therapy) may be beneficial (National Comprehensive Cancer Network, 2012).

Medications appropriate for use in the pediatric client include ondansetron, lorazepam, promethazine, dexamethasone, metoclopramide, diphenhydramine, octreotide, meclizine, olanzapine, scopolamine, and hydroxyzine (Hellsten & Kane, 2006; Hinds, Oakes, Hicks, & Anghelescu, 2005; Santucci & Mack, 2007). As with the adult patient, identification of the possible cause as well as treatment of the source when possible is paramount to symptom control.

■ **Nonpharmacological and Complementary Interventions for Nausea and Vomiting.** Often there are adjunct interventions to accompany medications. Establishing a research basis for those interventions is more difficult, although much has been written using anecdotal data. Research studies in the literature are based on patients with CINV and not specifically patients with N&V at the end of life.

Simple self-care strategies may be instituted to control N&V (Table 23.3), which may start with dietary and environmental changes. Avoidance of environmental stimuli, such as sights, sounds, or smells that may initiate nausea, is recommended (Glare et al., 2011). Encouraging the patient to use interventions that have relieved N&V at other times in his or her life, such as during pregnancy, illness, or times of stress, may be helpful. A particular food associated with a positive past experience can be suggested (Enck, 2002). Dietary changes such as drinking clear liquids and eating bland foods may be helpful as well. Minimizing

**TABLE 23.3 Self-Care Activities for Nausea and Vomiting**

■ Oral hygiene after each emesis
■ Cool, damp washcloth to the forehead, neck, and wrists
■ Eat bland, cool foods
■ Have fresh air with a fan or open window
■ Limit environmental stimuli that precipitate nausea and vomiting
■ Lie flat for 2 hr after eating
■ Eat small meals
■ Practice relaxation techniques and/or guided imagery
■ Provide distraction

Sources: Adapted from Enck, 2002; Glare et al., 2011; Kemp, 1999; King, 2001; Rhodes & McDaniel, 2001.

or even eliminating liquids prior to a meal or during a meal may decrease nausea (Kemp, 1999). Patients with advanced disease often have decreased or altered taste (Tyler, 2000). When that occurs, they may prefer different foods than what they have previously enjoyed.

Patients and their families should be encouraged to keep a self-care log of symptoms, interventions, and responses. The log reinforces interventions that work for the patient and may demonstrate “good days” when the N&V was tolerable. The log can also help the patient feel more in control of his or her life in addition to providing the caregiver with information on which to base interventions.

Music therapy has shown some benefits as an adjunct therapy. Ezzone, Baker, Rosselet, and Terepka (1998) demonstrated that music therapy was a statistically significant adjunct treatment during high-dose chemotherapy to reduce N&V. Relaxation techniques and guided imagery are also complementary therapies that can be used to decrease N&V and reduce anxiety. However, the research basis of these

nonpharmacological interventions (Table 23.4) needs to be established to support evidence-based practice. While there is literature that supports the use of some nonpharmacological strategies in controlling N&V, this again is focused primarily on CINV. Tentative recommendations can be made for cognitive distraction, exercise, hypnosis, music therapy, relaxation, and systematic desensitization to CINV (Lotfi-Jam et al., 2008).

Acupuncture and ginger are two common complementary interventions used to manage N&V (Thompson & Zollman, 2005). Acupuncture is an ancient healing art using insertion of fine gauge needles to palliate symptoms. The needles are inserted into carefully chosen acupuncture points and left in place for up to 20 minutes. Multiple studies have looked at the use of acupuncture/acupressure in patients with CINV and found that evidence supports the addition of electroacupuncture by clinicians competent in its administration (Naeim et al., 2008). It has been shown that the addition of acupuncture has

**TABLE 23.4 Nonpharmacological Interventions for Nausea and Vomiting**

Behavioral Intervention	Description	Comments
Self-hypnosis	Evolution of physiological state of altered consciousness and total body relaxation. This technique involves a state of intensified attention and receptiveness to an idea	Use to control anticipatory N&V; limited studies, mostly in children and adolescents; easily learned; no side effects; decreases intensity and duration of nausea; decreased frequency, severity, amount, and duration of vomiting
Relaxation	Progressive contraction and relaxation of various muscle groups	Often used with imagery; can use for other stressful situations; easily learned; no side effects; decreases nausea during and after chemotherapy; decreases duration and severity of vomiting; not as effective with anticipatory nausea and vomiting
Biofeedback	Control of specific physiological responses by receiving information about changes in response to induced state of relaxation	Two types of electromyographic and skin temperature; used alone or with relaxation; easily learned; no side effects; decreased nausea during and after chemotherapy; more effective with progressive muscle relaxation
Imagery	Mentally take self away by focusing mind on images of a relaxing place	Most effective when combined with another technique; increases self-control; decreases duration of nausea; decreases perceptions of degree of vomiting; feel more in control, relaxed and powerful
Distraction	Learn to divert attention from a threatening situation and to relaxing sensations	Can use videos, games, and puzzles; no side effects; decreases anticipatory N&V; decreases postchemotherapy distress; inexpensive
Desensitization	Three-step process involving relaxation and visualization to decrease sensitization to aversive situations	Inexpensive; easily learned; no side effects; decreases anticipatory N&V

N&V, nausea and vomiting.

Source: Adapted from King, 1997.



a significantly positive effect on the control of CINV as opposed to antiemetic therapy alone in the pediatric population as well (Gottschling et al., 2008).

Various other alternative therapies have been studied to assess relief of N&V; however, again they tend to focus on CINV, with little evidence that is supportive of their use in other palliative care settings. Herbal interventions such as ginger, lemon, chamomile, and peppermint all have been suggested as adjuncts to traditional treatment. At best, they offer complimentary benefit to traditional and established therapy as has been described (Tipton et al., 2007).

### **Family Concerns and Considerations Regarding Nausea and Vomiting**

N&V are visible signs of an unhealthy state; as such, family caregivers can be distressed and anxious about their loved one. It is important that the nurse addresses the family's anxiety associated with N&V. Family education is vital to facilitate functioning as a care team member and helping the loved one experience an optimal quality of life.

Families should be taught to systematically assess the patient's N&V. Use of a simple log of what activity the patient is engaging in when the episode of N&V occurs provides evidence to the family and patient when the nausea increased or decreased, and how and when the vomiting occurred as well. The family and health care professional can then assess the situation by viewing the log and determine what pharmacological or nonpharmacological interventions may have offered the most relief.

## **■ DYSPHAGIA**

Dysphagia is difficulty in transferring liquids or solids from the mouth to the stomach (Regnard, 2005, p. 468). Most of the data on incidence of dysphagia come from clients with head and neck cancer. These clients may suffer from dysphagia in the early, middle, and terminal stages of the disease. One source indicates that 79% of those patients have significant eating problems (Barbour, 1999). In the late stages of MS, dysphagia is reported in 10% to 33% of clients (Dahlin & Goldsmith, 2006). In ALS, 25% of clients present with dysphagia as their initial complaint at diagnosis (Dahlin & Goldsmith, 2006). Sixty-three percent of patients with Parkinson's disease have objective evidence of difficulty with swallowing (Regnard, 2005).

### **Etiology of Dysphagia**

Swallowing is a complex activity that requires intact anatomy, normal mucosa, normal functioning of six

cranial nerves, the brainstem, the coordination of the cortex, limbic system, basal ganglia, cerebellum, brainstem centers involved in respiration, salivation, and motor function of 34 skeletal muscles (Regnard, 2005). Dysphagia may occur as a result of a disruption in any of the four stages of swallowing: oral preparatory stage; oral stage; pharyngeal stage; and esophageal stage.

Both the oral preparatory and oral stages of swallowing are voluntary actions. In the oral preparatory phase, food is taken into the mouth and saliva helps form a paste bolus. During the oral phase, the bolus is centered and moved to the posterior oropharynx. The pharyngeal phase is not voluntary, but reflexive, as the swallowing reflex carries the food bolus through the pharynx. Peristaltic waves carry the food bolus to the stomach during the esophageal phase.

Each of the stages of swallowing is affected by aging, and dysphagia is a common complaint of the older adult. The skeletal muscles involved with swallowing may undergo age-related changes of atrophy and weakness that occur in all skeletal muscles (Plahuta & Hamrick-King, 2006). Similarly, there are aging changes that occur in the nerves that innervate the oral region. Each of the stages of swallowing is a precisely timed contraction/relaxation sequence and can be affected by the aging process. The sequence may become desynchronized and the entire process of swallowing may become ineffective (Timiras, 1994).

Dahlin and Goldsmith (2006) list the causes of dysphagia commonly seen in palliative care: neoplasm (includes brain tumors, head and neck cancer, and esophageal tumors); progressive neuromuscular diseases such as ALS, Parkinson's disease, and MS; dementia; systemic dysphagia as a result of inflammatory and infectious factors; and general deconditioning that may include multisystem disease and failure, and the side effects of medications and/or polypharmacy. Each cause of dysphagia may occur for a different reason. For example, in Parkinson's disease there is disruption in the oral stage of swallowing because of rigidity of the lingual musculature (Dahlin & Goldsmith, 2006). As a result of this rigidity, pharyngeal swallow responses are delayed and aspiration may occur before or during the swallow. Regnard (2005) suggests there is a defect in the nondopaminergic pathway from the medulla and a disturbance of the oral phase due to bradykinesia (p. 468). In head and neck cancers, dysphagia may occur because of the pressure and size of the tumor, or as a result of chemotherapy, radiation, or the surgery itself.

Common side effects of radiation, mucositis and xerostomia, may further exacerbate dysphagia as well as pain on swallowing, dry mouth, anorexia, or anxiety (Baines, 1992; Rudd & Worliding, 2005).

Dysphagia may not be a part of the terminal illness itself but may be a result or symptom of other comorbidities. For example, an older adult who is terminally ill with cancer and also has advanced Parkinson's disease or has suffered a previous cerebrovascular accident has issues with dysphagia likely caused by a combination of these diagnoses.

## Signs and Symptoms

An initial indication of dysphagia is choking or coughing when eating or drinking. A patient may complain of having the feeling that something is caught in his or her throat. These signs of dysphagia are often accompanied by fear and anxiety on the part of the patient, fear that food may actually be trapped in his or her lungs, and the anxiety that he or she will be unable to breathe because of food "going down the wrong pipe." Some patients exhibit no signs of choking, although food or liquids may be entering the trachea and lung; these patients are known as "silent aspirators." Noting the quality of the patient's voice and whether or not any expressive aphasia or dysphasia is present may provide clues to the nurse that the patient may be aspirating (Easton, 1999).

Depending on the phase of swallowing that is affected, the signs of dysphagia may differ. Table 23.5 outlines characteristics of dysphagia associated with the oral, pharyngeal, and esophageal phases. Each characteristic may have varying degrees of seriousness.

## Assessment of Dysphagia

In the terminal stages of illness, it is likely that dysphagia is not a new symptom, but one that has been present for some time and is worsening. In assessment during palliative care, the goals of the swallowing evaluation should be clear. Dahlin and Goldsmith (2006, p. 202) list the following goals of assessment:

1. Identify the underlying physiological nature of the disorder
2. Determine whether any short-range interventions can alleviate the dysphagia
3. Collaborate with the patient, family, and caregivers on the safest and most efficacious method of providing nutrition and hydration

Difficulty with specific food consistencies provides the nurse with some assessment data, but may be misleading. Lesions and/or tumors that produce an obstruction generally produce dysphagia for solids first as opposed to liquids. However, clients with neuromuscular disorders may have dysphagia with both solids and liquids (Regnard, 2005).

**TABLE 23.5 Signs and Symptoms of Dysphagia**

Oral phase	Drooling
	Pocketing of food
	Excessive chewing
	Facial asymmetry or weakness
	Tongue weakness
	Inability to close lips tightly or move lips
	Weakness or absence of gag reflex
	Weakness or absence of a swallowing reflex
	Nasal drainage due to nasal regurgitation
Pharyngeal phase	Loss of internal or external sensation of the oral cavity or face
	Delayed or absence of swallowing
	Coughing while drinking or eating fluids
	History of aspiration pneumonia
	Wet, gurgling, moist, or nasal voice
	Frequent clearing of throat
Esophageal phase	Complaints of burning
	Burping or substernal distress due to esophageal reflux
	Coughing or wheezing

Source: Adapted from Hickey, 1997.

Castell (1996) suggests that 80% of dysphagia can be diagnosed with a thorough history. Key questions include the following: What type of food causes the symptom? Is the swallowing problem intermittent or progressive? Is heartburn present (Cowely, Diebold, Coleman Gross, & Hardin-Fanning, 2006)?

The physical examination involves cognitive, neuromuscular, and respiratory assessment. Cognitive assessment includes interest in eating, ability to focus on and complete a meal, and ability to remember and follow directions for safe eating. Neuromuscular and respiratory assessment include testing sensory and motor components of the cranial nerves, breath sounds, strength of cough, and ability to clear the throat (Cowely et al., 2006). The gag reflex is not a reliable indicator of the patient's ability to swallow (Regnard, 2005). Evaluation of the patient's current medications is an important component of the assessment. Contributing medications to dysphagia are those



that decrease saliva, decrease cognition, and decrease the strength of the muscles used in swallowing.

The prognosis of the patient will determine whether a professional swallowing evaluation merits consideration. If the patient's life expectancy is reasonably long and the patient is clearly in distress, a comprehensive evaluation performed by a speech-language pathologist with expertise in swallowing disorders may be indicated. A modified barium swallow is used to radiologically determine the phase of swallowing where the disturbance is occurring and thus identify potential interventions, as well as evaluating the compensatory mechanisms of the patient (Dahlin & Goldsmith, 2006).

## Management of Dysphagia

If the patient has a very short prognosis (days), it may be determined by the patient, family, and caregivers that hydration and/or feeding are not warranted. If the patient has a longer prognosis, medically assisted feeding and hydration may be attempted. Regnard (2005) offers the following factors to help determine the appropriateness of interventions:

1. Rate of decline of the patient
2. Patient's opinion
3. Opinions of significant other and/or family
4. Opinions of formal caregivers
5. Feasibility/advantages/disadvantages of alternative feeding routes

Transnasal intubation, percutaneous endoscopic gastrostomy or jejunostomy, or surgical gastrostomy or jejunostomy may be considered if the prognosis of the patient determines that these interventions will provide optimal palliation. Any surgical intervention must be undertaken with significant input from the patient and family, and is determined by the overall goals of care.

■ **Pharmacological Interventions of Dysphagia.** If dry mouth and/or oral lesions are present and are exacerbating the dysphagia, pharmacological treatment is appropriate. The most common mucosal infection causing oral lesions is candidiasis. Antifungal medications such as nystatin, ketoconazole, miconazole, and fluconazole may be used in treatment (Dahlin & Goldsmith, 2006; Regnard, 2005).

Dry mouth (xerostomia) could occur as a result of prescribed medications, particularly anticholinergics and opiates. These medications may need to be continued if there are limited alternatives to treat other symptoms, making the dry mouth unavoidable. In that case, artificial saliva, such as Salagen or porcine mucin, may be used. Glycerin and lemon should be

avoided because glycerin dehydrates the mucosa and lemon affects the salivary glands (Regnard, 2005). A prokinetic agent such as metochloperamide may be prescribed for poor esophageal motility. Proton pump inhibitors (e.g., omeprazole) and H<sub>2</sub>-blockers (e.g., ranitidine) may be used in patients with gastroesophageal reflux disease to reduce gastric acid secretion and reduce symptoms.

## ■ Nonpharmacological Interventions of Dysphagia.

After a thorough evaluation of the patient, and once it has been determined oral intake is appropriate, the guiding principle of management should be optimization of caloric intake while minimizing the effort to obtain it (Dahlin & Goldsmith, 2006). If the degree of dysphagia is minimal, simple positioning may be the primary intervention. Patients should be positioned in an upright, nearly 90° angle, with the head tilted slightly forward and the chin tucked in to prevent food moving to the posterior oropharynx before it is properly chewed. If the patient is unable to hold his or her head independently, the caregiver can assist the patient in maintaining this position. If the older adult has had a past stroke, pocketing of food on the affected side of the mouth is a common problem. The patient, family, or caregiver can sweep the mouth with a finger after each bite to alleviate this problem.

In 2003, the American Dietetic Association published a monograph entitled the *National Dysphagia Diet: Standardization for Optimal Care (NDD)*. This diet aimed to establish standard terminology and practice applications of dietary texture modification in dysphagia management (McCullough, Pelletier, & Steele, 2003). A group consisting of speech-language pathologists (SLPs), dietitians, and food scientists developed a hierarchy of diet levels. Provided here is an example of the different stages of semisolid/solid foods:

- Level I: Dysphagia-Pureed (homogeneous, very cohesive, pudding like, requiring very little chewing ability)
- Level II: Dysphagia-Mechanical Altered (cohesive, moist, semisolid foods, requiring some chewing)
- Level III: Dysphagia-Advanced (soft foods that require more chewing ability)
- Level IV: Regular (all foods allowed)

Liquid consistencies included spoon thick, honey like, nectar like, and thin (McCullough et al., 2003). Viscosity ranges were prescribed for each level of liquid. At this point, there is no standardization for this nomenclature, however.

Simple dietary changes such as providing pureed or blenderized food may be appropriate. Patients with oropharyngeal dysphagia may require thickened

liquids. There are a number of commercial products that are used in rehabilitation facilities (e.g., Thick-it) to address these issues; however, simple food starch can be used as effectively.

### Family Concerns and Considerations Regarding Dysphagia

Positioning techniques that allow the patient to continue oral feeding can be easily explained and taught to the patient and/or his or her family. Dietary changes, such as using thickening agents, if appropriate, should be suggested to the family as well. Any interventions that can be taught to the family or caretakers may increase their feeling of wanting to help the individual.

As described previously, eating is considered a social activity as much as it is a necessity of life. Society has conditioned us to believe that eating wholesome, healthy food will keep us well. As a family member sits by the bedside of his or her loved one and sees that oral intake is impossible due to dysphagia and potential aspiration, feelings of helplessness and anxiety may also occur. Family may feel like they are neglecting their obligation to the person. For both the patient and the family, the act of eating is viewed as compatible with life; the inability to eat is a harbinger of death. Such factors influence decisions regarding feeding at the end of life.

Even if the decision to discontinue oral feeding and initiate alternate feeding methods is made, the decision is not easy. It is clearly difficult to make the initial decision to feed a patient or loved one “artificially,” and more difficult if a decision is made to discontinue feedings. The patient and family must be fully aware of the risks and benefits of artificial nutrition and hydration. During this period of time, the support of the nurse to the patient and family is paramount.

## ■ CONSTIPATION

Constipation is often seen in advanced disease related to bowel obstruction, adverse effects from medications, hypercalcemia, dehydration, and inadequate dietary intake (Esper & Heidrich, 2005). Similar to the concept of pain, constipation is a subjective complaint and often undertreated (Economou, 2006). Dalal et al. (2006) define constipation as the infrequent and difficult passage of hard stool (p. 395). These authors also classify constipation as difficult to treat and to assess due to the wide variation in what is considered a normal stool. There is a wide variation of the “normal” frequency for passage of stool, anywhere from three times daily to three times weekly, and therefore assigning a precise definition is difficult, although fundamentally it is defined by the patient.

Constipation is a common cause of morbidity in the palliative care setting and the numbers increase if the patient is treated with opioids. The incidence of constipation in older adults or ill persons may be 20% to 50% (Economou, 2006).

There are various tools available for the assessment of constipation in the palliative care patient, each of which has been designed to evaluate the presence and severity of constipation. Larkin et al. (2008) do note, however, that while using them to allow the patient to understand his or her own bowel habits, or when communication between the patient and clinician may be difficult, their utility in clinical practice is marginal. Four of the most frequently used scales are the Bristol Stool Form Scale, Constipation Assessment Scale (CAS), Constipation Visual Analogue Scale, and Eton Scale Risk Assessment for Constipation (Larkin et al., 2008).

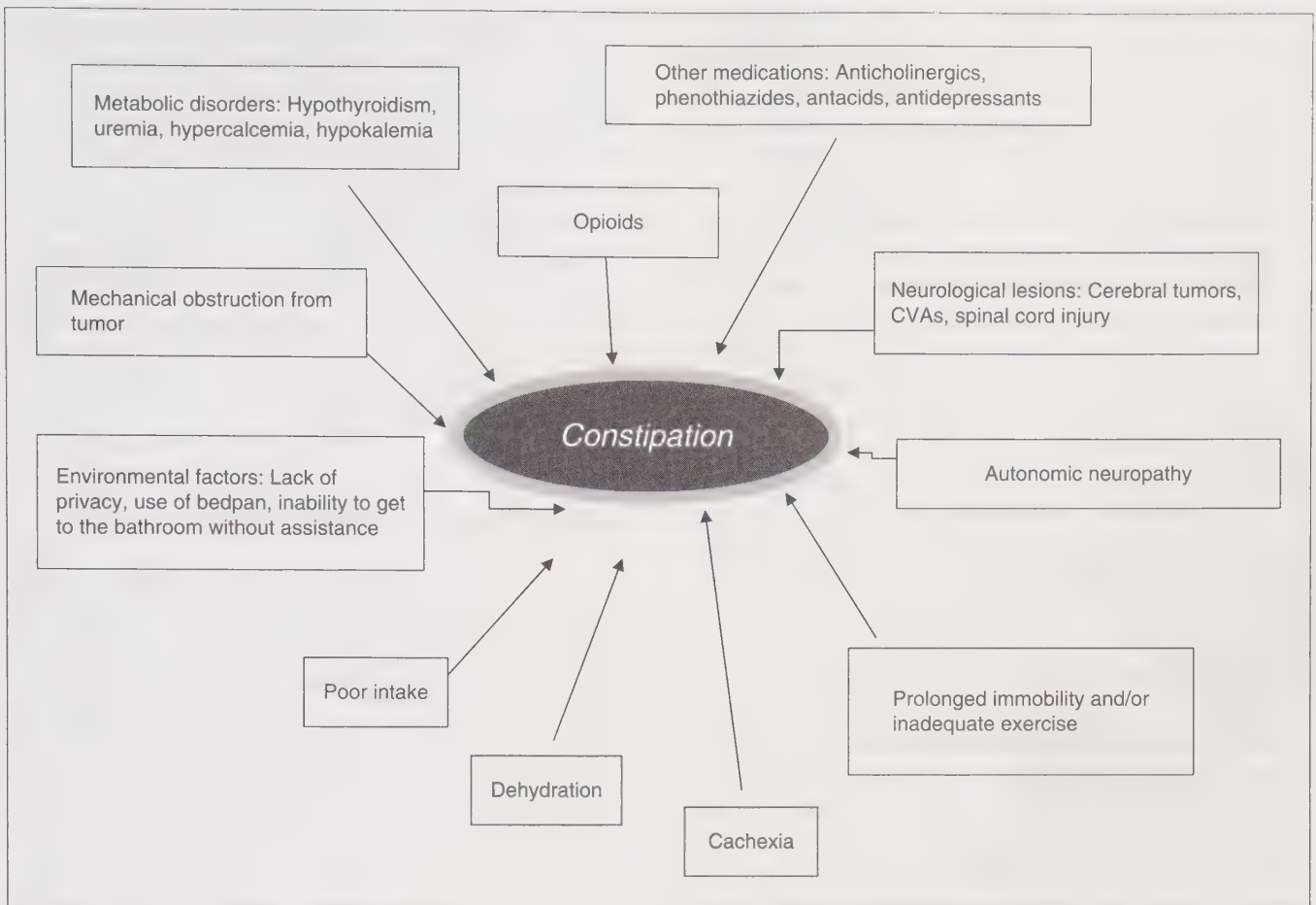
Children are often symptomatic, and their symptoms increase with time, particularly within the terminal phase of illness (Collins, 2005). Constipation in children is distressing, although often more disturbing for the caregiver than the child. Laxative use is generally not recommended in children and there is inadequate evidence to endorse the use of laxatives to treat constipation in the pediatric population (Pijpers, Tabbers, Benninga, & Berger, 2009). The research recommends a change in dietary intake, fluid intake, and increased mobility as opposed to laxative use (Collins, 2005). If these changes do not help in relieving the constipation, laxatives may be used, but the dosing is difficult to manage due to few resources for pediatric dosing; therefore, they must be approached cautiously.

### Etiology of Constipation

Bowel function includes three areas of control: small intestinal motility; colon motility; and defecation (Economou, 2006, p. 220). If any of these processes malfunction or is delayed, it can affect defecation. The small intestine moves contents through in 1 to 2 hours, whereas the colon moves content much slower, in 2 to 3 days. Not eating properly; going without food, fluids, or fiber; a decrease in activity; or even less privacy when using the bathroom can all affect defecation and result in constipation. Other factors that may affect bowel elimination are opioid pain medications; specific cancers, especially those causing luminal obstruction; ascites; confusion; and diuretics (Economou, 2006). Dehydration is a common cause of constipation in the pediatric palliative care population (Dean et al., 2006). Figure 23.2 outlines some of the common causes of constipation.

Pharmacological-induced constipation may occur due to the use of opioids to control pain. Opioids affect the small bowel and the colon by binding with the receptors of the smooth muscle, thus affecting





**FIGURE 23.2** Common causes of constipation in palliative care. *Source:* From Dalal et al., 2006.

contractions and peristalsis of the bowel. Lengthening the time that the contents are in the colon allows more absorption of fluids and electrolytes, which in turn dries out and hardens the stool. However, there is some newer evidence, particularly associated with transdermal fentanyl use, indicating that constipation severity may differ among opioids (Economou, 2006).

Cimprich (cited in Economou, 2006, p. 220) describes three types of constipation:

1. Primary—generally caused by reduction of fluids and fiber intake, decrease in activity, and lack of privacy.
2. Secondary—related to the pathological changes the patient experiences.
3. Iatrogenically induced—constipation related to pharmacological interventions.

### Assessment of Constipation

The patient receiving palliative care has multiple risk factors for constipation and the assessment should begin with a history of the patient's typical GI and bowel habits. Questions to ask include the

following: Is the patient able to chew food? Does the patient wear dentures and do they fit properly? What has the patient's bowel pattern been prior to diagnosis? Was there a history of constipation prior to diagnosis? Has the patient been experiencing abdominal cramping, bloating, and N&V? Does the bowel movement feel complete? Does the patient have an urge to defecate? Is the patient requiring the use of laxatives and/or enemas? What pain medication does the patient take? Has there been a change in fluid intake or appetite?

Physical exam may reveal a normal exam or abdominal distention, diminished or hypoactive bowel sounds, and palpation of stool in the large intestine. Distention, however, may be associated with obesity, fluid, tumor, or gas. Percussion of the bowel may result in tympani over the abdomen, thus indicating gas in the bowel. Dullness is related to a solid mass, which could be intestinal fluid, tumor, or feces (Economou, 2006). Deep palpation may result in feeling a "sausage like" mass; however, determining if the mass is stool or a tumor is difficult with palpation alone. Sykes (2005) suggests that a fecal mass usually indents, if the patient can tolerate firm pressure, and may give a crepitus-like sensation because

of entrapped gas. A fecal mass may also move over time. A digital rectal exam may reveal impaction, impaired sphincter tone, anal fissures, hemorrhoids, tumors, or even a rectocele (Economou, 2006).

■ **Diagnostic Tests.** Diagnostic tests are used to confirm or determine the extent of bowel dysfunction due to constipation. The need for an extensive workup in palliative care is rare, and should only be done when necessary to continue with comfort measures. If indicated, testing may include an upright and flat plate of the abdomen to determine air/fluid levels indicative of a partial or complete intestinal obstruction either due to tumor or secondary to fecal impaction. Radiographic examination, MRI, or CT may also be appropriate to assess the abdomen. Laboratory data used to evaluate constipation may include blood urea nitrogen (BUN), as an elevation may signify dehydration, and blood glucose levels, as an elevation may indicate a diversion of fluids from the GI tract to the kidneys with excess renal fluid loss (Bisanz, 1997). It is important to note, however, that these laboratory tests are more to assess for issues that may result from constipation as opposed to evaluating for constipation itself.

Dalal et al. (2006) suggest the use of a constipation score based on findings from an abdominal x-ray. Scores from 0 to 3, based on the amount of feces, are obtained from each quadrant. A score of “0” indicates no stool; 1 indicates less than 50%; a score of 2 indicates greater than 50%; and a score of 3 indicates full occupancy of the lumen with stool. Scores range from 0 to 12; with a score of 7 or greater indicating severe constipation. Although other radiological scoring methods do exist, it is felt that there is poor reliability between any of them and their use is of limited value in the assessment of constipation (Pensabene, Buonomo, Fishman, Chitkara, & Nurko, 2010).

Another tool developed in 1989, the CAS, has also proved to be useful in the assessment of constipation. The CAS has been tested for validity and reliability in measuring moderate to severe constipation (McMillan & Williams, 1989). The questionnaire is easy to complete (see Figure 23.3). It should be noted that the literature again focuses on the assessment of constipation in the pediatric, adult, and geriatric populations, not specifically those in palliative care. While there are data to support assessment on constipation in the palliative care setting, it generally is concentrated on patients with pain and constipation presumed related to opioid use.

Management of Constipation

Prevention of constipation is an essential strategy in providing palliative care. A mix of dietary alterations in addition to pharmacological agents may be required. Bulk-forming agents and stool softening agents assist with normal peristaltic function (Beckwith, 2000). All patients beginning opioid therapy should be started on a laxative (Beckwith, 2000). Generally, a combination of a stool softener and laxative offer the most relief of constipation.

Each patient reacts differently to constipation and to the treatments used; thus, individual assessments and interventions must be developed. Interventions that work for one patient may not work for the other and, in fact, may change in their efficacy for the individual patient. Increasing fluids is an initial intervention with a plan as simple as increasing fluids as little as 100 mL. Care needs to be taken in increasing the fiber content. Fiber without increasing fluids absorbs what little fluid the patient may have available and contributes to more constipation (Economou, 2006). Because

Item	No Problem	Some Problem	Severe Problem
Abdominal distention or bloating	0	1	2
Change in amount of gas passed rectally	0	1	2
Less frequent bowel movements	0	1	2
Oozing liquid stool	0	1	2
Rectal fullness or pressure	0	1	2
Rectal pain with bowel movement	0	1	2
Smaller stool size	0	1	2
Urge but inability to pass stool	0	1	2

Patient Signature \_\_\_\_\_

Date \_\_\_\_\_

FIGURE 23.3 CAS Questionnaire. Directions: Circle the appropriate number to indicate whether, during the past three days, you have had no problem, some problem, or a severe problem with each of the items listed. (Source: McMillan & Williams, 1989).



of the significant increase in fluid intake needed to balance the required ingestion of fiber to prevent constipation in patients that generally are already suffering from limited oral nutrition, it is felt that for reasons of both efficacy and safety, relying on dietary fiber intake alone for the relief of constipation is not suitable in palliative care patients (Larkin et al., 2008).

The goals of treatment of constipation in the palliative care setting should be to reestablish comfortable bowel habits to the satisfaction of the patient, relieve the pain and discomfort caused by constipation and improve the patient's sense of well-being, restore a satisfactory level of independence in relation to bowel habits, consider individual patient preference, and prevent related GI symptoms such as nausea, vomiting, abdominal distention, and pain (Larkin et al., 2008).

■ **Pharmacological Management.** Even with appropriate preventive strategies, most patients with advanced disease will require laxatives (Sykes, 2005). Laxatives are classified by their action:

Bulk laxatives—provide bulk in the intestine, increase mass, and stimulate the bowel (used in mild constipation).

Lubricant laxative—lubricate the stool surface and soften the stool, leading to easier bowel movements.

Surfactant and/or detergent laxative—increase absorption of water and fats that leads to a softer stool.

Osmotic laxative—used more often in chronic constipation and in patients who have elevated ammonia levels, such as patients with hepatic failure. This form of laxatives has an osmotic effect not only on the small bowel but also on the large intestine by increasing the colon volume in a short period of time.

Saline laxative—increase gastric, pancreatic, and small intestine motility along with increasing the bowel secretions to form a stool.

Stimulant laxative—works on the colon increasing motility and inducing peristalsis (Economou, 2006, pp. 224–225).

Table 23.6 provides a listing of stool softeners and laxatives that may be used in palliative care.

Other approaches to management of constipation may include injectable methylnaltrexone, which is part of the naltrexone molecule. The medication is

**TABLE 23.6 Stool Softeners and Laxatives**

Type	Action	Comments
Lubricant softeners: Mineral oil	Penetrates stool and prevents water absorption	Less palatable than some others
Bulk-forming laxatives Methylcellulose Psyllium Polycarbophil	Resists bacterial breakdown, increasing bulk and shortening transit time	Must maintain fluid intake of 1.5–2 L of fluid a day
Emollient/surfactant softeners: Docusate sodium	Increases water penetration	Increased transit time caused by opioids negates action of these laxatives
Osmotic laxatives: Lactulose Sorbitol Glycerin	Creates osmotic gradient in the intestine	High oral doses to be effective may cause bloating, cramping, and diarrhea
Saline laxatives: Magnesium citrate Magnesium hydroxide Sodium bisphosphate/ sodium phosphate	Creates immediate osmotic gradient in the intestine	Oral forms are effective in 0.5–3 hr; enemas often effective within 15 min
Stimulant laxative: Senna Cascara sagrada Bisacodyl	Stimulates submucosal nerve plexus to increase motility	May cause cramping; often used in combination with a softener

Source: Adapted from Gullatte et al., 2005.

intended for the treatment of opioid-induced constipation as the medication antagonizes opioid actions at GI mu-opioid receptors but without impairing analgesia mediated by opioids in the central nervous system (CNS). While its use has been studied in both the adult and pediatric palliative care settings, and the evidence is promising for the relief of opioid-induced constipation, further studies are needed to ensure its adequacy of treatment in these patient populations (Bader, Weber, & Becker, 2012; Yeomanson, Chohan, & Mayer, 2013).

Researchers are investigating the use of erythromycin in patients who do not respond to traditional treatments to relieve constipation. Erythromycin may cause diarrhea in patients who use it as an antibiotic. Management of constipation with rhubarb or constituents of mulberry, which are similar to senna, can be used by patients who prefer not to use over-the-counter laxatives. These patients need to be cautioned in purchasing herbal remedies and be aware of the side effects or the interaction with other medications they may be taking (Economou, 2006). Medications used in both the prevention and treatment in the pediatric palliative care population include docusate, lactulose, polyethylene glycol, and senna (Santucci & Mack, 2007).

It is a fine balance in managing the patient with constipation (Gullatte et al., 2005). The care provider does not want to have the stool so soft that it is leaking continuously. On the other hand, the patient should not suffer from cramping. The need to balance the effect of the stimulant and softener to facilitate bowel movement is contrasted with overachieving their effects and leading to an alteration in the patient's "normal" bowel habits and limit secondary side effects.

### Family Concerns and Considerations Related to Constipation

Family concerns regarding constipation can be addressed through education about potential causes and methods of prevention and limiting complications. Special attention should be given to the patient or family preferences with treatment modalities. Comfort level with routes of medication administration should be assessed; in particular, if rectal administration is not something the family is capable or comfortable with, caregiver assistance should be provided.

Another concern includes dealing with patient privacy and the use of bedpan versus bedside commode. Privacy is a concern with patients in the hospital and in their homes. Often if sharing a room in the hospital, using a bedside commode can be embarrassing to the patient and his or her family. The smell and noises during defecation may make the patient unable to go. In the home or in the hospital, trying to use the bathroom in front of another person can lead to

apprehension, which may add stress and anxiety to the patient. Typically, bedside commodes are better tolerated than bedpans in facilitating a bowel movement when constipation is a concern.

## ■ BOWEL OBSTRUCTION

Bowel obstructions are common in patients with advanced abdominal, pelvic, ovarian, or primary bowel cancer (Chilton & Faull, 2005). An intestinal obstruction is complete or partial occlusion of the lumen or absence of normal propulsion that produces elimination from the GI tract (Economou, 2006; Sykes, 2005). Disruption or dysfunction in motility may lead to a mechanical obstruction but without occlusion of the intestinal lumen. This obstruction results in the accumulation of fluids and gas proximal to the obstruction (Economou, 2006). Abdominal distention occurs because of intestinal gas, ingested fluids, and digestive secretions. It then becomes a self-perpetuating phenomenon in that as distention increases, intestinal secretion of water and electrolytes increases (p. 233).

### Etiology of Bowel Obstruction

Bowel obstructions can present in the clinical setting acutely or gradually and intermittently. Bowel obstructions can be due to constipation, adhesions, drugs, benign conditions, and/or progression of tumors in or around the intestine. Electrolyte abnormalities such as hypokalemia and hypercalcemia can lead to ileus or pseudoobstruction formation as well (Chilton & Faull, 2005).

### Signs and Symptoms

Signs and symptoms are based on the site of the obstruction (Ripamonti & Mercadante, 2005). If the obstruction is in the duodenum, the patient may experience severe vomiting with a large amount of undigested food. Pain or distention is typically not present, and the patient may have a succession splash present in the bowel sounds. In the small intestine, there may be moderate to severe vomiting. Bowel sounds may be hyperactive with borborygmi, moderate distention is present, and there is pain in the upper and central abdomen that is colicky in nature.

With an obstruction in the large intestine, vomiting is generally a later side effect, borborygmi bowel sounds and severe distention are present, and the colicky pain is in the central to lower abdomen (Economou, 2006). It is important to note that in the older adult, obstruction may present differently. Instead of a "board-like" abdomen, many older adults may have cramps, dehydration, stringy stool



or diarrhea, and vague complaints of not feeling well (Amella, 2004). Diagnosis is suspected by clinical symptoms but is confirmed with abdominal radiography. Abdominal CT scan may be useful in evaluating the patient as well (Ripamonti & Mercadante, 2005).

## Management of Bowel Obstruction

Lynch and Sarazine (2006) determined that nurses could improve symptom management and quality of life for patients that are experiencing malignant bowel obstruction by frequent assessments and being aware that patients with intra-abdominal tumors are at the highest risk for bowel obstruction. Physical assessment that reveals dehydration, dry mucosa, tachycardia, and hypotension are all signs of possible bowel obstruction. Examination of the abdomen may reveal distention, pain, and varied bowel sounds. Bowel obstruction from a malignant source is a pivotal point in the patient's illness and nurses should have an active role in helping the patient through the decisions that need to be made about aggressive treatment or a more palliative approach to the bowel obstruction.

In managing a bowel obstruction, it should be determined if the obstruction is related to an underlying condition, such as a history of malignant bowel obstruction, a tumor, or an opioid-induced obstruction or opioid syndrome, which can occur when there is treatment with narcotics. Medical management may offer suitable symptom control. Patients may live for surprisingly long periods of time, taking in small quantities of food and fluid, without the addition of nasogastric tubes or IV fluids (Chilton & Faull, 2005, p. 174).

Surgical intervention is the primary treatment for a complete bowel obstruction; however, in the palliative care population this is not typically an option. Self-expanding metallic stents may be used at the gastric outlet, proximal small bowel, and colon instead of surgery (Ripamonti & Mercadante, 2005). The use of continuous analgesics, antisecretory drugs, and/or antiemetics may be effective in controlling pain and N&V in patients who are not surgical candidates.

Ocreotide may be an option in early management to prevent a full-blown obstruction. Its action slows the irregular and ineffective peristaltic movements of obstruction through reducing activity and balancing out the intestinal movement (Economou, 2006). Lynch and Sarazine (2006) note that once a bowel obstruction has occurred, the mean survival of the patient decreases to approximately 3 months in patients who are terminally ill. This sobering fact makes prevention of constipation and bowel obstruction imperative both for the health care team and to patients and their families.

## ■ DIARRHEA

Patients dealing with chronic and terminal illness may encounter bouts of diarrhea depending on the treatments they are receiving. Leakage of stool is common in bowel obstructions, and constipation can be over-treated, causing the patient to experience diarrhea. Abrahm (1998) states that diarrhea may be associated with lactose intolerance postchemotherapy, bowel obstruction, fecal impaction, sphincter incompetence, chronic radiation enteritis, and infection.

Diarrhea is defined as the passage of frequent stools with urgency, typically unformed and at an increased urgency. For adults, stool weight greater than 200 g/day can generally be considered diarrheal (Longo, Fauci, Kasper, Hauser, & Jameson, 2012). Objectively, it is considered more than three unformed stools within a 24-hour period (Sykes, 2005). Although diarrhea occurs less frequently than constipation in the palliative care setting, patients report having acute episodes of diarrhea related to treatments, overeating of fruits and vegetables, and the use of antibiotics. Generally, in episodes lasting a few days, the nurse needs to be aware of complications that can occur, along with the family being aware of potential complications that could occur with diarrhea that is left untreated.

## Etiology of Diarrhea

There are four mechanisms of diarrhea: secretory, osmotic, hypermotile, and exudative (Economou, 2006). Secretory diarrhea persists with fasting and may be difficult to control because it occurs because of hypersecretion tumors as well as endogenous mediators that effect electrolyte and water transport (Ratnaike, 1999). Enteral feedings, bleeding in the bowel, and lactose intolerance are all related to osmotic diarrhea. Increased intestinal motility in hypermotile diarrhea may result from overgrowth of bacteria; incomplete digestion of fat in the small intestine, causing it to be expelled in stool (steatorrhea); or due to chemotherapeutic agents. Prostaglandins are released secondary to inflammation of the intestinal mucosa in exudative diarrhea, commonly associated with radiation therapy (Economou, 2006).

## Assessment of Diarrhea

As with other complications, the initial assessment includes identification of the underlying cause of diarrhea. Specific description of previous bowel habits, along with current symptoms, may help to identify the etiology and appropriate management approaches. Fatty, pale yellow stool that is difficult to control may indicate an etiology of malabsorption. If diarrhea

occurs after a period of constipation, fecal impaction should be suspected (Sykes, 2005). Diarrhea that persists beyond 2 to 3 days of fasting may be attributed to osmotic or secretory mechanisms (Economou, 2006).

Varying bowel habits make it difficult to assess diarrhea from the history alone. Typically, the complaint of loose, watery, or frequent stool is indicative of diarrhea. However, some patients describe diarrhea as frequent bowel movements even if consistency remains normal. Although definitions of diarrhea can be imprecise because patterns of bowel elimination can vary from person to person and even from day to day, it is generally agreed that it involves an increase in the number of bowel movements and in the water content or volume of stool (Blush & Matzo, 2012). The most accurate account of diarrhea is obtained from a 24- to 48-hour collection and measurement, although Wadler (2001) states that this type of assessment in clinical practice is rarely a reasonable method of assessment to assess diarrhea. Moreover, there is little need for this type of investigation in the palliative care setting. A more logical and objective approach to assessment would be the criteria for grading severity of diarrhea instituted by the National Cancer Institute (Table 23.7).

The most common cause of diarrhea in palliative care is an imbalance in laxative therapy (Sykes, 2005). It is also important to review all past, current, and new medications or treatment modalities. Metabolizing capabilities vary in older adults, but generally, this population is more susceptible to medication side effects. Use of laxatives in conjunction with fiber intake should be explored. Antibiotics can also contribute to diarrhea. In the GI tract, microflora produce protective substances deadly to harmful bacteria. Antibiotics can reduce the number of protective native bacteria and allow the proliferation of bacteria such as *Clostridium difficile* and the *Salmonella* species to proliferate, causing diarrhea. Enterotoxin-producing

strains of methicillin-resistant *Staphylococcus aureus* (MRSA) have been shown to cause nosocomial diarrhea in patients taking antibiotics (Blush & Matzo, 2012). These should be considered in patients in palliative care settings as clinically appropriate. Additionally, the patient that has abdominal or pelvic radiation may experience diarrhea up to 2 to 3 weeks after completion of treatment (Sykes, 2005).

Psychosocial effects of diarrhea, whether the diarrhea is acute or chronic in nature, must be evaluated. Physical activity may be limited due to dehydration and weakness if it has been an ongoing problem. The inability to control bowel movements can cause depression and insecurity for the older adult (Economou, 2006). Diarrhea may also prevent patients from completing their activities of daily living and cause social isolation.

### Management of Diarrhea

Supportive care and medications are typically appropriate care for individuals in palliative care. The goal of treatment should be to eliminate the factors that led to the diarrhea, provide dietary intervention, and maintain fluid and electrolyte balance (Economou, 2006).

■ **Pharmacological Interventions.** The antidiarrheal therapies of choice in palliative medicine are opioids, specifically loperamide (Imodium; Benson et al., 2004).

Loperamide is the agent of choice for adults and works through antisecretory and antiperistaltic properties. Loperamide is beneficial in allowing reabsorption of fluid in the colon through its antimotility effects, and it has been shown that its use does not lead to negative outcomes. It is indicated in the adult population, with an initial dose of 4 mg followed by 2 mg doses with each loose stool, not to exceed 16 mg total dose in 24 hours. This agent should be considered

**TABLE 23.7 National Cancer Institute Common Toxicity Criteria for Grading Severity of Diarrhea**

	Grade 1	Grade 2	Grade 3	Grade 4
Patients without a colostomy	Increase of less than four stools per day over pretreatment	Increase of four to six stools per day or nocturnal stools	Increase of greater than or equal to seven stools per day or incontinence or need for parenteral support for dehydration	Physiological consequences requiring intensive care, or hemodynamic collapse
Patients with a colostomy	Mild increase in loose, watery colostomy output compared with pretreatment	Moderate increase in loose, watery colostomy output compared with pretreatment, but not interfering with normal activity	Severe increase in loose, watery colostomy output compared to pretreatment and interfering with daily activity	Physiological consequences requiring intensive care or hemodynamic collapse

Source: Adapted from [www.nci.nih.gov](http://www.nci.nih.gov)



in adult patients who are not febrile or having bloody diarrhea (Blush & Matzo, 2012).

Similar to loperamide is diphenoxylate, which is recommended as a second line agent to loperamide in the adult population. It works in a related fashion but has a greater risk of central opiate-like effects as well as anticholinergic properties (Tintinalli, Kelen, Stapczynski, Ma, & Cline, 2004). There are no practical benefits to either of these medications in the pediatric population for which the focus of therapy should remain on hydration and nutritional status as mentioned.

Secretory diarrhea, specifically with HIV patients, is often treated with octreotide (e.g., Sandostatin) 50 to 200 mg subcutaneously two to three times daily (Levy, 1991). Although costly, octreotide is a somatostatin analogue with the ability to control even the most severe, intractable diarrhea (Doyle, 1994). Reduction of peristalsis and gastric secretions can also be accomplished using anticholinergics such as atropine and scopolamine (Economou, 2006).

Management of diarrhea also includes encouraging the patient and family to omit lactose-containing foods, spicy foods, and foods that contain high quantities of fat from the patient's dietary intake. Foods that can be added or that are tolerated well are potatoes, rice, and macaroni. Patients and families generally require instruction to not overuse the laxatives that they have been given to control constipation, which can lead to excessive diarrhea.

■ **Nonpharmacological Interventions.** It is important to prevent dehydration and associated complications for patients who are at the end of their lives. With significant diarrhea, dehydration is a concern and therefore recommendations for management should have the primary goal as prevention of or adequately rehydrating those with dehydration. Paramount to this goal is the use of oral rehydration solution (ORS), which is a solution of sugars and salt in water meant to provide caloric, electrolyte, and fluid replacement in those where volume depletion is of concern related to diarrhea. There are commercially available mixtures of ORS (e.g., Pedialyte, Gastrolyte) offered in various forms (liquid, oral, tablet), all of which have predetermined concentrations of sodium, potassium, chloride, bicarbonate, and glucose to be given in a mixture of clean water. In addition to these compounds, recommendations are available for making the mixture at home if necessary. Several recipes are available; an example is mixing one level teaspoon of salt and eight level teaspoons of sugar into one liter of clean drinking water along with 4 ounces of orange juice ("Solutions," 2009). For those patients where parenteral hydration is necessary, the degree of volume deficit as well as specific patient characteristics (e.g., age, previous medical history) should dictate the appropriate

selected interventions (Blush & Matzo, 2012).

Along with hydration, nutritional supplementation with continued feedings should be instituted as soon as the patient can tolerate. The use of the "BRAT" diet (bananas, rice, applesauce, and toast) in children and supplementation with items such as salted crackers and soups in adults can provide initial nutritional support until the patient can tolerate advancing his or her diet. As the episode resolves, proteins and fats can be added gradually into the diet (Economou, 2006).

## Caregiver Concerns Related to Diarrhea

Incontinence of stool can be a disturbing problem for the patient and the caregiver. Frequent checks and toileting should be made in cases where patients are confused or unable to express when they need to have a bowel movement. Nurses play a significant role in educating caregivers and family members regarding these issues. Care should be taken to prevent skin breakdown, perineal pain, and other complications with infection. Protective ointments and anesthetics can be applied for comfort measures, and should be initiated prior to skin problems developing (Kemp, 1999). It is also helpful to avoid toilet tissue after a few days of diarrhea; a spray bottle of warm water washes or mild skin cleansers may be less painful.

In the pediatric population, oral zinc supplementation has shown to cause a decrease in the duration and severity of acute diarrhea. The benefit of zinc supplementation occurs because of its role in cellular and humoral immune function as well as direct effects on the GI tract with antisecretory processes and transport of fluid and electrolytes across the mucosa (Blush & Matzo, 2012). There are no studies, however, that have looked at this therapy in the palliative care population specifically.

If the etiology of diarrhea is infectious, appropriate contact precautions should be instituted. The potential benefit of antibiotic therapy must be weighed against not only the benefit of therapy but also the possibility of negative outcomes such as growing antibiotic resistance. Patients, family members, and caregivers should be instructed on proper handwashing techniques and food preparation to prevent the spread of infection. Disposable briefs should be discarded and tied in plastic bags to prevent contamination.

## ■ OTHER CONDITIONS

### Hiccups

Hiccups, also referred to as singultus, are typically an intermittent phenomenon that is annoying, but benign. The exceptions are those termed persistent or protracted,

lasting longer than 48 hours (Dahlin & Goldsmith, 2006). Chronic recurring hiccups can negatively impact advanced conditions by causing dehydration, insomnia, or abdominal muscle pain (Kemp, 1999). Hiccups lasting longer than one month are considered intractable (Kolodzik & Eilers, 1991), and can produce exhaustion if sleep is disturbed for an extended period of time (Dahlin & Goldsmith, 2006). Intractable or persistent hiccups are more likely to be associated with anatomical or organic disorders, and may have complications including oxygen desaturation, ventilatory disturbances, and cardiac arrhythmias (Rousseau, 1995).

The characteristic sound of a hiccup is the result of a sudden, involuntary contraction of one or both sides of the diaphragm, causing a sudden inspiratory response and closure of the glottis (Regnard, 2005). The incidence of hiccups in patients with cancer is approximately 10% to 20% (Dahlin & Goldsmith, 2006). Protracted hiccups are 82% more common in males than females (Rousseau, 1995). Children are more at risk than adults.

■ **Etiology of Hiccups.** Although the exact pathophysiology is unknown, common causes of hiccups include esophagitis, gastric distention, diaphragmatic irritation, phrenic nerve irritation, uremia, infection, brain tumor, or possibly psychogenic in origin (Lewis, 1985). The hiccup reflex is thought to be composed of three parts: an afferent limb (e.g., phrenic nerve, vagus nerve, sympathetic chain), a central mediator, and an efferent limb (e.g., phrenic nerve with accessory connections to the glottis and inspiratory accessory/intercostal muscles) Smith & Busracamwongs, 2003.

The numerous causes for hiccups are described with relationship to the type: benign, persistent (chronic), or intractable. Some of the most common causes of benign hiccups are alcohol intake, emotional stress, sudden excitement, smoking, laughter, gastric distention from carbonated beverages, eating too fast, overeating, and indigestion. Gastric distention is thought to be the most common cause of hiccups in older adults with terminal cancer (Regnard, 2005).

Persistent and intractable hiccups can be classified according to causes from the CNS, diaphragmatic (phrenic nerve) irritation, vagal nerve irritation, drug or toxin induced, postoperative, infectious, metabolic, psychogenic, and idiopathic. CNS causes of hiccups include structural lesions, neoplasms, hydrocephalus, encephalitis, epilepsy, vascular lesions, and head trauma (Kolodzik & Eilers, 1991). Diaphragmatic irritation may result from a hernia, organomegaly, esophageal neoplasms, pericarditis, intra-abdominal abscess, and gastroesophageal reflux disease. Irritation of any of the branches of the vagus nerve (auricular, meningeal, pharyngeal, laryngeal, thoracic, and abdominal) may cause intractable or

persistent hiccups. Medications such as steroids, chemotherapy, dopamine antagonists, megestrol, methyldopa, nicotine, opioids, and muscle relaxants may contribute to hiccups (Dahlin & Goldsmith, 2006). It is noteworthy that many of these pharmacological agents are used in the treatment of palliative care patients and may provoke their symptoms.

Recent evidence suggests that there is a correlation between partial pressure of carbon dioxide ( $p\text{CO}_2$ ) and hiccups. A correlation was observed when there was an increase in  $p\text{CO}_2$  resulting in a decrease in hiccups. It was also noted that a decrease in  $p\text{CO}_2$  was related to increased frequency of hiccups (Dahlin & Goldsmith, 2006).

■ **Assessment of Hiccups.** In obtaining a thorough assessment of symptoms, it is necessary to inquire about duration, prior episodes, and the impact on activities of daily living. Interference with resting and sleeping may cause a patient to present with symptoms of exhaustion and fatigue. If the hiccups are so severe that eating habits are affected and appetite is diminished, the patient may be dehydrated, thin, weak, and even appear cachectic. The already predisposed terminally ill adult may exhibit signs of sepsis or metabolic dysfunction secondary to immunocompromised states. It may be necessary to perform lab work to determine if metabolic dysfunction is the underlying cause of the hiccups (Dahlin & Goldsmith, 2006). These causes are often easily treated and may resolve persistent symptoms. In palliative care, a comprehensive workup to determine the etiology of persistent hiccups is only appropriate if the result assists in identifying an intervention. A chest x-ray may be necessary if mediastinal or pulmonary processes are suspected (Dahlin & Goldsmith, 2006).

#### ■ Management of Hiccups

**Pharmacological Interventions (Table 23.8).** Pharmacological interventions are selected based on the presumed etiology of hiccups. Hiccups are generally preventable or manageable by decreasing gastric distention and resolving esophageal irritation.

Gastric distention is likely to be the focus of an initial treatment approach in palliative care. Among the most effective medications for gastric distention are simethicone and metoclopramide (Reglan). Simethicone 15 to 30 mL is recommended before and after meals and at bedtime. Metoclopramide 10 to 20 mg orally or IV, up to four times a day, can be used alone or in combination with simethicone. Metoclopramide works to decrease gastric distention by increasing overall gastric motility. This medication should be used with caution in older adults. Metoclopramide should not be used concurrently with peppermint water, another alternative



**TABLE 23.8 Pharmacological Treatment Suggestions for Hiccups**

<b>Agents to decrease gastric distention</b> Simethicone 15–30 mL PO q4h Metoclopramide 10–20 mg PO/IV q 4–6 hr (do not use with peppermint water)
<b>Muscle relaxants</b> Baclofen 5–10 mg PO q 6–12 hr up to 15–25 mg/day Midazolam 5–10 mg
<b>Anticonvulsants</b> Gabapentin 300–600 mg PO TID Carbamazepine 200 mg PO QD–TID, titrate up as needed Valproic acid 5–15 mg/kg/day PO, then increase by 250 mg/wk until hiccups stop
<b>Corticosteroids</b> Dexamethasone 40 mg PO QD
<b>Dopamine agonists</b> Haloperidol 1–5 mg PO/SQ q 12 hrs Chlorpromazine 5–50 mg PO/IM/IV q 6–8 hrs
<b>Calcium channel blockers/antiarrhythmics</b> Phenytoin 200 mg IV, 300 mg PO QD Nefopam 10 mg IV QD–QID Lidocaine bolus 1 mg/kg/hr IV, then 2 mg/min until hiccups terminated Quinidine 200 mg PO Nifedipine 10–80 mg PO qd
<b>Other medications</b> Mephenesin 1,000 mg PO qd Amitriptyline 25–90 mg PO qd Methylphenidate 5–20 mg IV, 5–20 mg QD Sertraline 50 mg PO QD

Source: Adapted from Economou, 2006, p. 215.

treatment, because of opposing effects on the lower esophageal sphincter (Regnard, 2005). Esophageal disorders or irritation can be treated with peppermint water, which decreases gastric distention that sometimes leads to esophageal irritation.

Chlorpromazine (Thorazine) 25 to 50 mg orally works by reticular formation and hiccup reflex suppression, and may be taken up to three times per day (Kolodzik & Eilers, 1991). It is an option for prophylactic treatment of intractable hiccups. However, due to side effects of CNS depression and postural hypotension, caution should be exercised in older adults (Regnard, 2005).

Haloperidol (Haldol) 3 mg orally at bedtime for acute treatment followed by regular dosing at bedtime for prophylactic management is successful in resistant cases of hiccups (Regnard, 2005). Anticonvulsants such as carbamazepine (Tegretol), phenytoin

(Dilantin), and valproic acid (Depakote, Depakene) are most effective when the cause of hiccups is of a central origin (Kolodzik & Eilers, 1991). There has been an increased use of Gabapentin in the treatment of hiccups as well (Dahlin & Goldsmith, 2006; Regnard, 2005). The skeletal muscle relaxant, Baclofen 5 to 10 mg orally, twice a day, is also effective for treatment of hiccups (Regnard, 2005).

Proton pump inhibitors may be effective in treating hiccups when their origin is related to gastroesophageal reflux disease. Other more novel treatments include nifedepine, midazolam, lidocaine, sertraline, and even dexamethasone, despite being acknowledged as a possible cause (Woelk, 2011). In severe cases, phrenic nerve stimulation may be necessary to improve the patient's quality of life.

**Nonpharmacological Interventions (Table 23.9).** Determining the underlying cause of hiccups is the primary factor to consider when selecting treatment. This is not always possible, and therefore, the health care provider should be most concerned with assessing the overall effect of persistent hiccups on the patient's quality of life. The aggressiveness of treatment depends on how bothersome the hiccups.

Patients and family members often attempt nonpharmacological measures before they report hiccups to their health care provider. Pharyngeal and glottic stimulation by drinking a cold liquid or swallowing sugar granules or dry bread have been effective with acute attacks of hiccups. Other anecdotal "cures" include drinking a glass of water upside down, eating a spoonful of peanut butter, chewing on a lemon, and inhaling pepper to induce a sneeze. Although not entirely understood, it is felt these treatments result in either blocking or stimulation of the nerves involved in the hiccup action (Woelk, 2011).

Increasing retention of carbon dioxide by rebreathing into a paper bag has also been suggested to relieve an acute attack (Baines, 1992). Digital rectal massage and carotid massage can be used for vagal stimulation (Dahlin & Goldsmith, 2006). Gastric distention can be relieved by nasogastric tube insertion for decompression or lavage along with induction of vomiting (Lewis, 1985). Collaborative and complementary therapies that may be useful in the management of hiccups include chest physiotherapy to disrupt diaphragmatic spasms (Regnard, 2005).

■ **Family Concerns and Considerations Related to Hiccups.** Various treatment benefits, along with medication side effects, are necessary to make an informed decision regarding regimens they would like to pursue. When hiccups become overly disruptive to daily life, the patient may be willing to explore more aggressive therapies to obtain relief.

**TABLE 23.9 Nonpharmacological Interventions for Hiccups**

<b>Respiratory measures</b>
Breath holding
Re-breathing in a paper bag
Diaphragm compression
Ice application in mouth
Induction of sneeze or cough with spices or inhalants
<b>Nasal and pharyngeal stimulation</b>
Nose pressure
Stimulant inhalation
Tongue traction
Drinking from far side of glass
Swallowing sugar
Eating soft bread
Soft touch to palate with cotton-tipped applicator
Lemon wedge with bitters
<b>Miscellaneous vagal stimulation</b>
Ocular compression
Digital rectal massage
Carotid massage
<b>Psychiatric treatments</b>
Behavioral techniques
Distraction
<b>Gastric distention relief</b>
Fasting
Nasogastric tube to relieve abdominal distention
Lavage
Induction of vomiting
<b>Phrenic nerve disruption</b>
Anesthetic block
<b>Miscellaneous treatments</b>
Bilateral radial artery compression
Peppermint water to relax lower esophagus
Acupuncture

Source: Adapted from Economou, 2006, p. 214.

## Ascites

Ascites can present either centrally, peripherally, or mixed. Central ascites is a condition that is related to a tumor that has invaded the hepatic parenchyma. This type of tumor generally compresses the portal venous and/or lymphatic system (Economou, 2006). Peripheral ascites is associated with tumor cells from the parietal or visceral peritoneum. There is blockage within the peritoneal space resulting in a marked increase in macrophages causing ascites by increasing capillary permeability (Economou, 2006). The third type is called mixed type and involves both central and peripheral ascites.

■ **Etiology of Ascites.** In chronic liver disease, ascites initially begins as a result of portal hypertension that leads to increased levels of nitric oxide, vasodilation, sodium retention, and decreased renal function. These lead to elevation of pressure within the portal vein, smooth muscle contraction and fibrosis, and splanchnic arterial vasodilation that results in pooling of blood and an effective loss of circulating volume. This results in compensatory vasoconstriction by antidiuretic hormone release, resulting in renal sodium and water retention (Longo et al., 2012). Other disorders associated with the development of ascites due to increased hydrostatic pressure include congestive heart failure, constrictive pericarditis, and hepatic vein occlusion (Runyon et al., 1992). According to Runyon et al. (1992), tuberculosis, bacterial peritonitis, and malignant disease of the peritoneum may cause ascites, along with the decreased colloid osmotic pressure seen in malnutrition, nephritic syndrome with protein loss, and end-stage liver disease.

■ **Signs and Symptoms of Ascites.** Patients often complain of abdominal bloating and that their clothes no longer fit across their abdomen. Pain is often associated with the bloating and increase in abdominal girth. Some patients may have heartburn, nausea, and a decreased appetite. If the ascites is pronounced, dyspnea may be apparent (Economou, 2006).

■ **Assessment.** The most distressing physical symptom associated with ascites may be abdominal discomfort or pain caused by the distention. Additional complications such as dehydration and electrolyte imbalances should be considered in the older adult. Depending on the extent of fluid present, scrotal edema may occur along with weakened hernial orifices (Heneghan & O'Grady, 2001). Physical mobility may be difficult, especially for patients who are weakened or fatigued secondary to the excess weight and pressure that occurs with ascites.

The most obvious sign of ascites is increased abdominal girth. Patients may complain of bloating, nausea, and decreased appetite. Secondary to increased abdominal pressure, there may be worsening of gastroesophageal reflux or heartburn as well as dyspnea or orthopnea (Economou, 2006; Kichian & Bain, 2005). In the supine position, physical exam may reveal dullness on abdominal percussion in the dependent flank areas as ascitic fluid typically follows gravity. Tympany may be present toward the center of the abdomen. Shifting dullness can be assessed by turning the patient onto one side, noting the dullness of percussion shifts to the dependent side while tympany shifts to the top. Generally about 1,500 mL of fluid is present before dullness occurs with percussion of fluid alone (Cattau, Benjamin, Knuff, & Castell,



1982). A fluid wave test is performed by asking an assistant to press down firmly on the midline of the abdomen (to stop transmission of a wave through fat) while tapping on one flank of the abdomen. This causes an impulse to be transmitted through ascitic fluid that is felt on the other flank; if the impulse is easily palpable, it suggests the presence of ascites. Liver enlargement, tumor, or mass may also be palpable.

### ■ Management of Ascites

**Pharmacological Interventions.** The use of diuretics to decrease sodium reabsorption and urinary retention, along with increasing urinary excretion, are the primary interventions for ascites. As helpful as diuretic therapy may be, approximately 10% to 20% of patients will not respond to this intervention (Heneghan & O'Grady, 2001). The potassium-sparing agent, spironolactone (100–400 mg/day), is the diuretic of choice for ascites; however, it may be necessary to initiate diuresis with a loop diuretic such as furosemide also (40–80 mg/day; Kichian & Bain, 2005). Sodium and fluid restriction as well as diuretic are of limited benefit in patients with peripheral ascites. A trial of diuretics and sodium restriction may be of use in individuals with mixed-type ascites (Kichian & Bain, 2005).

Ascitic fluid may be analyzed to determine if albumin replacement is necessary, as well as bacterial infection of the fluid, which may require antibiotic therapy. Practitioner discretion and family requests will determine if antibiotic therapy is appropriate, given the goals of care of older adults who are at the end of their lives. However, in patients with elevated ammonia levels as is common with severe liver disease, as well as in older adults who are infected, confusion and delirium are common and should be considered when discussing treatment options with the patient and family.

Administration of medications to help with diuresis and pain control is a primary intervention with ascites. Treatment for infection or albumin and potassium replacement may also be warranted. Paracentesis or shunt placement and the prevention of infection may be important components of management. Nursing interventions include monitoring the client to promote symptomatic relief, and educating the client and family about ascites and the interventions being performed.

If diuresis is accomplished with pharmacological therapy, it is necessary to make urination as easy as possible for the patient and caregivers. This may include urinary catheterization if needed to prevent injury if the patient has difficulty getting out of bed or in patients who are confused and become agitated from urinary distention. Although it is important to monitor for signs and symptoms of urinary tract infection with catheterization, this intervention is usually considered a safe and effective treatment for patients at the end of life.

**Nonpharmacological Interventions.** The goal of providing palliative care to a client with ascites is to relieve discomfort. The poor prognosis related to ascites lends itself to palliation of symptoms without the expectation of altering patient survival rates. Management of ascites includes sodium restriction to prevent additional fluid retention. Ascites will be decreased from a dietary sodium restriction of 40 to 60 mcg/day, or 1 to 1.5 g of salt without the need for any further interventions (Heneghan & O'Grady, 2001). When there is marked sodium retention, restriction of sodium must be less than 20 mcg/day, a goal that is not only difficult to achieve, but may impair nutritional status (Heneghan & O'Grady, 2001).

Severe ascites requires therapeutic paracentesis alone or in combination with dietary sodium restriction. Symptomatic relief of malignant ascites may be accomplished with the removal of 5 to 10 L of fluid with each paracentesis (Kichian & Bain, 2005). Complete drainage of peritoneal fluid may actually cause an increase in pain (Doyle, 1994). Following removal of the ascitic fluid, diuretic therapy is often initiated to prevent reaccumulation. While large-volume paracentesis (greater than 5 L) is generally faster and has less significant negative outcomes than diuretic therapy, it is not without its complications, one of which is the associated risk of postparacentesis circulatory dysfunction. In patients who are already at a compromised hemodynamic state because of their underlying diagnoses, performing a large volume paracentesis can further exacerbate this issue, leading to hemodynamic collapse. Several studies have looked at complementary albumin infusions and found that they are significantly more effective against prevention of postparacentesis circulatory dysfunction and hyponatremia than if not instituted (Bernardi, Caraceni, Navickis, & Wilkes, 2012). One consideration, however, is the benefit of albumin replacement specifically in the palliative care patient where, according to Doyle (1994), it is rarely justified and should be discussed with the patient and family.

Refractory ascites occurs when repeated attempts to restrict sodium and diuretic therapy are both unable to prevent reoccurrence of ascitic fluid. If drainage is frequently required or there is increased discomfort for the client, placement of a shunt may be warranted. Peritoneovenous shunting provides symptom benefit; however, it is not without complications, including shunt occlusion, infection, loculation, and coagulation disorders. In appropriate patients, however, it has been shown to significantly reduce symptoms approximately 70% of the time (Racca et al., 2010). Candidates for shunting include those with abdominal scars preventing serial paracentesis, and limited access or distance from a physician able or willing to perform serial paracentesis (Heneghan & O'Grady, 2001).

Comprehensive nursing assessment is essential to identify any complications that may occur with ascitic fluid accumulation. The nurse should observe for signs and symptoms of infection or peritonitis. Monitor the patient for increased shortness of breath or dyspnea and notify the physician if positioning does not relieve dyspnea. With diuresis, older patients are also at increased risk of dehydration leading to poor nutritional status and skin breakdown. Frequent repositioning is necessary not only for comfort, but also for prevention of pressure ulcers.

Collaborative care may include dietary consultation to aid with planning meals for sodium restriction, and it may also involve frequent discussions with the physician or palliative care team to accomplish symptom relief from refractory ascites.

■ **Family Concerns and Considerations Related to Ascites.** Caregivers will need instruction on positioning. It may be difficult to achieve a comfortable position in which the pressure of ascitic fluid does not inhibit or make breathing more strenuous. Explain the importance of sodium restriction and provide education regarding how this may help to prevent fluid retention and the associated discomfort. If refractory ascites is present, the risks and benefits of paracentesis should be clearly discussed to ensure that informed decisions about management could be made. It is important that patients and caregivers understand the risks associated with reaccumulation of fluid.

## Xerostomia

Xerostomia is a subjective feeling of dry mouth, which may or may not be accompanied by decreased saliva flow (DeConno, Sbanotto, Ripamonti, & Ventafridda, 2005). Xerostomia receives little attention so prevalence is unable to be estimated.

■ **Etiology of Xerostomia.** A reduction in the salivary production by the parotid, submaxillary, and sublingual glands may occur as a result of radiotherapy, oral surgery, medication side effects, gland obstruction, brain neoplasms, and hypothyroidism. Typical saliva production a day is 1,000 to 1,500 mL (DeConno et al., 2005). It is an important aspect of oral health functioning to protect against bacteria and fungi, facilitate transport of nutrients and digestive enzymes, lubricate the oral cavity, and help with remineralization (Hopcraft & Tan, 2010).

Medications may contribute to xerostomia either indirectly or directly. These may include anticholinergics, anticonvulsants, antidepressants, antihistamines, corticosteroids, opioid analgesics, nonsteroidal anti-inflammatory agents, calcium channel blockers, beta-blockers, and diuretics. Indirect effects involve impairment of taste sensation, leading to a decreased

secretion of saliva. Polypharmacy is common for older adults, especially those who are terminally ill, and may be a contributing factor in the incidence of xerostomia. A study by Davies, Broadley, and Beighton (2001) revealed a positive correlation between the total number of drugs taken and the presence of xerostomia in older adults with cancer.

Oral cancer, chemotherapy or radiotherapy, stomatitis, and oral infections may cause actual erosion of buccal mucosa. Local causes of dehydration, such as oxygen therapy or mouth breathing, may contribute to xerostomia, along with the systemic causes of diarrhea, vomiting, anorexia, and polyuria (Dahlin & Goldsmith, 2006).

■ **Signs and Symptoms of Xerostomia.** Xerostomia is generally considered a subjective sensation; the severity is related to the amount of discomfort or pain that the individual experiences. Symptoms that are most frequently voiced in relation to dry mouth include diminished taste (dysgeusia), difficulty in chewing foods without fluids (dysmasesis), dysphagia, needing fluids during the night, and a burning sensation on the tongue (DeConno et al., 2005).

■ **Assessment of Xerostomia.** Assessment should begin by discussing with the patients the impact of symptoms on their lives. This is especially important to consider in the geriatric population, as they are more likely to be affected by polypharmacy, as well as those patients who are suffering from head and neck pathology. Important questions to ask include the following: Does the patient feel the amount of saliva in his or her mouth seems to be too little, too much, or he or she does not notice it? Do he or she have any difficulty swallowing? Does his or her mouth feel dry when eating a meal? Does he or she sip liquids to aid in swallowing dry food (Hopcraft & Tan, 2010)?

When assessing the oral cavity, inspect the oral mucosa for dryness, cracking, fissures, pale color, ulcerations, and gingivitis (Cooke, Ahmedzai, & Mayberry, 1996). Remove the dentures to inspect for problems that may otherwise be hidden. Structures that should be evaluated on routine examination are the hard and soft palate, pharynx, buccal areas, floor of the mouth, gum and tooth or denture condition, and upper, lower, and sides of the tongue. Also, evaluate the lips for dry, cracked areas or lesions along with the degree of mouth opening.

Xerostomia can be determined at the bedside utilizing a quick and easy test. Following inspection of the oral cavity, attempt to stick the tongue blade on the top surface of the tongue. If it remains in place, xerostomia is present (Cooke et al., 1996). Another test that can be attempted is the cracker/biscuit test. This involves asking the patient to eat a dry cracker or biscuit, and if he or she is unable to do so, xerostomia is present (Sreebny & Valdin, 1987). It may be



difficult to perform this second type of test if patients are limited in their ability to tolerate oral intake. Caution should be used to prevent aspiration.

The Oncology Nursing Society has a documentation tool for xerostomia and nursing care that assists in making the assessment and documentation standardized. A 0 is recorded for no evidence of dry mouth; 1 = mild dryness, slightly thickened saliva, minimal taste change; 2 = moderate dryness, thick and sticky saliva, markedly altered taste change; 3 = complete mouth dryness; and 4 = actual salivary necrosis (Oncology Nursing Society, 2002).

■ **Management of Xerostomia.** Managing xerostomia is not based on prevention, but on interventions to alleviate this complication from disease. With that in mind, the health care team, including the patient and family, concentrate on preventing further complications. A stepped approach is used in the management of xerostomia (Table 23.10).

**Pharmacological Interventions.** Implications for reversing symptoms accompanying xerostomia include discontinuing or changing medication

regimens, when possible. In palliative care, this is rarely a reasonable option when the medications are utilized for pain and symptom management. There are more than 250 medications that can cause xerostomia (Jackson & Chambers, 2000). Options for helping with the symptoms include both pharmacological and nonpharmacological measures (see Table 23.11).

**TABLE 23.10 Stepwise Process for Managing Xerostomia**

■ Treat underlying infections
■ Review and alter current medications
■ Stimulate salivary flow
■ Replace lost secretions with saliva substitutes
■ Protect teeth
■ Rehydrate
■ Modify diet

Source: Adapted from Dahlin & Goldsmith, 2006, p. 210.

**TABLE 23.11 Review of Interventions of Xerostomia**

Intervention	Role/Effect	Benefit	Side Effect
<b>Nonpharmacological</b>			
Peppermint water	Mucous saliva	Inexpensive	Interacts with metoclopramide
Vitamin C	Chemical reduction	Inexpensive Reduces viscosity	Can irritate mouth if sores present
Citric acid/sweets	Mucous saliva	Inexpensive	Can irritate like vitamin C. In sweets, can cause caries
Chewing gum, mints	Watery saliva	Inexpensive More volume Only dentate	No side effects if sugarless; otherwise, can promote caries
Acupuncture	Increased production	Noninvasive	Expensive
<b>Pharmacological</b>			
Pilocarpine	Nonselective muscarinic	Increases saliva production	Sweating, nausea, flushing, and cramping
Bethanechol	M-3 muscarinic	Relieves side effect of tricyclic antidepressants (TCAs)	
Methacholine	Parasympathetic	Increases saliva	Hypotension
Cevimeline	M-1 and M-3 muscarinic agonist	Increases saliva	Less effects than pilocarpine
Yohimbine	Blocks alpha-2 adrenoreceptors	Increases saliva	Drowsiness, confusion, atrial fibrillation

TCA, tricyclic antidepressant

Source: Adapted from Dahlin & Goldsmith, 2006, p. 211.

**Nonpharmacological Interventions.** Independent interventions for prevention of xerostomia include maintenance of good oral hygiene as frequently as every 2 hours and humidifying the air, especially when oxygen is being administered (Ventafridda et al., 1998). Gustatory stimulation can be enhanced using peppermint water or sugarless gum; however, the results from these interventions tend to be short lived (Cooke et al., 1996). Vitamin C and citric acids may be helpful, but have been found to cause a burning sensation, and generally should be avoided if oral lesions are present (Davies, 1997). Acupuncture has been suggested to be an effective intervention in management of various types of xerostomia as well. Evidence demonstrated that twice a week treatments for 6 weeks increased saliva for up to 1 year (Dahlin & Goldsmith, 2006). Overall, it is felt that the greatest benefit of xerostomia treatment is found in the frequency of use of a product as opposed to the specific product itself (Chilton & Faull, 2005).

## ■ CONCLUSION

GI symptoms are a common symptom in terminal illness. Many patients have described the constant nausea,

vomiting, and diarrhea as more disabling and disturbing than pain. GI symptoms affect patients' activities of daily living and influence their quality of life.

Other common GI symptoms in palliative care patients include dysphagia, constipation and bowel obstructions, hiccups, and xerostomia. All of the GI symptoms may be related to the pathology of the diseases as well as treatments. Having an understanding of both is crucial for the nurse caring for patients in this setting.

As in all palliative care, ongoing assessment of the patient is necessary to determine what interventions are working and which need modification. Interventions include pharmacological, nonpharmacological, and complementary therapies. Patient and family input remains the most important data to be considered in the assessment, planning, implementation, and evaluation of interventions in palliative care. Being thoughtful of the goals of treatment and the wishes of the patient and family are essential when caring for patients in palliative care who are suffering from GI symptoms.

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## CASE STUDY Conclusion

Following a chest CT, Dr. Jameson requested the family to visit with him. Dr. Jameson informed Mrs. Adams and her family that the cancer had spread to her spleen. Before the physician could say anything else, Mrs. Adams interrupted him and said, "I have lived a good life and I'm ready to go when God calls me home. What can be done to make me comfortable until that time comes?" Dr. Jameson explained to Mrs. Adams and her family the options of IV fluids, pain medications, and medications for nausea. Mrs. Adams requested time to be by herself. She called to speak with the physician 30 minutes later. She informed the physician that she wanted to be made comfortable, needed a do-not-resuscitate order in place, and wanted to remove the nasogastric tube. The family called the remainder of her family and friends, and Mrs. Adams died 72 hours later in her sleep.

What diagnoses should the registered nurse consider as possible causes of Mrs. Adams's symptoms? What tools might the nurse utilize to help assess the severity of symptoms? What treatment strategies would be appropriate for use in Mrs. Adams? How might the nurse help Mrs. Adams and her family deal with this diagnosis?

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## Evidence-Based Practice

Davis, M. P., & Hallerberg, G. (2010). A systematic review of the treatment of nausea and/or vomiting in cancer unrelated to chemotherapy or radiation. *Journal of Pain and Symptom Management*, 39(4), 756–767.

This systematic review evaluated 93 publications between 1950 and 2008 that evaluated the treatment of nausea and/or vomiting in cancer patients that was unrelated to either chemotherapy or radiation treatment. The purpose of the review was to determine the level of evidence for the use of antiemetics in the management of nausea and vomiting (N&V) in advanced cancer unrelated to chemotherapy and radiation, and to discover gaps in the evidence that may lead to areas for future research.

There were 14 randomized control trial (RCTs) that were all felt to be of low quality with only Level B1 evidence that existed to support any treatment. From the review, it was felt there was no clear Level I evidence that supported the use for any one antiemetic. From these data it was determined that a dose–response relationship could not be established from these RCTs.

The results from the B1 evidence found that chlorpromazine, levomepromazine, olanzapine, and thiethylperazine are effective antiemetics. In addition, continuously infused or high-dose injection metoclopramide is effective, octreotide is effective in the management of bowel obstructions, and corticosteroids reduce N&V in bowel obstructions. Overall, there is moderate evidence for using metoclopramide as an initial antiemetic choice and to use octreotide for bowel obstructions. However, there is no evidence that supports the use of multiple antiemetics as preliminary treatment. There is moderate evidence that dexamethasone does not add to the antiemetic efficacy of phenothiazines or metoclopramide. Ondansetron or metoclopramide does not reduce emesis from opioids. The addition of antiemetics with complementary approaches (such as adding Serotonin [5-HT<sub>3</sub>] receptor blockers to dopamine [D<sub>2</sub>] receptor blockers) in those whose emesis is unresponsive to D<sub>2</sub> receptor blockers has rationale behind the recommendation but lacks evidence regarding efficacy. In addition, switching antiemetics is often done, but there is little evidence to guide this practice. The best evidence for an antiemetic drug exists for metoclopramide.

### Nursing Implications

Each patient in a palliative care setting is unique in his or her symptoms and the successful treatment. A treatment that might be effective in treating the nonchemo- or radiation therapy-induced N&V in one patient (as an example) may not be effective in a similar patient. There continues to be a lack of evidence to clearly support one treatment of N&V in the palliative care population versus another. The registered nurses should be thoughtful of these treatment implications as they offer care to their patients in palliative care settings.

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# Fatigue

## CHAPTER

### KEY POINTS

- Fatigue in older adults may be underreported in patients who believe that fatigue is a normal part of aging.
- Chronic obstructive pulmonary disease (COPD)-related fatigue is complicated by interactions with other symptoms and is manageable through planned rest periods and treatment of related symptoms and comorbid conditions.
- Patients may need to be evaluated and treated for symptoms of fatigue, including anxiety and depression, before treatment begins.
- Participation in an exercise program that includes a class or short exercise sessions in the home can be effective in reducing symptoms of pain, depression, and fatigue associated with rheumatoid arthritis, as has been found in other chronic conditions.
- Quality of life (QOL) is an important goal of care and an outcome variable in palliative care (PC); it is a priority of patients, families, and health professionals.
- Evaluation of fatigue at the end of life (EOL) must be targeted to those causes that, if treated, have the best likelihood of improving the QOL for the patient: anemia, polypharmacy, cognitive function, anxiety and depression, complications of therapies, nutrition, and infection.
- A daily fatigue journal is an important communication tool between the patient and the practitioner that supports counseling for symptom management.

### CASE STUDY

Ms. Seigal is a 52-year-old woman with a history of bilateral mastectomy and a four-cycle course of chemotherapy, followed by radiation secondary to metastatic breast cancer. Her most recent diagnosis of heart failure is a complication of cancer treatment though she is a 5-year survivor of the treatment. She realizes that cure is not the intent of her current treatment regimen, but rather to prevent further disease progression and promote her quality of life (QOL). Members of the palliative care (PC) team followed Ms. Seigal for 2 years after treatment by the cancer center. She is now being cared for by a hospice team that is concerned with her physical, emotional, social, and spiritual health. The hospice nurse assesses her symptoms, including fatigue. Ms. Seigal reports “feeling exhausted with little or no physical or emotional energy for self-care or housekeeping.” She is a single woman who owns an advertising agency, but has assigned the day-to-day operation to a business

partner; however, she still feels the pressures of supervising and overseeing her business. She emphasizes the emotional investment she has in the business she built from scratch. Ms. Seigal indicates that she feels the same sense of overwhelming tiredness and fitful restlessness at night that she felt during and after her cancer treatment. Although she eventually regained her strength, she described this feeling as worse in that she “can’t seem to get going in the morning, it takes the complete breath out of me just to get my clothes on.” She also complained of “difficulty thinking straight and concentrating.” She has no immediate family but does have “some help from the folks at the community church.”

The hospice nurse requests the assistance of the PC nurse practitioner, who recognizes the cumulative effects of surviving cancer surgery, chemotherapy and radiation, and the emotional and existential burdens of diagnosis with another life-threatening illness. The hospice nurse and the PC nurse practitioner agree that a complete history, review of systems, physical examination, and laboratory data are warranted to discover the underlying, multidimensional aspects of the fatigue and weakness described by Ms. Seigal, and the changes that have occurred within the last 6 months. They also recognize that depression and fatigue can be correlated in patients with complex chronic medical conditions, specifically heart failure, and agree to an assessment of Ms. Seigal’s emotional well-being.

Ms. Seigal has experienced the physical and emotional trauma of surgery, anesthesia, and anesthetics, as well as fatigue induced by chemotherapy. She became neutropenic and anemic during the chemotherapy regimen and was treated with Procrit and Neulasta. Her fatigue was exacerbated by radiation therapy 3 years ago, which nearly 100% of patients experience toward the end of the cycle and from which few, if any, experience full restoration of energy. Given the extensive history of Ms. Seigal, and the various etiologies of fatigue and weakness, the hospice nurse and the PC nurse practitioner form a team in accordance with Ms. Seigal’s goals and preferences, the extent of her chronic heart failure, and coexisting symptoms, to develop a comprehensive plan of care that conforms to recommended competencies for end-of-life nursing care and guidelines for quality PC (National Consensus Project for Quality Palliative Care, 2013). The goals of care will be to focus on evaluation and management of symptoms that exacerbate fatigue, preventing fatigue by managing the activities that increase fatigue, and restoring energy with ultimate improvement in her overall QOL.

Fatigue is one of the most common symptoms experienced by persons with cancer, chronic pain (Kirkova, Aktas, Walsh, & Davis, 2011), multiple sclerosis (MS; Braley & Chervin, 2010), primary biliary cirrhosis (Abbas, Jorgensen, & Lindor, 2010), and other incurable, progressive illnesses. Fatigue has a negative influence on quality of life (QOL) when associated with medical conditions such as heart failure (Austin, Williams, & Hutchison, 2012) and end-stage renal disease with hemodialysis (Yong et al., 2009), as well as with inflammatory conditions such as rheumatoid arthritis (Hewlett et al., 2011), and ankylosing spondylitis (Davies et al., 2013). The ensuing fatigue affects how patients interact with others, their self-perception, their ability to function, and their sense of hopefulness. Its impact compounds the suffering associated with life-threatening illness.

Fatigue is not limited to muscular force or decline in function related to exercise tolerance across age and length of activity (Russ, Towse, Wigmore, Lanza, & Kent-Braun, 2008) or the emotional exhaustion experienced in relation to work (De Vries, Michielsen, &

Van Heck, 2003; Leone, Huibers, Knottnerus, & Kant, 2007). Chronic fatigue is an invisible thief that can steal physical and mental abilities, deeply affecting QOL and posing great challenges to care providers (Yennurajalingam & Bruera, 2007) including nurses in acute care, long-term care, and palliative care (PC) teams. Like pain, fatigue is what the patient says it is; it is a subjective experience that must be taken seriously by health care practitioners. It is important to the delivery of competent PC to recognize the complexity of fatigue as it is related to various disease states, to understand the patient’s experience of fatigue, and to utilize therapeutic intervention aimed at its management in chronic disease and at the end of life (EOL; Yennurajalingam & Bruera, 2007).

## ■ PREVALENCE OF FATIGUE

The overall prevalence of fatigue, generally defined as diminished physical, emotional, and mental energy, is associated with numerous chronic medical conditions



(Horneber, Fischer, Dimeo, Ruffer, & Weis, 2012). Generalized muscle fatigue involves changes in muscle force, velocity, and power (Fitts, 2008), yet its etiology in chronic conditions at the EOL is not clearly understood. Chronic, unrelenting fatigue is a common symptom in patients with chronic disease at the EOL, with a complex array of complaints including variations in level of irritability, nighttime sleeplessness, and daytime sleepiness. The clinical definition of fatigue at this stage of life includes lacking physical or mental energy, especially in patients with multiple sclerosis (MS), where fatigue is reported to occur in “most” patients (Induruwa, Constantinescu, & Gran, 2012; Johansson, Ytterberg, Hillert, Widén Holmqvist, & von Koch, 2008; Tartaglia, Narayanan, & Arnold, 2008). A study of older adults with heart failure (Stephen, 2008) revealed that the intensity of fatigue was related to a lower QOL and that fatigue was persistent in patients when their condition was stable.

Cancer-related fatigue (CRF), though it remains poorly understood, is multidimensional and includes psychosocial factors, side effects of chemotherapy, radiation treatments, medical states that include anemia, malnutrition, and infections, as well as exacerbation of other symptoms such as depression, sleep disturbance, and chronic pain (Berger et al., 2010). The prevalence among cancer patients experiencing CRF ranges from 70% to 100%, depending on the type of treatment, dose and route of administration, type and stage of cancer, and method and timing used to assess fatigue (Berger et al., 2010). Fatigue is both physical and cognitive, and evaluation of symptoms is necessary for effective treatment.

People living with HIV/AIDS should be evaluated for the co-occurrence of fatigue and depression (Barroso & Voss, 2013). Fatigue is a common symptom burden for patients with HIV/AIDS. A review of 42 studies relating to HIV therapies finds the prevalence of HIV-related fatigue ranging from 33% to 88% (Jong et al., 2010). In a study investigating a sample of persons with HIV/AIDS using the Functional Assessment of Chronic Illness Therapy—Fatigue (FACIT-F) subscale, the three most frequently reported symptoms—“lack of energy” (65%); “feeling drowsy” (57%); and “difficulty sleeping” (56%)—were all fatigue related (Butt et al., 2013). More specifically, Voss (2005) reported greater intensity of fatigue in HIV/AIDS patients among female (6.3 on 0–12 scale) participants than among males (5.4 on 0–12 scale). Voss (2005) found cultural and ethnic differences in the intensity of fatigue among participants who were African American, Caucasian, and Hispanic.

PC nurses are encouraged to recognize that fatigue does not occur in a vacuum and should not be assessed as such. People should be assessed for energy to perform daily living activities as well as co-occurring

symptoms related to chronic medical conditions. The results of a retrospective study of the medical records of 406 consecutive cancer patients who had been referred to a supportive care outpatient center indicated, based on the Edmonton Symptom Assessment Scale (ESAS), that fatigue, pain, anxiety, and depression were the most intense symptoms reported (Yennurajalingam et al., 2011). The authors concluded that the assessment and management of fatigue should be a priority of the palliative consultation team.

## ■ THE CONCEPT OF FATIGUE

The historical development of the concept of fatigue indicates specific identifying criteria of fatigue: (a) subjective perception; (b) alteration in neuromuscular and metabolic processes; (c) decrease in physical performance; and (d) deterioration in mental and physical activity (Dean & Anderson, 2001). There remains no clear consensus regarding the definition of fatigue or a description of the phenomenon. However, there is an appreciation of the differentiation between “normal” fatigue, from which the majority of the population can recover after a period of rest, and pathological fatigue associated with disease or its treatments that is common near the close of life and in patients receiving PC (Ream, 2007). The analysis of pathological fatigue and weakness, its etiology, severity, duration, and impact, are important aspects of the conceptual and operational definition of fatigue.

Although there is no generally accepted standard definition of fatigue documented in the literature, it is agreed that fatigue symptoms include a disabling and generalized weakness leaving the individual with feelings of significant distress or impairment (Ream, 2007). There is also agreement that fatigue is subjective, meaning it is described by the individual and, like pain, it is what the individual says it is. Fatigue is also generally accepted as unpleasant, with variation in duration and intensity. Since there are no clear criteria for differences in fatigue, chronic fatigue, and chronic fatigue syndrome (CFS), the duration (6 months) of the condition helps to distinguish its chronicity (Klimas, Broderick, & Fletcher, 2012). In a recent concept analysis of chronic fatigue, Jorgensen (2008) examined the use of the term in the disciplines of medicine, psychology, nursing, and medical sociology. Jorgensen reported that medicine associates the etiology of fatigue with physiological variables; psychology associates the condition with an overlap of coexisting psychopathology and linking the condition to thoughts and behaviors; and medical sociologists consider fatigue states in relation to underlying chronic illness with an impact on both the body and the living experience (sociomatic).

Nurse researchers were viewed as instrumental in laying the foundation of fatigue as a conceptual framework wherein the distinctive characteristics of the acute and chronic conditions were described (Aaronson et al., 1999; Jorgensen, 2008; Piper, 1989). In ethno scientific qualitative studies of perceived differences among tiredness, fatigue, and exhaustion, participants in advanced cancer states, as well as their family members and nurses, were interviewed regarding their experiences with each condition (Kirshbaum, Olson, Pongthavornkamol, & Graffigna, 2013; Olson, Krawchuk, & Quddusi, 2007). The researchers reported findings to support these three conditions as separate and distinct, though similar, states on a progression model the researchers named the “fatigue adaptation model.”

An early definition of fatigue included the influence of circadian rhythms on the feeling of tiredness, the variation in duration and intensity such that it encourages restorative rest or leads to an aversion to activity (Piper, 1989; Piper, Lindsey, & Dodd, 1989). The North American Nursing Diagnosis Association (NANDA) has defined fatigue as “an overwhelming, sustained sense of exhaustion and decreased capacity for physical and mental work at the usual level” (NANDA International, 2011). One of the most comprehensive definitions of fatigue, relevant to PC, is “the awareness of a decreased capacity for physical and/or mental activity due to an imbalance in the availability, utilization, and/or restoration of resources needed to perform activity” (Aaronson et al., 1999).

Neill (2005) conducted an analysis of the narratives of women with MS and rheumatoid arthritis in an attempt to learn about their life patterns in relation to the NANDA patterns. She found that the life pattern corollary of energy–fatigue was meaningful as a primary pattern in the daily life of the women she studied. These chronic conditions are associated with low energy and fatigue, and thus have a great impact on the women’s ability to work, take care of the home, or engage in social activities.

At various points in the course of illness, older adults may interpret fatigue differently. Older adults newly diagnosed with a life-threatening illness may have experienced fatigue as an early indication or warning symptom of the diagnosis. Over the course of treatment(s) for any number of conditions, fatigue may be understood as the side effect of treatment; for others with recurrence or exacerbation of illness, however, fatigue is interpreted as the end of a very long struggle (Dean & Anderson, 2001).

The concept of fatigue also encompasses emotional, cognitive, and behavioral dimensions. Psychosocial etiological factors of fatigue across an ethnically diverse population include social adversity, social support, physical inactivity, anxiety, and depression

(Bhui et al., 2011). In healthy individuals, overexertion may produce ordinary fatigue, which is relieved relatively quickly by rest (Aaronson, Pallikkathayil, & Crighton, 2003); fatigue may also be interpreted as satisfaction given the accomplishment of hard work. However, fatigue associated with illness is perceived as more severe, comes on after a shorter period of time, and occurs with less exertion than ordinary fatigue. It is often described as a general feeling of tiredness or “sapped” energy that occurs on a daily basis and is present intermittently throughout the day or during the evening after a day of normal activities.

Fatigue has been characterized by patients by such descriptors as “worn out, weary, exhausted, sleepiness, low energy, tired, worn down, bone-tired, and rubber knees.” Patients have said they feel weakness, “a lack of physical strength,...trapped in a failing body,...struggling in vain” (Lindqvist, Widmark, & Rasmussen, 2004, p. 240), suggesting that PC nurses should talk with patients about their feelings to gain understanding of the physical and psychological impact of fatigue. In a review and synthesis of qualitative research into patients’ experience with CRF, Scott, Lasch, Barsevick, and Pailt-Louis (2011) identified several concepts relating to patients’ experience of fatigue. These concepts are categorized as the sensation of fatigue, the impact of fatigue, and the effect of fatigue on coping strategies. The sensation of fatigue includes references to low energy level, weakness, or exhaustion. Patients reported the experience of fatigue as overwhelming, all encompassing, or extraordinarily severe and qualitatively different from tiredness experienced prior to their cancer diagnosis. The impact of this fatigue concept was present in more than 95% of the articles reviewed and included emotional (anger or frustration), physical (out of breath or debilitating), and social (feeling isolated or affecting relationships) aspects. Finally, the effect of fatigue on coping was conceptualized in terms of strategies for living with fatigue, such as increased exercise, eating healthy foods, or planning activities in advance (Scott et al., 2011). Additionally, a study of CRF in patients with advanced disease states found significant relationships between fatigue and multiple psychological and physical characteristics including physical and psychological symptoms of well-being (Yennurajalingam, Palmer, Zhang, Poulter, & Bruera, 2008). Yennurajalingam et al. (2008) found primary associations among psychological and physical symptoms of CRF including feelings of well-being, drowsiness, anorexia, and anxiety. These authors indicate that how fatigue is expressed is important in planning and delivering care for patients with cancer who experience fatigue.

PC nurse practitioners, hospice nurses, and general care nurses use terms such as listless, lassitude,



lethargy, and malaise to describe the fatigue observed in patients. Some practitioners differentiate fatigue from weakness, while others believe that they accompany each other and comprise a syndrome known as asthenia (Al-Osali, Al Qassabi, & Al-Harthi, 2013). Fatigue that persists through resting, is present at awakening, and occurs in the absence of muscle weakness is termed asthenia, and may be considered within the context of clinically chronic and inflammatory conditions previously mentioned involving the nervous system or endocrine system (Al-Osali et al., 2013; Kasatkin & Spirin, 2007). Asthenia and chronic fatigue are clearly related as unpleasant sensations of whole-body tiredness experienced when an individual's physiological resources are exceeded.

## ■ MULTIDIMENSIONAL ASPECTS OF FATIGUE

Fatigue is like pain, a multidimensional symptom, a subjective experience associated with diverse etiologies (Al-Osali et al., 2013). The complex phenomenon that is fatigue has physical, emotional, cognitive, and behavioral descriptors (Jorgensen, 2008) to which subgroups are not clearly measurable. The consensus between Chochinov and Breitbart (2012) is that physical etiologies of fatigue in the medically ill older adult include the underlying disease itself, associated treatment of disease (chemotherapy, radiation, surgery, biological response modifiers), co-occurring systemic disorders (anemia, infection, pulmonary disorders, hepatic failure, heart failure, renal failure, malnutrition, neuromuscular and neurogenic disorders), sleep disorders, chronic pain, and use of centrally acting drugs, as well as lack of mobility and lack of exercise. From a physiological perspective, fatigue has been attributed to excessive energy consumption and influenced by events occurring in both the peripheral and the central nervous system (CNS; Meeusen & Watson, 2007; Norheim, Jonsson, & Omdal, 2011).

## Independent Categories of Fatigue

Clinical fatigue, classified into independent categories, includes fatigue at rest (asthenia, chronic fatigue), fatigue on physical loading (pathological fatigue, acute fatigue), and fatigue as related to another condition (CRF, treatment-related fatigue) or exacerbation of a condition such as MS (Al-Osali et al., 2013; Kasatkin & Spirin, 2007). Fatigue is also linked clinically to metabolic changes such as infection, fever, tissue injury, anemia, hypoxemia, malnutrition, or to conditions involving sleep or mood disorders including major depression.

In the case of CRF, asthenia, and weakness, three associated physiological mechanisms may affect the CNS or muscles:

1. Direct tumor effects (mechanically by destruction, such as metastasis, or metabolically by lipolytic factors or tumor degradation products)
2. Tumor-induced products (such as tumor necrosis factors [asthenin/cachectin], and other cytokines such as PEG2, Il-1, Ifn, or IL6)
3. Tumor-accompanying factors (cachexia, infection, anemia, hypoxia, neurological disorders, pharmacological side effects, paraneoplastic, metabolic, or dehydration; Neuenschwander & Bruera, 2011)

In cancer populations, there has been a documented relationship between asthenia and cachexia, although one may exist without the other (Tuca, Jimenez-Fonseca, & Gascón, 2013). However, in patients with advanced cancer, both are usually present with asthenia as an epiphenomenon of the cachexia syndrome. In malignancy, changes in carbohydrate, fat, and protein metabolism, as well as direct tumor factors and cytokines previously mentioned, lead to cachexia and resultant loss of muscle mass. This partially explains cachexia-related asthenia.

## Clinical Classification of Fatigue

Research indicates that the mechanisms or pathophysiology of fatigue, weakness, and asthenia differ from one clinical condition to another and are not consistent in the literature (Kasatkin & Spirin, 2007). The individual perception of fatigue is multidimensional and may include physical, psychological, and cognitive complaints, each contributing to the physiological basis for the syndrome (Evans & Lambert, 2007). Fatigue has been classified as either acute physiologic, secondary to a medical condition, or chronic (Rosenthal, Majeroni, Pretorius, & Malik, 2008). Physiologically, fatigue is classified into two types: central or peripheral. Signal, Taylor, and McNair (2008) reviewed central and peripheral influences on neuromuscular fatigue in people after experiencing stroke or cerebrovascular accident (CVA). They reported that patients experience a relatively decreased level of peripheral neuromuscular fatigue and an increased level of central fatigue after suffering a stroke. In central fatigue, the motor pathways in the CNS fail to sustain recruitment and/or frequency of motor units or the generation of descending volleys in the motor cortex due to neurotransmitter modulation (Anish, 2005). Research data suggest that alterations in brain dopamine and 5-HT levels may influence arousal level, sleepiness, mood, and the perception of fatigue. These findings suggest that fatigue can contribute to functional impairment; therefore,

the recognition and treatment of fatigue by a PC provider is an important consideration. Admittedly, the role of neurotransmitters in the development of central fatigue requires further study of correlates with chronic disease as well as extensive physical exercise (Anish, 2005; Klimas et al., 2012).

In peripheral fatigue, there are metabolic changes in the muscle and a failure in the muscle fiber components' potential, resulting in decreased postural stability (Dickin & Doan, 2008). This failure to exert effort results from a combined effect of failure in the neural drive, such as fatigue in the mind or CNS, and failure of neurotransmission in the muscles though continued research is in progress to understand the mechanisms (Anish, 2005; Kisiel-Sajewicz et al., 2012). Peripheral fatigue has known associations with chronic diseases related to muscle wasting, inflammation, or joint abnormalities including rheumatoid arthritis and systemic lupus erythematosus, HIV/AIDS, and neurological abnormalities including Parkinson's disease and postpolio syndrome (Norheim et al., 2011).

Fatigue leads to a decline in mental or intellectual activities and a diminished motivation or capacity to attend (Scott et al., 2011; Tartaglia et al., 2008; van Kessel et al., 2008). Tartaglia et al. (2008) studied mental fatigue and its impact on motor task impulse activation in patients with MS. They found that MS patients with physical fatigue also experience fatigue for mentally challenging tasks, which can affect unrelated motor activities unrelated to age. Similarly, van Kessel et al. (2008) randomized patients with MS into groups for two study treatments: cognitive behavioral therapy (CBT) sessions to address contributory factors related to fatigue including behavioral, cognitive, emotional, and environmental issues; and relaxation training (RT) sessions during which relaxation techniques were taught and practiced without advice or strategies for maintaining the practices. Van Kessel et al. reported that both methods result in significant improvements, with the CBT group showing more improvement in fatigue-related impairment, depression and anxiety, and stress level.

■ **Acute (Physiological) Fatigue.** Acute or physiological fatigue is a protective state that is identifiably linked to a single cause in usually healthy individuals. Acute fatigue is a clinically significant state of tiredness and diminished ability to expend effort as in exercise-induced states (Al-Osali et al., 2013; Norheim et al., 2011) to which individuals may recover after a period of restoration. Antecedents to acute fatigue may be associated with physical exertion or lack of sleep that limits the usual activities of daily living (Evans & Lambert, 2007). Acute fatigue has a rapid onset and short duration, is viewed as normal in the usually healthy person, and can be alleviated by

restorative techniques such as rest, diet, exercise, and stress management. Acute fatigue may have immediate effects on activities of daily living and minimal effects on QOL.

■ **Chronic Fatigue.** In contrast, chronic fatigue has no known physiological purpose and can occur without any relationship to exertion or activity. Chronic fatigue is commonly associated with severe deconditioning or limited mobility as seen in patients with anemias and diminished aerobic capacity, including those with heart failure, chronic lung conditions, and neurological disorders (Evans & Lambert, 2007). Chronic fatigue is frequently experienced by patients with life-threatening illness, is insidious in onset, and persists over time, typically longer than 6 months (Scott et al., 2011). Scott et al. (2011) found patients' conceptualization of chronic fatigue as severe, unrelieved after rest, and having a cognitive, physical, social, and emotional impact. Therefore, chronic fatigue has a significant negative effect on independence, instrumental activities of living, and QOL (Rosenthal et al., 2008).

CFS is an illness with symptoms of fatigue that are more intense than the feelings experienced by persons who have a difficult workday, or who have a stressful interaction. When unexplained fatigue occurs for more than 6 months and is accompanied by an array of primary symptoms, the Centers for Disease Control and Prevention (CDC) recommends further evaluation and differentiation of CFS from illnesses that may mimic its symptoms (CDC, 2012). For example, persons with CFS commonly complain of impaired cognitive function that lasts more than a day or two, and persons with co-occurring conditions or other illnesses may exhibit psychological problems including depression, irritability, mood swings, anxiety, and panic attacks (CDC, 2012). Symptoms that occur with other disease conditions in which fatigue also occurs signal health care professionals to evaluate possible coexistence to determine the level of contribution to functional decline and impairment.

■ **Secondary Fatigue.** When a person is experiencing the stress and pathology of chronic disease or cancer, the body reserves can become depleted and ultimately unable to counterbalance the physiological insults (Evans & Lambert, 2007). The patient may experience fatigue in association with the advanced stage of chronic disease, and concurrent malnutrition, anemia, and cachexia, as well as further deconditioning and weakness. The patient interview should include reviewing the effect of fatigue on lifestyle, the presence of other physical or mental conditions, and possible side effects of medicines or drugs (Rosenthal et al., 2008).

CRF is reported by nearly 100% of patients undergoing radiation therapy and 95% of those receiving



chemotherapy; it is also associated with anemia, cytokine activation, and mood changes including anxiety and depression (Berger et al., 2010). A study of Thai Buddhist patients described consuming concerns about cancer treatment and outcomes that produced uncertainty, fear, weakness, and difficulty sleeping, leading to feelings of fatigue (Lundberg & Rattanasuwan, 2007). Bower et al. (2011) conducted a study of 103 patients with breast cancer who had recently completed treatment of surgery, radiation, or chemotherapy. They revealed symptoms were highest at the end of treatment with 65% of patients reporting problems with fatigue and sleep and 25% reporting depressive symptoms. Furthermore, an increase in inflammatory markers taken from blood samples suggests that fatigue, sleep disturbance, and depression may stem from biological processes in posttreatment survivors, with inflammatory signaling contributing relatively specifically to fatigue (Bower et al., 2011). Coexisting symptoms such as nausea and vomiting, inadequate nutrient intake, pain, immobility, loss of muscle mass, infection, metabolic disturbances, shortness of breath, possible gastric obstruction, and anxiety or depression also are associated with the experience of fatigue in the older adult.

The treatment for cancer (surgery, radiation, chemotherapy, biotherapeutic therapy) can cause feelings of fatigue. The level of role functioning before surgery, preoperative fatigue, state anxiety, insomnia, and QOL in most domains have been demonstrated as the strongest predictors for an increase in fatigue following surgery (Rotonda, Guillemin, Bonnetain, Velten, & Conroy, 2013). Klampfer (2011) studied patients of colorectal surgery and reported that locally occurring proinflammatory cytokines and neopterin may increase postsurgical fatigue; therefore, treating inflammation may reduce the fatigue experienced after major surgery. A secondary analysis of data on patients after coronary artery bypass graft surgery confirms the negative impact of fatigue on postsurgical recovery (Zimmerman et al., 2010).

For patients treated with radiotherapy, nearly 100% experience dose-dependent fatigue, which tends to peak toward the end of the cycle. Approximately 95% of patients who receive chemotherapy report that fatigue is one of the worst symptoms they experience within the first 2 weeks after treatment. Biotherapeutic agents (interferon, interleukins) are used as maintenance therapies in older adults, especially those in remission from acute myeloid leukemia (Melchert & Lancet, 2008; Scott et al., 2011). Interferon and cytokines can induce dose-related loss of sleep and fatigue through side effects of flu-like symptoms including chills, fever, weakness, and dyspnea (Raison et al., 2010).

Patients with chronic conditions, such as fibromyalgia, may manifest progressive symptoms of

psychogenic fatigue, physiological fatigue, pain, depression, sleep disorders, and loss of adaptability (Van Houdenhove, Kempke, & Luyten, 2010). Given the unknown etiology of fibromyalgia, there are limited treatment options for this disease, with relief primarily achieved by the palliation of symptoms. Porter, Jason, Boulton, Bothne, and Coleman (2010) conducted a systematic review and found positive results from treatment with complementary and alternative medicines. The results showed positive effects in terms of laboratory test results, physical functioning, psychological functioning, and QOL warranting further investigation (Porter et al., 2010). Exercise is also recommended in levels that help sufferers to feel better without initially aiming at training or conditioning. Older adults who live with chronic conditions such as fibromyalgia, rheumatoid arthritis, or CFS should be the recipients of primary and secondary prevention efforts targeted toward comorbid depression and the impact on overall QOL and quality of health (Fiest, Currie, Williams, & Wang, 2011). Interventions such as psychotherapy and medication management should be initiated to prevent suicidal ideation or attempt.

The causes of HIV-related fatigue are typically related to physiological and/or psychological factors that influence symptoms associated with fatigue (Barroso et al., 2010). The physiological factors of HIV-related fatigue include hepatic function, thyroid function, HIV viral load, immunological function, gonadal function, hematological function, and cellular injury. Psychosocial factors include childhood and adult trauma, anxiety, depression, unemployment, social support, stressful life events, and post-traumatic stress disorder (Barroso et al., 2010). The fatigue experience in patients with HIV/AIDS includes complaints of tiredness and exhaustion, with varying reports that women in some studies experience higher fatigue severity than men (Barroso & Voss, 2013).

## ■ CORRELATES OF FATIGUE IN SPECIFIC PATIENT POPULATIONS

### Fatigue: Pediatric Considerations

For children with advanced cancer, fatigue is the most common symptom reported in the last month of life (Ullrich et al., 2010). The prevalence rate of this symptom is reported as 96%, with nearly 50% reporting as suffering significantly from it (Ullrich et al., 2010). In a longitudinal descriptive study, Erickson et al. (2010) found that every adolescent cancer patient experienced fatigue during the month of treatment, with variability in severity and duration. Reports of fatigue were independent of chemotherapy agents,

doses, and routes of administration and showed an increase in the days immediately following chemotherapy administration (Erickson et al., 2010). In children, as in adults, fatigue typically results in decreased activity, loss of control, and a sense of loneliness and isolation (Ullrich et al., 2010). Left untreated, fatigue can negatively impact QOL and interfere with opportunities for growth and closure at the EOL.

Assessment of fatigue is dependent on subjective reports of the patient. In children, clinicians may need to rely on the reports of the parents regarding the experience of fatigue. Hockenberry et al. (2003) developed a fatigue-rating tool that took into consideration the perspective of the child, parent, and staff. The experience of fatigue by adolescents is expressed as a distressing, dynamic symptom with physical, psychological, and emotional components while younger children experience fatigue as a physical sensation (Erickson et al., 2010; Hooke, Garwick, & Gross, 2011). Parents and staff share the view that the child's fatigue is manifested by physical, emotional, and mental changes that interfere with the child's ability to participate in activities.

To date, there is no evidence to support that interventions aimed at the management of fatigue are any different between children and adults, although there are little evidence-based studies documenting the efficacy of these interventions in children. However, a recent review and meta-analysis lends support to the idea that exercise interventions may reduce general fatigue in children and adolescents with cancer (Chang, Mu, Jou, Wong, & Chen, 2013). For children, studies are needed regarding assessment of fatigue in light of developmental stages. Education for children with life-threatening illnesses, their families, and clinicians is needed regarding recognition and treatment of this symptom to lessen this source of suffering.

## Fatigue in the Older Adult

Fatigue is common in older adults and associated with advanced disease, functional decline, and mortality (Hardy & Studenski, 2010). A review study consisting of a prospective cohort of 495 community-dwelling primary care patients aged 65 years or older found 70% reporting one or more fatigue qualities and 43% reporting feeling tired most of the time. Hardy and Studenski (2010) found these reports to be associated with worse health and functional status.

Fatigue is particularly evident in the older adult in long-term care facilities. In a review of literature related to the unmet symptom needs of residents in long-term care, fatigue was named as one of the more common symptoms in persons with cancer who were not near the EOL (Duncan, Forbes-Thompson, & Bott, 2008). Furthermore, assessment and evaluation of fatigue is

not specified in the Minimum Data Set (MDS) required by each nursing home certified by Medicare or Medicaid (Centers for Medicare & Medicaid Services, 2008).

In a study of resident-to-resident aggression among residents of long-term care, researchers conducted 15 focus group interviews with 7 residents and 96 staff members in one facility (Rosen et al., 2008). The residents formed one focus group and staff of differing job levels and responsibilities formed the remaining groups. Although fatigue was named as a nonfrequent trigger or reason for aggression, the research report indicated that fatigue may occur during both public (group) and private (bathroom) activities involving residents, and may also be related to end of day staff fatigue (Rosen et al., 2008). Policy recommendations for prevention of resident violence and aggression include specific staff training in geriatrics and long-term care, as well as staff levels that allow sufficient time to attend to the physical and emotional needs of residents (Robinson & Tappen, 2008). Each study suggests that fatigue may be poorly recognized and undertreated in older people in nursing home facilities.

Palliative treatment of the older adult must encompass the potential for confounding pathology secondary to aging. Clear associations between fatigue and depression (National Institute of Mental Health, 2013), cancer-related treatment modalities (Carlotto, Hogsett, Maiorini, Razulis, & Sonis, 2013), heart failure (Austin et al., 2012), anemia (Balducci, 2010), malnutrition (Tennant, Takacs, Gau, Clark, & Russ, 2012), end-stage renal disease (Hallan & Orth, 2010), and fibromyalgia (Shillam, Dupree Jones, & Miller, 2011) appear in the literature. Health care providers, in accordance with the clinical practice guidelines for PC (National Consensus Project for Quality Palliative Care, 2013), should regularly and carefully assess symptoms of fatigue and weakness, and the symptoms that frequently accompany these, for all older adult patients and persons near the EOL. Nurses are expected to assess for and recognize the need to treat generally occurring symptoms that may include pain, breathlessness (dyspnea), constipation, anxiety, changes in appetite, nausea, vomiting, changes in sleep pattern, and alterations in cognition and function. Often the conventional wisdom is that because a person is of advanced age, fatigue is a normal consequence of the aging process.

Many elders and their families erroneously consider fatigue to be an inevitable aspect of aging, and therefore not a symptom to be treated. In fact, older adults may not even report symptoms of weakness and fatigue to their primary care provider. Even for the older adult in PC, many causes of fatigue can be successfully treated by examining for and treating the underlying cause. The goal for the health care provider related to the symptom fatigue is to improve the patient's QOL by



treating the symptom and teaching the older adult coping mechanisms and lifestyle changes.

■ **Parkinson's Disease.** A recent study on the influence of disease severity on fatigue in patients with Parkinson's disease suggests that disease severity directly affects three domains of fatigue: increased levels of general fatigue, physical fatigue and reduced activity, and mental fatigue (van Dijk et al., 2013). In another study, Herlofson, Ongre, Enger, Tysnes, and Larsen (2012) found 55% of patients with Parkinson's disease had clinical significant fatigue in both advanced and early, untreated stages of disease. Additionally, the researchers determined that fatigue was related to, but not causally determined by, depressive symptoms and found no correlation between fatigue and cognitive impairment (Herlofson et al., 2012).

■ **Frailty.** Fatigue is commonly included in characterizations of frailty. Evidence exists indicating fatigue and early development of weight loss may be significant predictors of frailty, occurring in up to 80% of transitions to frailty (Xue, Bandeen-Roche, Varadhan, Zhou, & Fried, 2008). Avlund (2010) identifies fatigue without disability as representing an early stage of frailty prior to causing disability. Additionally, both frailty and fatigue are understood to be the result of complex interactions between a multitude of biological, physiological, and psychosocial systems. Avlund (2010) goes on to suggest that placing an emphasis on frailty may result in less attention paid to the individual components of frailty, such as fatigue, which may be an important predictor for practitioners to assess.

■ **Depression.** Depressive symptoms were also associated with baseline frailty in the Women's Health Initiative Observational Study (WHI-OS), and being underweight, overweight, or obese were described as risk factors for frailty, a component of which is poor physical functioning or exhaustion. In a cohort study of older adult women from the WHI-OS, depressive symptoms and antidepressant use were associated with frailty after an initial assessment and a 3-year follow-up (Lakey et al., 2012). The American Psychiatric Association (APA) identifies fatigue as a symptom of depression, and depression screening is often measured with criteria that reflect energy level (ability to get going), or effort required to conduct daily activities (APA, 2013).

■ **Inflammatory Conditions.** Fatigue is identified by researchers as occurring in patients with inflammatory conditions including biliary cirrhosis (Biagini et al., 2008; Björnsson, Simren, Olsson, & Chapman, 2005), rheumatoid arthritis (Repping-Wuts, Fransen, van Achterberg, Bleijenbergh, & van Riel, 2007), ankylosing spondylitis (Turan et al., 2007), and after

an episode of infectious mononucleosis (Petersen, Thomas, Hamilton, & White, 2006). Biagini and colleagues studied a group of 49 patients with biliary cirrhosis and 30 healthy adults and reported that fatigue scores were higher among patients with biliary cirrhosis. Scores were also higher when those patients had concurring illnesses, including depression.

Björnsson et al. (2005) studied 96 patients with biliary cirrhosis and a group of matched persons from the general population, patients with functional gastrointestinal disorders, and patients with organic gastrointestinal disorders such as inflammatory bowel disease. They reported that patients with functional gastrointestinal disorders and organic gastrointestinal disorders had higher fatigue scores than the persons from the general population and those with biliary cirrhosis. Both these studies indicate the necessity to evaluate fatigue in patients with biliary cirrhosis, which, while present, may not be related to actual liver function but instead to the comorbidities including depression, alteration in sleep patterns and quality, or other psychological or psychiatric conditions.

In a study of 68 patients with ankylosing spondylitis, researchers reported an increase in fatigue that was associated with greater disease severity, functional disability, and disease activity (Turan et al., 2007). Repping-Wuts et al. (2007) studied a group of 150 patients with rheumatoid arthritis and found that the general health of the patient and the level of disability predicted high scores on measures of fatigue. Severe persistent fatigue was defined as a score of at least 35 at the beginning of the study and after 12 months using the fatigue subscale of the Checklist Individual Strength questionnaire. These two studies underscore the relationships among fatigue, functional disability, and level of general health. It is therefore important to assess for fatigue and institute measures to reduce its severity in patients with inflammatory conditions such as ankylosing spondylitis and rheumatoid arthritis.

In a randomized control study of the effect of exercise on common symptoms in patients with rheumatoid arthritis, 220 patients participated in a guided exercise group, exercised at home with a videotape, or were in a control group (Neuberger et al., 2007). All exercises were low impact during which one foot was always in contact with the floor. Findings indicated that fatigue, pain, and depression diminished among participants in the exercise class, whereas participants in the home exercise program experienced no changes (possibly related to less intensity and duration of exercise sessions in the nonguided home exercise participants). Participants who believed that exercise would be beneficial to their overall health tended to exercise more.

■ **Heart Disease.** Patients typically experience increasing fatigue as heart failure progresses, characterized by symptoms of systolic dysfunction and refractory

symptoms of dyspnea and fatigue while resting (Austin et al., 2012). However, Austin et al. (2012) found fatigue levels respond positively to cardiac rehabilitation programs and the adoption of a better exercise profile. The breathlessness and dyspnea associated with fatigue may be treated with opioids (narcotic agonist analgesics), which may contribute pharmacologically to the experience of fatigue (Bascom, 2013). Given that fatigue is integral to the experience of heart failure, interventions are needed to assist patients to cope with the experience of fatigue, such as pacing of activities, relaxation, and restful sleep.

One study of 84 patients with heart failure indicated that fatigue was a common symptom in 95% of participants while engaged in daily activities (Heo, Doering, Widener, & Moser, 2008). While fatigue was just one of several physical symptoms self-reported by participants, it was often associated with dyspnea; higher levels of symptoms were associated with poorer QOL in relation to health. Significant measures of physical symptom status in these heart failure patients included employment status, patient-perceived control over the management of the condition, anxiety, and depression. In another study of patients with heart failure, a group of 53 older adults completed the fatigue subscale of the Profile of Mood States (POMS; Stephen, 2008). Results indicated that, without regard to actual age, older adults who believed that fatigue was related to their aging scored higher on fatigue intensity than older adults who did not believe the relationship. Stephen found that the intensity of fatigue was predicted by the severity of the illness, negative affect (e.g., sadness and depression), perception of health status, satisfaction with life, severity of current co-occurring symptoms, and marital status.

■ **Chronic Obstructive Pulmonary Disease.** A study of 19 women and 17 men with chronic obstructive pulmonary disease (COPD; i.e., not asthma or cancer) was compared with a control group of regional participants statistically matched for sex, marital status, and social support to explore fatigue and its impact on the daily lives of participants (Theander & Unosson, 2004). Findings indicated that fatigue had a great impact on how participants with COPD felt each day and on their ability to perform daily tasks. Nearly half (44%) of the participants reported that fatigue was experienced daily and was one of their worst symptoms. Participants in this study also reported higher fatigue scores as measured by the Fatigue Impact Scale (FIS; Theander & Unosson, 2004), developed for assessment of the perceived impact of fatigue on QOL for persons with chronic illness (Fisk et al., 1994).

Fatigue and weakness were reported in 96% of patients with COPD near the EOL in a descriptive,

retrospective study using informants of the deceased (Elkington, White, Addington-Hall, Higgs, & Edmonds, 2005). The researchers found that accompanying symptoms including low mood, sleep disturbances, anxiety, pain, and breathlessness were frequently among the patients' EOL experiences. In a study of persons with moderate to severe COPD, researchers were able to document an association between fatigue and the daily function and activities of persons with COPD (Kapella, Larson, Patel, Covey, & Berry, 2006). The sample of 130 participants reported situation-specific fatigue that was controllable and responsive to planned amounts of rest and sleep. They developed a model describing the direct influence of depressed mood on fatigue, and the indirect influence of anxiety and quality of sleep on fatigue, thereby contributing to diminished functional capacity. In a state-of-the-science article examining over 75 articles related to anxiety and depression in patients with COPD, Putman-Casdorff and McCrone (2009) acknowledged the complexity of anxiety and depression and their negative impact on physical performance, compliance with prescribed regimen, symptom burden, and overall QOL.

■ **Cancer.** The National Comprehensive Cancer Network (NCCN) defines CRF as "a distressing, persistent, subjective sense of tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning" (NCCN, 2013). CRF is influenced and modulated by a number of critical factors, and the mechanism that is both necessary and sufficient to induce development of severe fatigue in patients with cancer has not yet been identified. Specific research efforts to understand the factors that may contribute to CRF development have been made, including studies of the direct effects of tumor burden, the effects of cancer treatment, and other pathophysiological and psychosocial conditions.

Compared with fatigue reported by healthy people, CRF is described as more distressing, as interfering with usual functioning, and as less likely to be relieved by rest. Most importantly, if left untreated, CRF is a major factor in patient QOL scores (Wang, 2008). Although reported by 60% to 100% of patients undergoing therapy for CRF, fatigue is still considered an underreported symptom for which there are multiple overlapping etiologies, confounding an explanation of its specific pathophysiological mechanisms. CRF may be more prevalent in patients undergoing multimodality treatment such as chemoradiotherapy for rectal carcinoma. CRF may continue for years after treatment is completed, even when the cancer has been cured (Wang, 2008).

CRF has a complex etiology (Table 24.1), possibly regulated by physiological, psychological, and



**TABLE 24.1 Etiology of Cancer-Related Fatigue**

<b>Tumor-Related Causes</b>	<b>Treatment-Related Causes</b>
Disease site	Surgery and postoperative recovery
Paraneoplastic syndrome	Psychological distress
Increased cytokine production	Chemotherapy and chemotherapy effects
Decreased availability of metabolic substrates	Radiotherapy and radiotherapy effects
Cachexia	Anemia
Pain	Pain

Source: Adapted from Wang, 2008.

situational factors: changes in the production and balance of muscle proteins, glucose, electrolytes, and hormones; a catabolic process resulting from decreased daily energy expenditure and bed rest; and disease-related and treatment-induced anemia. Distinguishing between fatigue and depression is an important aspect of fatigue evaluation. Complex interplay exists between etiological factors such as cancer treatment, infection, concomitant medications, and susceptibility of the patient to CRF.

Multiple risk factors, rather than a single risk factor, appear to put patients with cancer at risk for CRF. These risk factors include poor nutrition, sleep disorders, stress, cancer comorbidities (i.e., cardiac, pulmonary, renal, liver, neurological, thyroid, and endocrine, and associated medications), hypoxia, pain, infection, deconditioning, and ongoing therapy. Cancer patients may report severe fatigue even before the start of therapeutic intervention, which might add to the subsequent occurrence of fatigue (Borneman, 2013; Goedendorp, Gielissen, Verhagen, Peters, & Bleijenberg, 2008). In the study of 240 patients with varying forms of cancer, almost one quarter of participants with a diagnosis of cancer reported severe fatigue 1 to 3 years before starting treatment. For example, fatigue was categorized by disease process, and of the 23% of participants who complained of severe fatigue, the highest occurrence was in persons with “other” tumors (33%), including gastrointestinal, urogenital, or gynecological. Of participants who reported severe fatigue, 14% were persons with prostate cancer and 20% were persons with breast cancer. Participants with severe fatigue after diagnosis but before therapy also experienced more pain, less physical activity, more sleep disturbance, more depressive feelings, and more anxiety than participants without severe fatigue. The researchers found that although anxiety might be a normal and expected response to

a diagnosis of cancer, there was no significant association between the diagnosis of cancer and severe fatigue.

Differences in fatigue by treatment methods in women with breast cancer has been studied by numerous researchers (Halkett, Kristjanson, & Lobb, 2008; Hwang et al., 2008; Minton & Stone, 2008). Minton and Stone (2008) conducted a literature review to address the issue of fatigue after treatment for breast cancer in survivors. Their findings indicate that fatigue may persist for 5 years following therapeutic intervention including surgery, radiotherapy, and chemotherapy. Halkett, Kristjanson, and Lobb (2008) conducted semistructured interviews with 34 patients who discussed their experiences with radiotherapy treatments for breast cancer. They found that fear of fatigue, or “anticipating tiredness” (Halkett et al., 2008, p. 881), was often greater than the actual experiences of side effects. A randomized control study of 37 women with breast cancer in radiotherapy examined the effect of exercise on their QOL, including levels of fatigue (Hwang et al., 2008). The study protocol included use of the Brief Fatigue Inventory (Korean version). Results indicated a significant difference ( $p < .05$ ) between the two groups. Fatigue decreased after exercise and radiotherapy in the treatment, but increased after radiotherapy in the control group. Although these studies did not specifically address co-occurring illnesses, the findings in each suggest the need for anticipatory guidance regarding the side effects, such as fatigue, of various treatment regimens, as well as methods for managing or decreasing the fatigue.

## ■ FATIGUE AND QUALITY OF LIFE

Regardless of the age of the patient, fatigue has a profound effect on QOL. Researchers conducted a study of 526 adults aged 75 years and older in groups representing those who did or did not report pain and those who did or did not require in-home assistance with daily activities (Jakobsson, Hallberg, & Westergren, 2007). Decreased ability to carry out role performance tasks was found to be associated with mobility, sleep quality, and mood, which were found to have an impact on overall QOL for persons in pain. The findings indicated that fatigue was one factor that contributed to the health-related QOL experienced by participants; the remaining contributors were associated with the need for special living accommodations and functional problems with walking or mobility (Jakobsson et al., 2007). This study suggests that to promote health-related QOL, fatigue, as a symptom that often coexists with pain, must be appropriately assessed and effectively treated.

## ■ ASSESSMENT OF FATIGUE

NCCN convened a committee of experts to make recommendations for future studies of CRF. The committee reviewed the current data on the incidence, clinical measurement, and treatment of CRF. The assessment of fatigue is largely derived from self-report questionnaires that address the symptom of fatigue, and do not correlate the presence of fatigue with change in physical activity. The committee noted a strong interaction among fatigue, pain, difficulty sleeping, and distress and recommended that future clinical research address these interactions (Mortimer et al., 2010). As a subjective symptom, practitioners most often rely on the patient's self-report of fatigue to evaluate its severity. However, the assessment of fatigue does include observable characteristics and the impact of the symptom on QOL. A comprehensive assessment of fatigue is obtained through a health history and review of systems. Fatigue assessment, physical examination, and laboratory data can assist the practitioner in discriminating between physiological and psychogenic fatigue, depression, and the presence of correctable causes of fatigue (Piper et al., 2008). Appendix 1 reviews the characteristics of commonly used fatigue assessment tools.

- I. **Health History:** Should include a medical, psychiatric, family, social, and medication history, which may reveal associated conditions, such as diabetes, hypothyroidism, sleep apnea, anxiety or depressive disorders, inherited metabolic disorders or a history of alcohol or illegal drug use, and the possibility of sexually transmitted infections often associated with fatigue, even in older populations.
- II. **Review of Systems:** Focuses on changes in other body systems that may indicate potential health problems associated with fatigue, such as respiratory disorders (e.g., dyspnea), cardiac problems, anemia, cancers, depression, or electrolyte disorders. For patients with chronic, incurable illness, fatigue may also be a side effect of medical treatments, including both prescription and over-the-counter medications. Furthermore, in speaking with the patient, it is important to determine his or her emotional status, particularly whether the person speaks of his or her own death or suicidal ideations.
- III. **The Fatigue Assessment:** Includes questions related to the six dimensions of fatigue (Piper et al., 1998; Appendix 2), specifically the following:
  1. **Temporal Dimension:** Includes the assessment of the timing of fatigue (when it occurs), onset (from seconds to years), duration (chronic for

more than 6 months), and the pattern (wake up fatigued, evening fatigue, transient, etc.), and changes in this dimension over time.

2. **Sensory Dimension:** Focuses on how the fatigue feels. For example, is the fatigue localized (e.g., tired eyes, arms, legs) or generalized (e.g., whole-body tiredness, weariness, weakness, lethargy), and what is the intensity or severity of fatigue (using 0–10 scale)? Additional assessment questions include what exacerbates the fatigue (e.g., pain, nausea, vomiting, environmental heat, or noise). What helps the patient feel better or alleviates the symptoms (e.g., rest, food, listening to music, etc.)?
3. **Mental/Cognitive Dimension:** Questions the patient's ability to concentrate and focus, attention span, recall, and if the patient reports being "mentally tired."
4. **Affective/Emotional Dimension:** Assesses the patient's irritability, impatience, mood changes, depression, and the significance of the fatigue.
5. **Behavioral Dimension:** Considers the effect that the fatigue has on the patient's ability to perform activities of daily living (bathing, dressing, cooking, socializing, sexual activity). Family and practitioner observations regarding the patient's posture, gait, appearance (e.g., drooping shoulders), or lack of energy should also be assessed. Acute behavioral manifestations can include a change in alertness, while chronic manifestations may not be obvious to the practitioner because of the ability of many patients to adapt to their fatigue. If the patient also has a dementing illness, the behavioral dimensions may be the only clue that the practitioner has regarding the presence of fatigue.
6. **Physiological Dimension:** Includes biological mechanisms such as laboratory tests, a complete physical examination, and determining if comorbid conditions such as diabetes, cardiac illness, or other disease factors are present.

Table 24.2 offers questions related to the assessment of the pattern of sleep and rest, perceptions/ expression of fatigue, and the impact on their QOL.

**IV. Physical Examination:** Includes the following assessment parameters:

- Vital signs to determine if fever, low blood pressure, or weak pulse may be the cause of fatigue
- General appearance including affect (anxious, depressed, agitated, tearful, angry or flat), self-care behaviors, speech patterns, intonation, and general responsiveness



**TABLE 24.2** Assessment of Patterns of Sleep/Rest, Perceptions/Expressions of Fatigue, and Impact on Quality of Life

Sleep/Rest Patterns	Perceptions/Expressions of Fatigue	Impact on Quality of Life
Do you nap?	What do you believe is the cause of your fatigue?	Do you feel the quality of your life has changed because of fatigue?
Do you feel rested after a nap?	Are you distressed by fatigue?	Can you work?
Do you have difficulty falling asleep at night or staying asleep?	What do you think is the meaning of this symptom?	Do you socialize?
Has the quality of your sleep at night changed?	Do you feel hopeful?	Has fatigue affected your relationship with others?
How do you feel when you awaken?	Has your appetite changed?	Are you able to enjoy life?
Has your sleeping environment changed?	Do you have other symptoms, such as pain?	Has fatigue affected your outlook?

- Assessment of cardiac, respiratory, renal, musculoskeletal, and skin status to identify physiological conditions, including signs of infection or dehydration/nutrition that may be associated with fatigue
- Appropriate laboratory testing, such as complete blood count and other laboratory studies (electrolytes, blood gases, thyroid function tests), which may confirm diseases suspected

## ■ MEASURING FATIGUE

Given its subjectivity and the general lack of consensus in the literature regarding a definition of fatigue, the measurement of fatigue remains a challenge. In a study of fatigue in participants with COPD, Theander, Cliffordson, Torstensson, Jakobsson, and Unosson (2007) examined the validity of the Fatigue Intensity Scale (FInS) and reported reliability coefficients of .98 (Cronbach's  $\alpha$ ) and .94 test-retest stability, indicating statistically significant performance. Researchers reported a significant correlation between the level of fatigue and participant reports of fatigue greater than or less than 6 hours daily. The research group then reduced the number of items on the FInS to 25 from the original 40 and psychometric performance was maintained with Cronbach's  $\alpha$  at .96 and test-retest stability at .94 for the total scale.

Construct validity is difficult to establish for an instrument since fatigue measure may examine various aspects of fatigue, such as its character, precursors or causes, or the effects of fatigue. Each aspect can be addressed from a physiological, psychosocial, or behavioral perspective (see Appendix 1).

Significant aspects of fatigue to assess when measuring fatigue vary among scales, and may include combinations of symptoms that are physical, cognitive, affective, or behavioral. Participants in a qualitative investigation of fatigue among working adults described fatigue in characteristic themes that included manifestations in the physical, emotional, and behavioral realms (Aaronson et al., 2003). For example, objective physical manifestations of fatigue included the signs of slumped shoulders or drawn and slackened face that others can readily see, whereas the subjective physical manifestations of fatigue included symptoms not readily seen by others such as lack of energy and endurance, or weakness (Aaronson et al., 2003). Study participants described emotional, mental, and behavioral symptoms that might also represent depressive symptoms including sadness, inability to concentrate, and irritability.

As the first characteristic of fatigue, subjective quantification can be measured by the Multidimensional Assessment of Fatigue (MAF) measure (Tack, 1991), which examines the experience of fatigue in the past week and its severity, perceived distress, the timing of fatigue, and interference with activities of daily living index (Belza et al., 2001). The MAF provides a Global Fatigue Index (GFI; Appendix 3) developed to capture the subjective experience of fatigue for patients with rheumatoid arthritis (Belza, Henke, Yelin, Epstein, & Gillis, 1993) and has been used with multiple patient populations including persons with COPD (Belza et al., 2001; Belza et al., 2005) and older adults (Belza, 2005). The GFI has also been shown to be a valid and reliable measure of fatigue in community-based patients with HIV (Bormann, Shively, Smith, & Gifford, 2001; Whitehead, 2009).

As the second characteristic of fatigue, subjective distress can be measured by a single item on the MAF or by the Symptom Distress Scale (SDS; McCorkle & Young, 1978). The SDS was originally developed so as to contain 10 items on symptoms, which included a single item on fatigue, addressed as “tiredness,” in which patients respond to a 5-point semantic differential:

Could not feel more tired	5	4	3	2	1	I am not tired at all
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A more recent version of the SDS is a 13-item self-administered questionnaire that assesses the subjective distress of the patient and demonstrates satisfactory validity and reliability (Cooley et al., 2005). Additionally, significant ( $p < .05$ ) correlation has been found between fatigue and other physical and psychological symptoms, and it highlights the potentially confounding relationship between fatigue and these co-occurring symptoms experienced by different clinical populations (Badger, Segrin, & Meek, 2011; Yennurajalingam et al., 2008).

The third characteristic of fatigue, effect of fatigue on activities of daily living, can be measured by an 11-item subscale of the MAF, which provides a GFI with scores ranging from 1 to 50, indicating *no fatigue* to *severe fatigue* (Belza et al., 2005). The GFI has been shown to be sensitive to changes in the level of fatigue and as such is useful as a monitoring tool for patient response to treatment and rehabilitation. The report of activity interference may provide a more sensitive measure for assessing changes in fatigue or evaluation of the success of an intervention.

The fourth characteristic can be assessed through correlates of fatigue by evaluation of comorbidities and primary conditions, exacerbations, side effects of treatment, and psychosocial factors (Wagner & Cella, 2004). Measurement of comorbidities and primary conditions require attention to anemias, nutritional status, thyroid function, and infection. Additional correlates affecting fatigue that should be measured include sleep disturbance, changes in function, depression and anxiety, chronic pain, and adjustment to chronic illness. The POMS (McNair, Lorr, & Droppleman, 1996) is also a well-established measure of mood disturbance and includes subscales that measure fatigue and vigor.

These fatigue-rating scales are best used in research studies. A brief visual rating scale is recommended as the most efficient assessment tool for clinical practice (Hinds et al., 2010). The measure may include one or two items that ask the client to rate the severity of fatigue from 1 (*no fatigue*) to 10 (*severe fatigue*), and/or the degree to which fatigue prevents or interferes with desired daily activities (degree of impairment from fatigue), also from 1 (*no interference*) to 10 (*severe interference*). A cut score of about 5 has been

suggested for 10-point scales, or 3 for 4- to 5-point scales, so that persons with at least moderate fatigue will be captured (Z. Butt et al., 2008; Kirsh, Passik, Holtsclaw, Donaghy, & Theobald, 2001; Wagner & Cella, 2004). Clinicians should consistently use the same scale and give the same instructions each time. The patient should be asked to rate his or her fatigue at the time of assessment and in the last 24 hours.

## ■ MANAGEMENT OF FATIGUE

The goal of the management of fatigue is to achieve the best QOL that is possible given the patient's specific circumstances. Having the energy to do what is important to the person so that he or she may finalize specific tasks or interact in special relationships is a valuable outcome for treatment. Within the context of PC, the management of fatigue must be determined in relation to its ability to protect individuals from activities that may lead to suffering and subsequent detrimental consequences (Radbruch et al., 2008). The impact of fatigue on the QOL in patients at the EOL must be considered by nurses delivering PC.

Interventions for fatigue may focus on treating symptoms that exacerbate fatigue, thereby preventing fatigue from progressing to extreme exhaustion for which there may be no means of recovery (Olson et al., 2007). Nurses may assist patients and families to balance rest with activity and identify those activities that increase fatigue or that restore energy. Interventions for fatigue include nonpharmacological and pharmacological management, and are selected in accordance with the underlying cause of the fatigue. A multistage approach is recommended in the NCCN *Cancer-Related Fatigue Guidelines*: (a) screening of patients for the presence of fatigue; (b) evaluation of fatigue to determine its intensity or severity and its relationship to the stage of underlying disease processes; (c) management with nonpharmacological and pharmacological interventions; and (d) reevaluation of the patients for improvement, alleviation of symptoms, or worsening of condition followed by effective adjustment of management strategies (NCCN, 2013).

Learning to cope with fatigue is important to promoting QOL. Energy-conserving strategies may be used to manage and alter the fatigue; specifically, avoiding unnecessary or excessive use of energy by pacing yourself and taking extra rest periods, practicing energy restoration to avoid further deconditioning and deterioration in physical functioning through keeping muscles strong through exercising, continuing to be self-reliant by only asking for help when necessary, and taking into account the possibility of escalating fatigue at the EOL (NCCN, 2013). Encourage patients to rejuvenate their energy through



relaxation strategies such as “sitting down and resting,” “putting your feet up with a cup of tea,” and resting before activities by reading, watching television, or taking relaxing baths. In a case report of a retired nurse at the EOL, fatigue was described in association with a myriad of symptoms including anemia, weight loss, loss of interest, social isolation, dyspnea, chronic pain, deconditioning, and medications (Yennurajalingam & Bruera, 2007). This patient refused testing for additional medical information that was not directed at improving her QOL; this is an important point that highlights the importance of patient autonomy. It was important to the patient and her PC team that her symptoms be evaluated for the purpose of determining which interventions might reduce fatigue, thereby improving her QOL (Yennurajalingam & Bruera, 2007).

### Nonpharmacological Interventions

Nonpharmacological interventions for fatigue include education/cognitive interventions, exercise, energy balance and conservation, and nutritional considerations (Table 24.3). Education/cognitive interventions include preparatory information and anticipatory guidance regarding the likelihood of fatigue as a side effect of many treatment options, the disease itself, or the emotional reaction to the disease. It should be a standard of care that patients are educated about CRF to empower them to anticipate fatigue patterns and apply early home interventions (Borneman, 2013; Ream, 2007).

People are typically comforted to know that fatigue is often an expected outcome with illness, and not a sign of disease progression. An analogy that can be helpful in conceptualizing fatigue is of fatigue as a depletion of a “bank account” of energy. Patients are encouraged to plan the pace of activities for conservation of energy so that there is sufficient energy for selected, though perhaps fewer, activities (Ream, 2007). There is also a recommendation for acupressure or acupuncture for the relief of fatigue as has been demonstrated in patients with end-stage renal disease (Cho & Tsay, 2004; McDougall, 2005).

Patients may be encouraged to keep a daily journal to identify the factors and activities associated with fatigue, energy depletion, and its restoration (Radbruch et al., 2008). The journal could provide a daily entry regarding information learned about engagement in activities, level of energy or fatigue, and impact of treatment on energy or fatigue. Such a journal will also help patients communicate with the health care providers regarding various concerns, which may be alleviated by effective symptom management. The journal provides the practitioner with objective evidence of how the patient is doing on a

day-to-day basis and may then counsel the patient to plan his or her schedule to optimize peak energy times for high-priority tasks. The patient is then encouraged to accept help from available support persons for remaining tasks (Borneman, 2013).

Exercise is an effective intervention for older adults who are fatigued and has been shown to reduce fatigue and increase overall feelings of physical and psychological well-being (Borneman, 2013; Puetz, O'Connor, & Dishman, 2006). Exercise can take place in a structured rehabilitation or physical therapy department, particularly for those who would benefit from rehabilitation therapy for neuromusculoskeletal deficits and for those who are fatigued due to cardiac or respiratory problems (Cramp & Daniel, 2008; Przybylowski et al., 2007). For others, there may be simply a personal commitment to walk outdoors on a regular basis. Whichever is chosen, the exercise program should be individualized with consideration for the patient's physical condition and other medical problems.

Patients should be instructed not to exercise to exhaustion, but to conduct activities over several days of the week to be most beneficial. Movement can prevent loss of muscle tone that is difficult to regain and helps reduce the incidence of falls. Endorphins are released with even the slightest activity, resulting in increased mood and well-being. Exercise that utilizes the entire body will help maintain tone, strength, and flexibility. Walking, swimming, gardening, or golf are all good considerations; encourage the patient to exercise at least 6 hours before his or her typical bedtime so that he or she will not have difficulty falling asleep.

For patients with progressive illness, Potter, Hami, Bryan, and Quigley (2003) suggest that more appropriate than admitting patients to rehabilitation centers (which have a daily exercise program of 4 hours a day) is admission of these patients to a PC unit. On the PC unit, the majority of time can be devoted to promoting QOL and comfort, and the patient does not have to watch others improve dramatically while he or she is just too tired to participate. This approach balances QOL and the limited amount of therapy, which may be better tolerated.

Energy use and conservation involves finding a balance between rest and exercise that will give patients the most energy to do the things that they would like to do. Sleep disturbance, including insomnia, have been shown to be components of CRF and should be treated (Rao & Cohen, 2004). Although patients may believe that more rest and sleep will increase energy, sleep is not restorative of energy in chronic conditions associated with fatigue. Rao and Cohen (2004) suggest that the patient sleep no longer than 8 hours, which establishes a more solid, less fragmented

TABLE 24.3 Nonpharmacological Interventions for Fatigue

Nonpharmacological Interventions	Explanation
<b>Patient Education</b>	
Description of fatigue	Fatigue is a sense of feeling tired that impacts one physically, psychologically, and cognitively. It is different than being tired, which gets better with rest.
Common cause of fatigue	Anemia, uncontrolled symptoms such as pain, lack of appetite, or sleep problems, comorbidities, infection.
Use of the Q-10 scale to rate fatigue	1–3, mild; 4–6, moderate; 7–10, severe.
When to call the physician	Call if fatigue is getting worse and prevents patient from carrying out ADLs.
What to tell the physician	When it started, what makes it better/worse, description of interference with ADLs (due to the subjective nature of fatigue, this helps the clinician better understand the extent of fatigue impact).
<b>Exercise</b>	
Importance of exercising	Heart, lungs, and muscles require exercise to stay healthy. Exercise should be tailored to the patient's needs and capabilities and disease status. Exercise should be initiated slowly and increased over time. Safety should always be assessed before initiating exercise. Where warranted, refer to physical/occupational therapy
Energy conservation can help to reduce the burden of fatigue and use energy more effectively	Prioritize activities. Ask for help or delegate tasks. Balance rest and activities, performing activities during times of higher energy. Adhere to a regular bedtime. Sit instead of standing.
<b>Nutrition and Hydration</b>	
Importance of maintaining good nutrition and hydration Monitor weight	Will help increase energy levels. Preserves lean body mass. Better treatment tolerance. Refer to nutritionist when warranted.
<b>Complementary Therapies to Improve Fatigue</b>	
Acupuncture Cognitive behavioral therapy Hypnosis Massage therapy Reiki Relaxation therapy	

ADLs, activities of daily living.

Source: Adapted from Borneman, 2013.

sleep pattern. Waking up and going to sleep at the same time each day strengthens the circadian cycles, the disruption of which can contribute to depression. Since cancer patients have been shown to have worse sleep quality and more sleep disturbance (Dambrosio & Mazanec, 2013; Fernandes, Stone, Andrews, Morgan, & Sharma, 2006), strategies for establishing rest and sleep patterns may assist in improving sleep

quality. Strategies noted by nursing home residents in a study in Taiwan included taking prescribed medicines, lying down, changing position in bed, or taking a walk and thinking pleasant thoughts (Tsai, Wong, & Ku, 2008).

In a review of nonpharmacological management of fatigue in patients with specific autoimmune conditions including MS, systemic lupus erythematosus,



and rheumatoid arthritis, recommendations were in the categories of low-to-moderate impact exercise, behavioral therapies (self-help information, readings, life modifications), and physiological treatment of symptoms (Neill, Belan, & Ried, 2006). Additionally, a review of fatigue among health professionals offered several strategies that may also be applicable: encourage individuals to have some exposure to outside light each day; avoid bright light before bedtime; and establish a specific bedtime (with routines to prepare for sleep) and wake time (Borneman, 2013; Owens, 2007). In addition to an established bedtime, a light bedtime snack and something warm to drink promotes sleep.

Bedtime routines can help the reticular activating system in the brain shut down for about the last half hour in readying for sleep. Strategies to promote a restful sleep also include the reduction of environmental stimuli (e.g., noise, light), diversional activities to encourage sleep (music, aromatherapy, massage), and the avoidance of alcohol and stimulants (e.g., caffeine, nicotine, steroids). Adjusting the room temperature and humidity, as well as using pillows, may also be helpful in providing support and comfort. Neill et al. (2006) concluded that cooling activities should be tailored to the comfort of the individual and may include cool baths or placing the extremities in cool water. If the patient is unable to fall asleep in 20 minutes, suggest getting out of bed, going into another room to read with a dim light, and returning to bed when he or she gets sleepy.

It is important to acknowledge that fatigue is not a sequestered symptom but one that will affect all aspects of a person's life. As such, the patients will need to save their energy and plan for activities that are very important to them. They should be asked what activities they enjoy most and be encouraged to schedule those activities for the time of the day when they have the most energy. Breaks should be scheduled during activities to help restore energy levels, and taking short therapeutic naps (15–20 minutes) between the hours of 3 p.m. and 5 p.m. tend to be more restoring than getting into a longer, deeper sleep (Owens, 2007). Energy conservation techniques should be reinforced; for example, do activities sitting down, use a power scooter for grocery shopping, store frequently used items at chest level to avoid bending and stretching, put a terry robe on after the shower instead of using energy to dry off, or wear slip-on shoes. Providing devices such as a raised toilet seat, a reaching device, or a walker can also help conserve energy for people with progressive fatigue.

Patients should also be encouraged to ask for help with specific chores. Some find this type of interdependence as very threatening; try to help them see their energy as something to be “budgeted” and used

for something that they enjoy or that is very important for them to do. Jakobsson et al. (2007) studied factors related to QOL among older adults who were dependent on others for help with daily living and who were in pain. Their findings underscored the importance of evaluating and treating the complexity of accompanying symptoms, including fatigue and depression. The elders should be encouraged to feel that they have the option to “spend” their energy on anything that they wish, yet being mindful of their energy as a limited resource. Often reframing their fatigue as one of their resources gives them the enfranchisement that they need to ask for help.

Spending time with family and friends is also very important in promoting a sense of well-being, which may lessen the perception of fatigue. Prioritizing who they would like to visit with can be helpful, as well as planning such visits at a time of day when the patient has the most energy to avoid excessive fatigue. Health professionals may also assist in addressing the negative impact of psychological and social stressors and how to avoid or modify them (Winningham et al., 1994).

Nutritional status is also an important consideration; eating low-fat foods, consuming several small meals in a day, and avoiding high-sugar foods results in less energy used for digestion. Given that nutrition and hydration are important in preventing fatigue, increasing fluids may be of benefit, unless contraindicated by other medical problems. Protein intake and supplements can also be encouraged if the patient is having trouble with regular food. Recent data suggest that for patients with CFS, equal benefit was experienced from a low-sugar, low-yeast dietary regimen or from a diet of healthy eating, with evidence of decreased fatigue and improved QOL (Hobday, Thomas, O'Donovan, Murphy, & Pinching, 2008). The healthy eating control group and the low-sugar, low-yeast treatment group each demonstrated difficulty maintaining compliance with dietary recommendations. Food intake and appetite entries might be a helpful addition to a daily journal for some patients, though food journaling was not found helpful (Hobday et al., 2008). Pharmacological interventions may be necessary to boost appetite and energy.

## Pharmacological Management of Fatigue

PC for the fatigued patient is different from the management typically provided for other symptoms. Pharmacological management of other symptoms in PC often involves medications that are available to treat the actual cause of the symptom. Yet with fatigue, the cause may not be treatable; in many cases, medications may not be the primary intervention for this symptom. Furthermore, each medication that the

patient receives should be reviewed for its potential for producing sedation and fatigue. Symptoms, such as vomiting and pain, should be optimally treated as their relief often decreases associated fatigue, therefore improving feelings of general well-being. Patients should be made aware that the fatigue experienced with opioid therapy might decrease as tolerance to opioids develops. Optimizing the use of nonopioid analgesics and adjuvant therapies may also reduce fatigue associated with pain management. Treatment of proinflammatory cytokines (tumor necrosis factor) has been associated with improvements in symptoms of fatigue.

In addition to treating symptoms such as pain, vomiting, or dyspnea (that may induce fatigue), other medications such as corticosteroids, stimulants, and antidepressants have been of benefit (Table 24.4). There is empirical support for the use of low-dose corticosteroids for patients with fatigue and loss of general feelings of well-being, with recommendations for withdrawal of the medication if improvement does not occur within 5 to 7 days (Ream, 2007; Ream & Stone, 2004). Corticosteroids can improve appetite and elevate mood, resulting in an improved sense of well-being, although the duration of effect may be limited. It must be remembered, however, that corticosteroids may easily be overlooked as a contributor to fatigue (Cornuz, Guessous, & Favrat, 2006). Most commonly, dexamethasone 1 to 2 mg twice daily or prednisone 5 to 10 mg twice daily is prescribed.

In a review of the pharmacological treatment of CRF, the psychostimulant methylphenidate (Ritalin) was found to reduce fatigue over a period of 5 weeks when compared to placebo (Minton, Richardson, Sharpe, Hotopf, & Stone, 2008). Dosing of 10 to 20 mg/day is recommended, based on patient improvement over a period of 2 to 5 weeks (Minton et al., 2008; Ream, 2007). The dose can be gradually increased until favorable effects occur or until toxicities, such as anorexia, insomnia, anxiety, confusion, tremor, or tachycardia, supervenes. A randomized, double-blind, placebo-controlled trial indicated that dextroamphetamine produced short-term reduction of fatigue in survivors of breast cancer, patients with advanced cancer, and persons with HIV (Auret, Schug, Bremner, & Bulsara, 2009). Benefits were short-lived, however, with no continuation of improvement noted after the duration of the study (8 days). Preliminary data support the use of modafinil to promote wakefulness in persons with advanced cancer, and mixed results have been reported on the use of antidepressants (Breitbart & Alici, 2008). To limit toxicities in the medically ill population, dose escalation should be undertaken with caution, and over longer intervals (Portenoy, 2003).

When fatigue is associated with clinical depression, a trial of an antidepressant drug is appropriate. Depression and CRF may occur as separate conditions, and should be treated accordingly (Minton et al., 2008). Antidepressants such as serotonin-specific reuptake inhibitors (SSRIs) have fewer side effects than older antidepressants and are preferred in patients with such chronic conditions as ischemic heart disease, hypertrophic prostatic conditions, or glaucoma that are not controlled (Rao & Cohen, 2004). SSRIs are not associated with food and drug interaction restrictions. A sedating antidepressant can provide peaceful sleep as well as mitigating the depression; potential neurological and cardiac disadvantages may be of a lesser concern for the dying elder or for the PC patient at the EOL.

If the patient has had chemotherapy, the fatigue may be a result of anemia. Treatment with recombinant erythropoietin has been shown in randomized studies to increase hemoglobin level, which improves the energy levels and QOL of the patient with CRF (Minton et al., 2008; Ream, 2007), although the impact on the intensity of fatigue may be limited in advanced cancer states (Yennurajalingam et al., 2013). When the elder's hemoglobin level returns to 11 or 12 g/dL, many of the symptoms of anemia are assuaged. Treatment may also include addressing such nutrient deficiencies as iron, folate, or vitamin B<sub>12</sub>. Anemia can also be treated with blood transfusions, but this intervention is not without substantial risks to the patient's health (Yennurajalingam & Bruera, 2007) and carries the potential of increasing health care costs in the wake of transfusion complications. Risks associated with blood transfusions include systemic infections (e.g., HIV; hepatitis A, B, C) from inadequate screening of the blood supply, acute hemolytic reactions, bacterial contamination, subtle immune modulation, transfusion graft versus host disease, iron overload, and allergic reactions including urticaria and anaphylaxis (Yennurajalingam & Bruera, 2007).

It is important to evaluate the efficacy of both pharmacological and nonpharmacological fatigue interventions on a regular basis. Systematic documentation regarding the assessment, management, and evaluation of the success of the interventions in relieving fatigue is essential to quality care.

## ■ FATIGUE IN FAMILY CAREGIVERS

Family caregivers are often profoundly fatigued by the stressors inherent in caregiving. Caregivers bear the physical and emotional burden of assisting patients with activities of daily living, as well as with treatments. They often must assume new roles and responsibilities and at times deal with



TABLE 24.4 Pharmacological Therapies for the Treatment of Fatigue

Class of Drug	Examples	Mechanism of Action	Comments
Corticosteroids (glucocorticoids)	Dexamethasone (4 mg BID)	Mechanism of action is unclear. Low dosing recommended.	May mask the signs of acute infections. Use at the end of life after ruling out other causes of fatigue.
	Prednisone/Prednisolone (10–160 mg in two to three divided doses 30–45 min before meals) Methyl-prednisolone Hydrocortisone	Duration and benefits limited to weeks. May boost appetite and energy; improve activity levels and strength.	Evidence is inconclusive regarding lessening of fatigue; effectiveness may be short-lived.
	Methylphenidate (5–20 mg daily or BID)	Stimulates CNS and respiratory centers, increases appetite and energy levels, improves mood, reduces sedation.	Titrate to effect. Rapid onset of action, fewer side effects than many antidepressants. May cause agitation. Risk of toxicity increases with dose.
Stimulants	Dextroamphetamine (2.5–5 mg daily or BID) and Pemoline (18.75 mg daily or BID) have been used anecdotally.		No controlled comparisons between efficacies of each of these drugs. Response to one does not predict response to others. Sequential trials to determine the most useful drug are suggested.
	Modafinil (200 mg in the morning; with titration up to 400 mg daily)	Inhibits gamma aminobutyric acid; promotes release of neurotransmitters dopamine, norepinephrine, and serotonin, which promotes wakefulness.	Routine use of stimulants in palliative care is controversial as related to evaluation of evidence, and concerns that fatigue at the end of life may not be responsive.
	Amantadine	Centrally acting: affects cholinergic, dopaminergic, adrenergic, glutamatergic neurotransmission.	

(continued)

TABLE 24.4 Pharmacological Therapies for the Treatment of Fatigue (continued)

Class of Drug	Examples	Mechanism of Action	Comments
Antidepressants	Trazodone (25–50 mg at bedtime, increase to 25–50 mg/day as tolerated to a maximum of 300 mg/day)	Reduces depressive symptoms associated with fatigue. Can improve sleep. Primary choice for treatment of depression in cancer patients.	
Selective serotonin reuptake inhibitors (SSRIs)	Paroxetine (20 mg) Fluoxetine (10 mg) Sertraline (25 mg)	Inhibits serotonin reuptake.	Give once daily in the morning. Some SSRIs have long half-lives and should be used cautiously in the terminally ill older adult.
Norepinephrine dopamine reuptake inhibitor	Bupropion (100 mg daily for 3 days, then 100 mg TID at least 6 hr apart)	Acts as a stimulant.	
Tricyclic antidepressants	Amitriptyline (10–25 mg q hs) Nortriptyline (25 mg three to four times daily)	Block reuptake of various neurotransmitters at the neuronal membrane. Can improve sleep.	Amitriptyline contraindicated in patients on MAOIs or post MI. Use with caution in elders with cardiovascular disease, adverse reaction includes arrhythmias.
Cholinesterase inhibitors	Donepezil (5 mg hs; can increase to 10 mg after 4–6 weeks, maximum dose 23 mg after 3 months)	Reversible acetylcholinesterase inhibitor.	
Erythropoietin	150–300 units/kg SQ three times a week	Increases hemoglobin with effects on energy, activity, and overall quality of life while decreasing transfusion requirements.	Monitor hematocrit and reduce dose if hematocrit approaches 36% or increases by >4 points in 2 weeks. Safety concerns associated with higher mortality rates and thromboembolism have resulted in these drugs not recommended in the treatment of cancer-related fatigue

BID, twice a day; CNS, central nervous system; MAOI, monoamine oxidase inhibitors; MI, myocardial infarction; SQ, subcutaneously.

Source: Adapted from Beers et al., 2000; Breitbart & Alici, 2008; Glaspy, Degos, Dicato, & Demetri, 2002; Minton, Richardson, Sharpe, Hotopf, & Stone, 2010; National Consensus Project for Quality Palliative Care, 2013; Radbruch et al., 2008; Yennurajalingam et al., 2013.



additional financial distress (Jo, Brazil, Lohfeld, & Willison, 2007; National Cancer Institute, 2012). As a result, family caregivers may also develop anxiety or depressive disorders associated with fatigue. Severe family fatigue is commonly experienced in four situations: (a) inadequate relief of patient's pain and suffering; (b) inadequate resources to cope with home care; (c) unrealistic expectations of family caregivers of themselves or professional health care supports; and (d) emotional distress that persists even when there is adequate relief of patient suffering (Cherny, 2000).

PC practitioners recognize the patient and family as the unit of care, and therefore assessment and interventions to relieve caregiver burden are essential. Validating the needs and concerns of family caregivers is important. Helping family caregivers to set priorities with regard to competing demands, optimizing stress and coping strategies, and encouraging relaxation and rest while assisting caregivers with respite care, are important interventions in preventing or alleviating caregiver fatigue (National Cancer Institute, 2012).

## ■ CONCLUSION

Health care professionals view fatigue as a clue to illness, a side effect of therapeutic intervention, progressive illness, the residual physical change of illness and treatment, or the psychological and emotional strain of illness or caregiving. To the patients and their family, fatigue is a symptom that keeps them from moving forward fully with life (Hann et al., 1998). Health professionals can be supportive by acknowledging fatigue as real and taking fatigue and its frustrations seriously. Understanding the possible etiology of fatigue and the meaning of the symptom to the patient are important in determining its management. Assisting patients to live fully as they move along the illness trajectory may require consideration of non-pharmacological, as well as pharmacological, therapies to comprehensively and effectively treat fatigue. Learning how to prevent fatigue and/or restore energy is important to improving the elder patients' function, their ability to socialize, and ultimately their adjustment to a "new normal" baseline as they live with a life-limiting or chronic illness.

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### CASE STUDY Conclusion

Ms. Seigal's fatigue was managed through several therapeutic approaches. Laboratory data revealed a persistent anemia, which was treated with iron supplements. Discussion also focused on eating a well-balanced diet and taking daily multivitamin supplementation. Ms. Seigal agreed to make a personal commitment to regular exercise by walking outdoors for 20 minutes each day to promote muscle tone, increase endorphin levels, decrease fatigue, and improve mood and sense of well-being. The PC nurse helped Ms. Seigal to learn to balance rest with activity, shortening her workday, prioritizing activities, and carrying out activities when she had the greatest energy. Ms. Seigal was comforted by an understanding that fatigue is a common response to surgery, chemotherapy, and radiation for up to 5 years, rather than considering her fatigue as indicative of disease progression.

Screening by the PC team also indicated that Ms. Seigal suffered from depressive symptoms, which exacerbated her perception of fatigue. To treat her depressive symptoms, Ms. Seigal continued meeting with the psychologist referred by the cancer center to discuss her feelings and fears (talk therapy). She was prescribed an SSRI and vitamin B<sub>12</sub> by the PC nurse practitioner (pharmacological therapy), and was encouraged to rejoin the women's circle at her local senior center (social support). She refused a blood transfusion and erythropoietin therapy. Ms. Seigal was a participant in a breast cancer support group and recognized the value of providing support to those who were in the position where she had been, accepting help from willing friends (social support). She was counseled regarding strategies to promote a restful night's sleep, including establishing regular bedtime routines, and establishing a quiet, relaxing environment. The plan of care involved continual evaluation of the efficacy of such interventions for fatigue. If necessary, a trial of dexamethasone would also be considered to decrease a sense of fatigue and promote a maximal sense of well-being. During the follow-up evaluation, Ms. Seigal expressed a lessening of fatigue, greater sense of control, and improvement in health-related QOL.

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## Evidence-Based Practice

Oh, H. S., & Seo, W. S. (2011). Systematic review and meta-analysis of the correlates of cancer-related fatigue. *Worldviews on Evidence-Based Nursing*, 8(4), 191–201.

### Research Question

Fatigue is one of the most common problems experienced by cancer patients. The factors most frequently reported to correlate with cancer-related fatigue (CRF) are symptom distress (pain, nausea/vomiting, dyspnea, and lack of appetite) and psychological distress (depression and anxiety). This study was performed to examine the overall association of symptom and psychological distress with CRF using systematic literature review and meta-analysis. This study also aimed to determine which factors have a higher correlation with fatigue, and therefore should receive nursing priority.

### Design and Setting

A meta-analysis of 30 primary studies identified by searching computer databases, which included MEDLINE, PubMed, and CINAHL.

### Findings

Results showed that all symptoms (pain, dyspnea, nausea/vomiting, and lack of appetite) and psychological distress (depression and anxiety) included had a significant association with CRF with medium-to-large effect sizes, which were estimated using correlation coefficients. The overall correlations of psychological distress with CRF were found to be higher than those of symptom distress. The correlation of nausea/vomiting with CRF was higher than those of pain and dyspnea.

### Conclusions

The authors suggest that the importance of psychological distress in dealing with CRF in addition to the need to be attentive to a patient's symptom distress. Of the symptom distress, nausea/vomiting should be prioritized by nurses when managing CRF. This study provides sound empirical evidence that can be used to draft guidelines for the management of CRF.

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## FATIGUE ASSESSMENT INSTRUMENTS

Instrument	Description	Administration	Validity	Comments
Brief Fatigue Inventory (BFI)	9-item questionnaire 11-point Likert-type scale Evaluation period: past week, current, past 24 hr	Self-report Second party (interview) Estimated time for completion: 5 min	Validated in men and women Internal reliability verified Test–retest reliability not evaluated Construct verified Convergent: FACT (fatigue and anemia subscales) and POMS (fatigue and vigor subscales) Divergent not evaluated Discriminators: albumin, hemoglobin, and ECG-PSR	Able to capture physical and psychological aspects. Useful for screening and outcome assessments.  Able to distinguish severe fatigue, but less reliable when differentiating mild-to-moderate symptoms.
Cancer Fatigue Scale (CFS)	15-item questionnaire 5-point Likert-type scale Subscales: physical, affective, cognitive Evaluation period: current	Self-report Second party (interview) Estimated time for completion: 2–3 min	Validated in men and women Internal reliability verified Test–retest reliability verified up to eight days Construct: no healthy controls Convergent: VAS-F and Hospital Anxiety and Depression Scale Divergent: Mini-Mental State Discriminators: ECG-PSR (physical and affective subscales)	Able to capture physical and psychological aspects. Validation performed in Japanese population, which may affect generalization. Telephone test–retest: lower mean values but retained validity.
Chalder Fatigue Scale; also known as the Fatigue Questionnaire (FQ; Cella & Chalder, 2010; Chalder et al., 1993)	11-item scale; originally validated in a general practice setting. Main use has been in the investigation of chronic fatigue syndrome	Self-report Second party (interview) Estimated time for completion: 5 min	Validated in 274 adults (aged 18–45 yr) in general practice setting. Has also been used in population studies and so has normative data available for comparison with cancer patients	There is a high degree of internal consistency, and the principal components analysis supported the notion of a 2-factor solution (physical and mental fatigue.)
Fatigue Symptom Inventory (FSI)	14-item questionnaire 11-point Likert-type scale (12 questions) Remaining questions pertain to number of days/wk (0–7) fatigue is experienced and the pattern of daily fatigue (4-point Likert-type scale) Evaluation period: past wk, current	Self-report Second party (interview) Estimated time for completion: 5 min	Validated in men and women Internal reliability: interference subscale Test–retest reliability: low-to-moderate correlations Construct verified Convergent: POMS-F, SF-36, SLDS-C, and CES-D Divergent: MC-20 Discriminators not evaluated	Similar questions as BFI. Able to capture physical and psychological aspects. Useful for screening and outcome assessments (single assessments only, not repeated measures). Identified a second version of this tool that used a 5-point Likert scale for the final question pertaining to daily pattern of fatigue.

(continued)

Instrument	Description	Administration	Validity	Comments
Functional Assessment of Cancer Therapy (FACT-G)	27-item questionnaire 5-point Likert-type scale General cancer assessment tool derived from FACIT database Evaluates physical, functional, emotional, and social well-being (QOL); two questions regarding patient-physician relationships Evaluation period: past week	Self-report Second party (interview) Estimated time for completion: 5 min	Validated in men and women Internal reliability verified Test-retest reliability verified Construct: no healthy controls Convergent: POMS, SF-36, SLDS-C, and CES-D Divergent: MC-20 Discriminators: ECOG-PSR	General focus. Useful for screening and outcome assessments.
Functional Assessment of Cancer Therapy Fatigue Subscale (FACT-F)	13-item questionnaire administered with FACT-G 5-Point Likert-type scale Evaluation period: past week	Self-report Second party (interview) Estimated time for completion: 5–10 min	Validated in men and women Internal reliability verified Test-retest reliability: 3–7 days Construct: no healthy controls Convergent: PFS, POMS-F and -V (fatigue and vigor) Divergent: MC-20 Discriminators: hemoglobin and ECOG-PSR	Able to capture physical and psychological aspects. Useful for screening and outcome assessments.
Functional Assessment of Cancer Anemia Subscale (FACT-An)	20-item questionnaire (13 of which are identical to FACT-F) administered with FACT-G 5-Point Likert-type scale Assesses symptoms associated with anemia Evaluation period: past week	Self-report Second party (interview) Estimated time for completion: 5–10 min	Validated in men and women Internal reliability verified Test-retest reliability: 3–7 days Construct: no healthy controls Convergent: PFS, POMS-F and -V Divergent: MC-20 Discriminators: hemoglobin and ECOG-PSR	Able to capture physical and psychological aspects. Useful for screening and outcome assessments.
Lee Fatigue Scale (LFS or VAS-F)	18-item visual analog scale Fatigue subscale: 13 items Energy subscale: 5 items Evaluation period: current	Self-report Second party (interview) Estimated time for completion: < 5 min	Validated in men and women Internal reliability verified Test-retest reliability: limited data Construct verified Convergent: POMS (F and V) and Stanford Sleepiness Scale Divergent not evaluated Discriminators not evaluated	Able to capture physical and psychological aspects. Useful for screening and outcome assessments. Although this tool has been used to assess cancer fatigue, original validation performed in patients with sleep disorders.
Modified Fatigue Impact Scale (MFIS; Fisk et al., 1994; Kos et al., 2005; Learmonth et al., 2013)	5-item questionnaire 5-point Likert-type scale	Self-report Second party (interview) Estimated time for completion: 5 min	Validated in MS patients, Parkinson's patients, and in four European countries.	MFIS is simple, economical, and efficient at capturing the severity and impact of fatigue in MS, primarily the physical nature of fatigue.



Multidimensional Assessment of Fatigue (MAF) Scale (Belza et al., 1993); provides a Global Fatigue Index (Belza et al., 2001)	16-item questionnaire. 10-point scale for items 1–14; 5-point scale for item 15. 5 dimensions: degree, severity, distress, impact, timing	Self-report. Item 16 is not included in the scoring. Estimated completion time: 10 min. Scores range from 1 (no fatigue) to 50 (severe fatigue)	Validated in men and women Internal reliability verified Test–retest reliability not evaluated Construct verified Convergent: VAS (single item), BDS and Rhoten Fatigue Scale Divergent not evaluated Discriminators not evaluated	Able to capture physical and psychological aspects. Useful for screening and outcome assessments.
Multidimensional Fatigue Inventory (MFI-20)	20-item questionnaire 5-Point Likert-type scale Scales: general, physical, mental, reduced motivation, reduced activity Evaluation period: past 24 hr.	Self-report Second party (interview) Estimated time for completion: 5–10 min	Validated in men and women Internal reliability: both subscales Test–retest reliability: significant and equivalent correlations noted for both subscales Construct verified Convergent: POMS-F and SF-36 (vitality), STAI, and CES-D Divergent: MC-20 Discriminators: ECOG-PSR	Able to capture physical and psychological aspects. Validation performed in women only, which may affect generalization. Useful for screening; however, it may be too long or cumbersome for outcome assessments.
Multidimensional Fatigue Symptom Inventory (MFSI)	Same authors as FSI 83-item questionnaire 5-point Likert-type scale Rational subscale: global, somatic, affective, cognitive, and behavioral aspects Empirical subscale: general, physical, emotional, mental, aspects; also evaluates vigor Short form (MFSI-SF): developed to evaluate only empiric information Evaluation period: past week	Self-report Second party (interview) Estimated time for completion: 10 min	Validated in women Internal reliability: both subscales Test–retest reliability: significant and equivalent correlations noted for both subscales Construct verified Convergent: POMS-F and SF-36 (vitality), STAI, and CES-D Divergent: MC-20 Discriminators: ECOG-PSR	Able to capture physical and psychological aspects. Validation performed in women only, which may affect generalization. Useful for screening; however, it may be too long or cumbersome for outcome assessments.
Piper Fatigue Scale (PFS)	27-item questionnaire 22 items: 11-point Likert-type scale used to estimate fatigue scores 5 items: open-ended Subscales: behavioral-severity, affective meaning, sensory, and cognitive-mood Evaluation period: current	Self-report Second party (interview) Estimated time for completion: 5 min	Validated in women Internal reliability verified Test–retest reliability not evaluated Construct: no healthy controls Convergent: demographic profile (investigator-developed), POMS, and Fatigue Symptom Checklist Divergent: POMS-Vigor Discriminators not evaluated	Able to capture physical and psychological aspects. Useful for screening and outcome assessments. Used clinically to assess cancer-related fatigue in men; however, formal validation efforts have not yet been published.

(continued)

Instrument	Description	Administration	Validity	Comments
Quick Fatigue Assessment Survey (QFAS; Quick & Fonteyn, 2005)	17-item assessment designed for obtaining descriptive data about a patient's cancer-related fatigue. The QFAS identifies the initiation, duration, intensity, and relieving or aggravating factors of the fatigue experience with the use of dichotomous questions, open-ended questions, and ordinal ranking	Self-report Second party (interview) Estimated time for completion: 5–10 min	Validated in 114 patients from four outpatient oncology clinics; patients aged 22–84 yr represented a comprehensive sample of the adult oncology population	The QFAS appears to show promise as a clinically useful technique for obtaining an initial assessment of cancer-related fatigue.
QuickPIPER (Cuesta-Vargas et al., 2013)	15-item, validated one-dimensional model representing cancer-related fatigue, based on factor analysis testing of the Piper Fatigue Scale-revised (R-PFS)	Self-report questionnaire	111 breast cancer survivors participated in the prospective, observational study of the QuickPIPER validation	The 15-item QuickPIPER possesses similar properties to the 22-item R-PFS and offers the important advantage of brevity.
Revised Piper Fatigue Scale (Dagnelie et al., 2006)	22 items with 10-point numerical rating in four subscales: behavioral/severity; affective meaning; sensory; and cognitive/mood	Self-report questionnaire	Psychometric properties validated in Dutch cancer patients: 16 males, 13 females with lung cancer; 35 women with breast cancer. Construct validity was established with the MFI; criterion related validity was moderate with the MFI and the Rotterdam Symptom Checklist (RSCL)	Significantly lower ( $p < .01$ ) scores were found in sensory and cognitive/mood subscales among Dutch Breast cancer patients when compared to the original study population (Piper et al., 1998); no significant differences in behavioral/severity or affective meaning subscales.
Profile of Mood States (POMS)	65-item questionnaire 5-Point Likert-type scale Subscales: tension-anxiety, anger-hostility, vigor-activity, fatigue-inertia, and confusion-bewilderment Short form: 30 items (derived from the six subscales); developed for the elderly and individuals with medical disorders or disabilities Evaluation period: past week	Self-report Second party (interview) Estimated time for completion: 5–7 min (some individuals may require more time)	Validated in men and women Internal reliability: all subscales Test-retest reliability: all subscales Construct verified Convergent: Hopkins Symptom Distress Scale, Manifest Anxiety Scale, BDS, and Interpersonal Behavior Inventory Divergent: MC-20 Discriminators not evaluated	Only able to capture psychological aspects. Useful for screening; however, it may be too long or cumbersome for outcome assessments. Flexible scoring: entire document or individual subscales.



Schwartz Cancer Fatigue Scale (SCFS) (original version)	28-item questionnaire 5-point Likert-type scale Subscales (factors): physical, emotional, cognitive, and temporal Evaluation period: past 2–3 days	Self-report Second party (interview) Estimated time for completion: 5 min	Validated in men and women Internal reliability verified Test–retest reliability not evaluated Construct: limited evaluation Convergent: VAS-F Divergent not evaluated Discriminators not evaluated	Able to capture physical and psychological aspects. Described validation under experimental conditions, but validation was not maintained when used in a clinical setting.
Schwartz Cancer Fatigue Scale (SCFS-6) (revised version)	6-item questionnaire 5-point Likert-type scale Subscales (factors): physical and perceptual Developed because further testing was unable to confirm validation of original version Evaluation period: past 2–3 days	Self-report Second party (interview) Estimated time for completion: 1–2 min	Validated in men and women Internal reliability verified Test–retest reliability not evaluated Construct verified Convergent not evaluated Divergent not evaluated Discriminators: limited evaluation	Able to capture physical and psychological aspects. Requires further validation (in the clinical setting). Items are identical to those in POMS. Computerized version has been developed.
Symptom Distress Scale (Cooley et al., 2005)	13-item; 5-point Likert-type scale assessment of 11 symptoms (nausea, appetite, insomnia, pain, fatigue, bowel pattern, concentration, cough, appearance, outlook, breathing); and a frequency report for two symptoms (pain, nausea); evaluates feelings on day of administration	Self-report. Estimated completion time: 5 min. Scores range from 13 (little distress) to 65 (severe symptom distress)	Validity: reported accurately used and completed by over 98% of participants; preferred by participants with lower education when compared with other questionnaires Internal reliability demonstrated by repeated measure (Kukull, McCorkle, & Drier, 1986)	Developed for symptom assessment in adults diagnosed with cancer.

BDS, Beck Depression Scale; CES-D, Center for Epidemiological Studies-Depression Scale; ECOG-PSR, Eastern Collaborative Oncology Group Performance Status Rating; FACIT, Functional Assessment of Chronic Illness Therapy; MC-20, Marlowe–Crowne Social Desirability Scale; QOL, quality of life; SF-36, Health Outcomes Study Short Form; SLDS-C, Satisfaction with Life Domains Scale-Cancer; STAI, State-Trait Anxiety Inventory; VAS-F, Visual Analog Scale-Fatigue.

Source: Adapted from *Pharmacotherapy* (Schwartz, 2002).

## ■ APPENDIX 2

## PIPER FATIGUE SCALE

Directions: Many individuals can experience a sense of unusual or excessive tiredness whenever they become ill, receive treatment, or recover from their illness/treatment. This unusual sense of tiredness is not usually relieved either by a good night's sleep or by rest. Some call this symptom "fatigue" to distinguish it from the usual sense of tiredness.

For each of the following questions, please fill in the space provided for that response that best describes the fatigue you are experiencing now or for today. Please make every effort to answer each question to the best of your ability. If you are not experiencing fatigue now or for today, fill in the circle indicating "0" for your response. Thank you very much!

1. How long have you been feeling fatigue? (Check one response only.)
 

<input type="checkbox"/> 1. Not feeling fatigue									
<input type="checkbox"/> 2. Minutes									
<input type="checkbox"/> 3. Hours									
<input type="checkbox"/> 4. Days									
<input type="checkbox"/> 5. Weeks									
<input type="checkbox"/> 6. Months									
<input type="checkbox"/> 7. Other (Please describe)									
2. To what degree is the fatigue you are feeling now causing you distress?
 

									A Great Deal
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
3. To what degree is the fatigue you are feeling now interfering with your ability to complete your work or school activities?
 

									A Great Deal
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
4. To what degree is the fatigue you are feeling now interfering with your ability to socialize with your friends?
 

									A Great Deal
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
5. To what degree is the fatigue you are feeling now interfering with your ability to engage in sexual activity?
 

									A Great Deal
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
6. Overall, how much is the fatigue, which you are now experiencing, interfering with your ability to engage in the kind of activities you enjoy doing?
 

									A Great Deal
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
7. How would you describe the degree of intensity or severity of the fatigue that you are experiencing now?
 

									Severe
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
8. To what degree would you describe the fatigue that you are experiencing now as being?
 

									Unpleasant
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
9. To what degree would you describe the fatigue that you are experiencing now as being?
 

									Disagreeable
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
10. To what degree would you describe the fatigue that you are experiencing now as being?
 

									Destructive
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10
11. To what degree would you describe the fatigue that you are experiencing now as being?
 

									Negative
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6	<input type="checkbox"/> 7	<input type="checkbox"/> 8	<input type="checkbox"/> 9	<input type="checkbox"/> 10

(continued)



12. To what degree would you describe the fatigue which you are experiencing now as being?  
 Normal Abnormal  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐  
 1 2 3 4 5 6 7 8 9 10
13. To what degree are you now feeling:  
 Strong Weak  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐  
 1 2 3 4 5 6 7 8 9 10
14. To what degree are you now feeling:  
 Awake Sleepy  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐  
 1 2 3 4 5 6 7 8 9 10
15. To what degree are you now feeling:  
 Lively Listless  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐  
 1 2 3 4 5 6 7 8 9 10
16. To what degree are you now feeling:  
 Refreshed Tired  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐  
 1 2 3 4 5 6 7 8 9 10
17. To what degree are you now feeling:  
 Energetic Unenergetic  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐  
 1 2 3 4 5 6 7 8 9 10
18. To what degree are you now feeling:  
 Patient Impatient  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐  
 1 2 3 4 5 6 7 8 9 10
19. To what degree are you now feeling:  
 Relaxed A Great Deal  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐  
 1 2 3 4 5 6 7 8 9 10
20. To what degree are you now feeling:  
 Exhilarated Depressed  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐  
 1 2 3 4 5 6 7 8 9 10
21. To what degree are you now feeling:  
 Able to Concentrate Unable to Concentrate  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐  
 1 2 3 4 5 6 7 8 9 10
22. To what degree are you now feeling:  
 Able to Remember Unable to Remember  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐  
 1 2 3 4 5 6 7 8 9 10
23. To what degree are you now feeling:  
 Able to Think Clearly Unable to Think Clearly  
☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐ ☐  
 1 2 3 4 5 6 7 8 9 10
24. Overall, what do you believe is *most* directly contributing to or causing your fatigue?  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

(continued)

25. Overall, the *best* thing you have found to relieve your fatigue is:

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26. Is there anything else you would like to add that would describe your fatigue better to us?

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27. Are you experiencing any other symptoms right now?

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### Scoring Piper Fatigue Scale Survey Results:

#### PFS current format and scoring instructions:

1. The PFS in its current form is composed of 22 numerically scaled, "0" to "10" items that measure four dimensions of subjective fatigue: behavioral/severity (6 items; # 2–7); affective meaning (5 items: # 8–12); sensory (5 items: # 13–17); and cognitive/mood (6 items: # 18–23). These 22 items are used to calculate the four subscale/dimensional scores and the total fatigue scores.
2. Five additional items (# 1 and # 24–27) are not used to calculate subscale or total fatigue scores but are recommended to be kept on the scale as these items furnish rich, qualitative data. Item # 1, in particular, gives a categorical way in which to assess the duration of the respondent's fatigue.
3. To score the PFS, add the items contained on each specific subscale together and divide by the number of items on that subscale. This will give you a subscale score that remains on the same "0" to "10" numeric scale. Should you have missing item data, and the respondent has answered at least 75%–80% of the remaining items on that particular subscale, calculate the subscale mean score based on the number of items answered, and substitute that mean value for the missing item score (mean-item substitution).
4. Recalculate the subscale score. To calculate the total fatigue score, add the 22 item scores together and divide by 22 in order to keep the score on the same numeric "0" to "10" scale.

#### Severity Codes:

0	NONE
1–3	MILD
4–6	MODERATE
7–10	SEVERE

Source: Piper, B. F., Dibble, S. L., Dodd, M. J., Weiss, M. C., Slaughter, R. E., & Paul, S. M. (1998). The revised Piper Fatigue Scale: psychometric evaluation in women with breast cancer. *Oncology Nursing Forum*, 25(4), 677–684.



## ■ APPENDIX 3

**GLOBAL FATIGUE INDEX**  
**MULTIDIMENSIONAL ASSESSMENT OF FATIGUE SCALE**

Fatigue Dimension	Questions	Scoring
Degree	1. To what degree have you experienced fatigue?	1 (not at all)–10 (a great deal)
Severity	2. How severe is the fatigue that you have been experiencing?	1 (not at all)–10 (a great deal)
Distress	3. To what degree has fatigue caused you distress?	1 (not at all)–10 (a great deal)
Impact on activities of daily living (11 items)	4. Household chores?	1 (not at all)–10 (a great deal)
	5. Cook?	1 (not at all)–10 (a great deal)
	6. Bathe or wash?	1 (not at all)–10 (a great deal)
	7. Dress?	1 (not at all)–10 (a great deal)
	8. Work?	1 (not at all)–10 (a great deal)
	9. Visit or socialize with friends or family?	1 (not at all)–10 (a great deal)
	10. Engage in sexual activity?	1 (not at all)–10 (a great deal)
	11. Engage in leisure and recreational activities?	1 (not at all)–10 (a great deal)
	12. Shop and do errands?	1 (not at all)–10 (a great deal)
	13. Walk?	1 (not at all)–10 (a great deal)
	14. Exercise, other than walking?	1 (not at all)–10 (a great deal)
Timing	15. Over the past week, including today, how often have you been fatigued?	0 (hardly any days)–4 (every day)
	16. To what degree has your fatigue changed during the past week?	1 (decreased)–4 (increased)

*Scoring:* Total score for items 1, 2, and 3. Average items 4–14 (ADLs). Item 15 multiply the score by 2.5. Item 16 is not included in the score. Score ranges from 1 to 50; the higher the score, the greater impairment from fatigue.

*Source:* Adapted from Belza et al., 1993, 2001.





# Skin Alterations

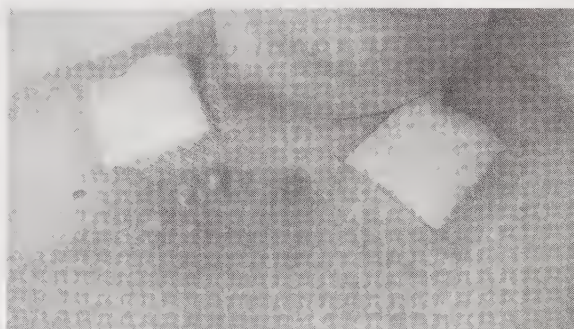
## CHAPTER

### KEY POINTS

- Prevention of skin injury may need to be balanced against the overall goals of care.
- Pressure ulcers are common occurrences during the dying process.
- Wound care should be aimed at providing comfort; relieving pain, odor, and containing exudates; and improving the patient's quality of life.

### CASE STUDY

Ms. D. L. is a 57-year-old female with metastatic ovarian cancer to the lower neck and breast areas that has gradually expanded over the last 3 years. Some of the lesions have become elevated above the skin surface with central ulceration. There is a heavy exudate, surface bleeding from tiny telangiectatic vessels, and an odor that is very disturbing to the patient. She has had previous radiotherapy and chemotherapy but reached the maximal dose of radiation and is now unresponsive to currently available chemotherapy. She is embarrassed to go out in public because of the visibility of the lesions on the neck and the associated odor.



The pain was partially controlled with a combination of Methadone and a fentanyl patch supplemented with oxycodone for breakthrough. She has become lethargic and confused at times.

As part of the interprofessional team looking after this patient: How would you approach the control of the exudate and odor? Do you have any suggestions for the management of her pain?

An evidence-based framework that can be applied to caring for a palliative care (PC) patient with a wound is the Wound Bed Preparation 2011 model, which can be used to guide the clinician in developing the care plan (Figure 25.1; Sibbald et al., 2011).

In the PC population, wound healing is not often the goal; nonetheless, classifying the healability with a realistic focus is important. Each individual is unique, and careful classification of wounds as healable, non-healable, and maintenance is required. Many wounds are treated as maintenance with important aspects of patient-centered care being wound odor, exudate, superficial critical colonization and deep/surrounding infection, bleeding, and wound-associated pain. The clinician's role is to advocate that the patient's quality of life (QOL) and comfort supersede care that concentrates on healing outcomes. Prevention of skin injury also needs to be balanced against the overall goals of care. "Strategies used to prevent pressure ulcers in other populations may seem to be in direct conflict with palliative care strategies" (Langemo, Bates-Jensen, & Hanson, 2001, p. 143).

Actual observation of the skin is needed to identify patients at risk for skin injury and to initiate prevention protocols. There is, however, no consensus in the literature as to what constitutes a minimum skin assessment. Baranoski and Ayello (2008) have suggested five elements to include in a basic skin assessment: skin temperature, color, moisture, turgor, and if the skin is intact or has areas of injury including open areas. In this chapter, several common skin problems (skin tears, pressure ulcers, tumor and treatment-related skin injuries, ostomy skin, and fistulas) will be discussed.

## ■ SKIN CHANGES AT LIFE'S END—SCALE

Despite optimal nursing care, not all pressure ulcers at life's end are preventable (Sibbald, Krasner, & Lutz, 2010). An expert group of panelists were assembled to make recommendations for the documentation and treatment of pressure ulcers at life's end. The recommendations are summarized in Table 25.1.

## ■ PRESSURE ULCERS

Pressure ulcers are common occurrences during the dying process. Eckman (1989) reported the results of a randomized study of 130 funeral homes across the United States. Of the 1,378 deceased persons, 1 out of 4 (23.6%) had a pressure ulcer. The number of ulcers ranged from 1 to 14. Of those with a pressure ulcer, 31.4% had one ulcer and 68.6% had more than one ulcer. Table 25.2 demonstrates the number of cases by location when location of death was known.

The National Pressure Ulcer Advisory Panel (NPUAP) extensively reviewed data (Pieper, 2012a) and found that, in the United States, the incidence of pressure ulcers in acute care ranged from 2.8% to 9.0%, with higher incidence occurring in older populations (Goldberg, 2012). In long-term care, the incidence data ranged from 3.6% to 59% (Pieper, 2012b) and in home care, it was 4.5% to 6.3% (Garcia, 2012). For PC, incidence ranged from 6.5% to 54.7% (Langemo, 2012). The NPUAP concluded that "significant gaps in knowledge are evident" and Table 25.3 summarizes some high points of the NPUAP recommendations and research implications (Langemo, 2012).

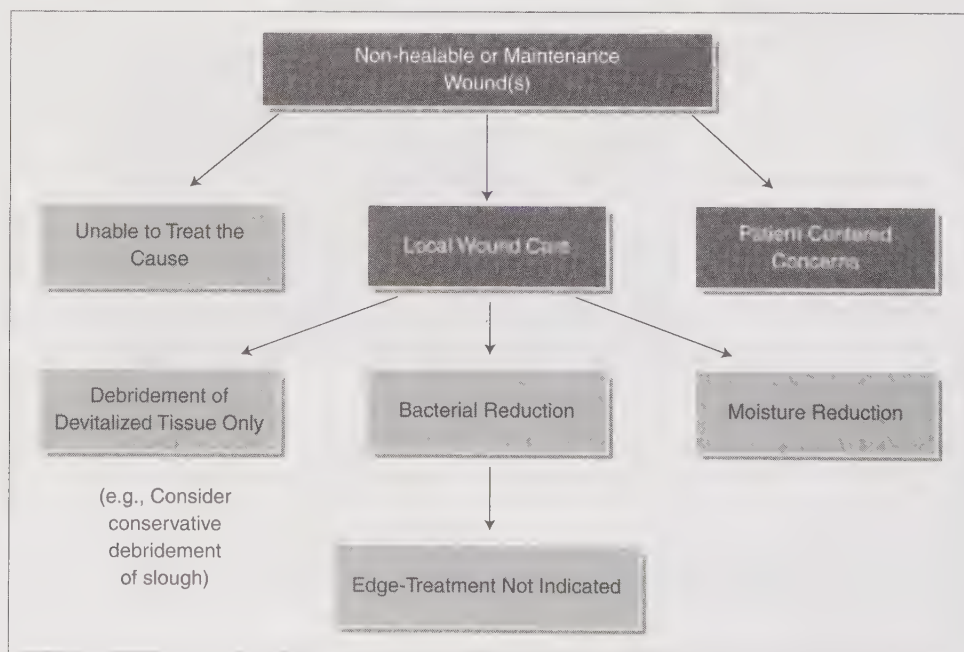


FIGURE 25.1 Wound Bed Preparation Model. (Source: Sibbald, et al., 2011)



TABLE 25.1 Skin Changes at Life's End (SCALE) Panel Statements

Statement Number	Panel Statement
1	Physiological changes that occur because of the dying process may affect the skin and soft tissues and may manifest as observable (objective) changes in skin color, turgor, or integrity, or as subjective symptoms such as localized pain. These changes can be unavoidable and may occur with the application of appropriate interventions that meet or exceed the standard of care.
2	The plan of care and patient response should be clearly documented and reflected in the entire medical record. Charting by exception is an appropriate method of documentation.
3	Patient-centered concerns should be addressed including pain and activities of daily living.
4	SCALE are a reflection of compromised skin (reduced soft-tissue perfusion, decreased tolerance to external insults, and impaired removal of metabolic wastes).
5	Expectations regarding the patient's end-of-life goals and concerns should be communicated among the members of the interprofessional team and the patient's circle of care. The discussion should include the potential for SCALE, including other skin changes, skin breakdown, and pressure ulcers.
6	<p>Risk factors, symptoms, and signs associated with SCALE have not been fully elucidated, but may include:</p> <ul style="list-style-type: none"> <li>■ Weakness and progressive limitation of mobility</li> <li>■ Suboptimal nutrition including loss of appetite, weight loss, cachexia and wasting, low serum albumin/prealbumin level, and low hemoglobin, as well as dehydration</li> <li>■ Diminished tissue perfusion, impaired skin oxygenation, decreased local skin temperature, mottled discoloration, and skin necrosis</li> <li>■ Loss of skin integrity from any of a number of factors, including equipment or devices, incontinence, chemical irritants, chronic exposure to body fluids, skin tears, pressure, shear, friction, and infections</li> <li>■ Impaired immune function.</li> </ul>
7	A total skin assessment should be performed regularly and document all areas of concern consistent with the wishes and condition of the patient. Pay special attention to bony prominences and skin areas with underlying cartilage. Areas of special concern include the sacrum, coccyx, ischial tuberosities, trochanters, scapulae, occiput, heels, digits, nose, and ears. Describe the skin or wound abnormality exactly as assessed.
8	Consultation with a qualified health care professional is recommended for any skin changes associated with increased pain, signs of infection, skin breakdown (when the goal may be healing), and whenever the patient's circle of care expresses a significant concern.
9	<p>The probable skin change etiology and goals of care should be determined. Consider the five Ps for determining appropriate intervention strategies:</p> <ul style="list-style-type: none"> <li>■ Prevention</li> <li>■ Prescription (may heal with appropriate treatment)</li> <li>■ Preservation (maintenance without deterioration)</li> <li>■ Palliation (provide comfort and care)</li> <li>■ Preference (patient desires)</li> </ul>
10	Patients and concerned individuals should be educated regarding SCALE and the plan of care.

Source: Adapted from Sibbald et al., 2010.

An earlier study reported data at an even higher rate. Reifsnnyder, Hoplamazian, and Maxwell (2004) identified 62.3% of 980 hospice patients were diagnosed with cancer and were at a higher risk of developing a pressure ulcer as compared to those without cancer. Hanson et al. (1991) reported an incidence of 13% for Stage I and II pressure ulcers. Locations of these pressure ulcers were the sacrum (38.4%), elbows (30.7%), and heels (15.4%). Pressure ulcers often occurred within 2 weeks of death. Waltman, Bergstrom, Armstrong, Norvell, and Braden (1991)

found a higher incidence of pressure ulcers in elder patients with cancer (85%) compared to a matched group without cancer (70%). In this prospective study, the average time to death after developing a pressure ulcer was 3 weeks.

Kennedy (1989) reported that 56% of patients who died in an intermediate care facility developed a pressure ulcer within the 6 weeks prior to their death. Furthermore, on her website ([www.kennedyterminalulcer.com](http://www.kennedyterminalulcer.com)), she has described the following characteristics of the Kennedy terminal

**TABLE 25.2** Location of Pressure Ulcers Among Deceased Persons

Location	Percentage of Cases	Percentage of Ulcers
Hospital	44.3	44.6
Nursing home	37.8	40.2
Family home	14.2	12

Source: Adapted from Eckman, 1989.

ulcer: pear-shaped; coccyx or sacrum; red, yellow, or black; sudden onset; and death was imminent. "Time in bed increases as their condition deteriorates, which occurs concomitantly as multi-system failure and growing weakness predispose them to risk factors including decreased activity and mobility, depleted nutrition and hydration, incontinence, and changes in sensory perception and consciousness" (Langemo et al., 2001, p. 143). In a 10-bed PC unit located in an acute care facility, 5% of the patients developed pressure ulcers (Brennan & Trombly, 2010).

### Preventing Pressure Ulcers: Risk Assessment

The European Pressure Ulcer Advisory Panel (EPUAP) and American NPUAP in 2009 collaboratively developed a joint international guideline for the prevention and treatment of pressure ulcers. This guideline outlines evidence-based recommendations for the prevention and treatment of pressure ulcers that could be used by health care professionals throughout the world. The current use of risk assessment scales to identify patients at risk for pressure ulcers are recommended by the 2009 NPUAP-EPUAP Pressure Ulcer Treatment

Guidelines (strength of evidence C). There are many pressure risk assessment tools available; McGough (1999) identified over 40 such tools from a literature search. Commonly used pressure risk assessment tools are the Braden Scale, the Waterlow Scale, the Norton Scale, or the Hunters Hill-Marie Curie Center Risk Assessment Tool that is specific to palliative patients (Bell, 2005).

A widely used risk assessment tool in the United States is the Braden Scale. This scale has six factor subscales—sensory perception, moisture, activity, mobility, nutrition, and friction/shear, which are ranked to provide a total risk score. A systematic literature review by Pancorbo-Hidalgo, Garcia-Fernandez, Lopez-Medina, and Alvarez-Nieto (2006) revealed that the Braden Scale had the best sensitivity/specificity balance (57.1%/67.5%) and is a good predictor of ulcer risk (odds ratio = 4.08, CI = 95%). One study by Hanson, Langemo, Olson, Hunter, and Burd (1994) reported data from the Braden Scale used to identify pressure ulcer risk in hospitalized cancer patients. The incidence was 8%, sensitivity 82%, and specificity 84% (Hanson et al., 1994).

Based on patients on a PC unit in England, Chaplin (2000) developed a pressure ulcer risk assessment tool. This scale, referred to as the Hunters Hill-Marie Curie Centre Pressure Ulcer Risk Assessment Tool, has two more subscales than the Braden Scale. While both have a subscale for sensory/perception, moisture, mobility, activity, and friction/shear, the Hunters Hill-Marie Curie Center Pressure Ulcer Risk Assessment Tool has a subscale for skin condition, which is graded on a scale of 1 (*skin condition good*) to the number 4 (*skin integrity broken*) and includes weight change pattern in the nutrition subscale. Perhaps one of the biggest differences between this scale and the Braden Scale (low scores are at risk, with 18 being onset of pressure ulcer risk) is that no impairments have low subscale numbers, whereas areas of high impairment have the highest numbers;

**TABLE 25.3** National Pressure Ulcer Advisory Panel Research Implications and Recommendations for Pressure Ulcers in Individuals at the End of Life: Palliative Care and Hospice

■ The extent and nature of prevalence and incidence of pressure ulcers in hospice and palliative care patients need further research.
■ Development of patient-sensitive protocols or adaptations of current prevention and treatment protocols for hospice/palliative care patients is needed.
■ Research into the reasonable limits of pressure ulcer prevention in hospice/palliative care patients at or near the end of life is needed. Do pressure ulcers develop in some patients despite the best of care?
■ To what extent can a pressure ulcer be attributed to the "dying condition"?
■ What are the appropriate interventions for pressure ulcer-related pain in hospice/palliative care patients?
■ What is "best practice" for pressure ulcer prevention in hospice/palliative care?



therefore, total scores of 12 or lower are at low risk, while scores 13 or higher are at medium risk. Experts have concluded that there is no ideal ulcer risk assessment tool for all clinical settings and therefore the choice of which to use should depend on their predictive validity (Royal College of Nursing, 2000).

The EPUAP/NPUAP 2009 pressure ulcer guidelines recommend that patients be evaluated on admission to a care setting and at periodic intervals. Guidelines for reassessment for pressure ulcer risk by specific settings have been suggested (Ayello & Braden, 2001). Although Table 25.4 gives these recommendations, just how applicable these are to PC patients is not known.

## Prevention Interventions

Pressure ulcers are suggestive of deterioration and are part of the disease trajectory (Brink, Smith, & Linkewich, 2006). In many cases, the primary treatment and prevention goal of care is displaced by a greater need for comfort (Brink et al., 2006). A study of 546 palliative home care patients found risk factors such as male gender, inability to lay flat, catheter or ostomy care, and a reduced ability to perform activities of daily living were associated with an increased risk of pressure ulcers (Brink et al., 2006).

The purpose of doing a risk assessment is to facilitate early identification and initiate preventive interventions. The goal of reducing risk factors is to prevent pressure ulcers; the utilization of prevention strategies for at-risk older adults is to spare them painful and sometimes tiresome treatments. Older adults are considered to be “at risk” when their Braden Scale is 18 or below; intervention protocols have been linked to levels of risk (Ayello & Braden, 2001; Braden Scale website, 2013). Attention to an elder’s score on subscales can also help to target prevention interventions to that specific factor

that places the patient at most risk. Based on the NPUAP/EPUAP 2009 Clinical Guideline, Table 25.5 summarizes prevention strategies.

The NPUAP/EPUAP 2009 guideline may need to be modified based on the overall goals of the older adult’s care. For PC patients, following a rigid set time interval for a repositioning schedule may cause the patients undue pain. Caregivers should negotiate a flexible time interval, premeditating prior to repositioning, and determining which positions provide the most comfort. Langemo, Black, and the NPUAP (2010) recommend that a repositioning schedule for patients receiving PC should be flexible and focused around the support surface used, coupled with the preference, needs, and tolerance of the patient. The patient and the family need to clearly understand the implications for skin injury; however, pressure ulcer prevention strategies in the palliative patient should be tailored to meet client’s wishes and general comfort. This variation in the patient’s treatment plan also needs to be documented in the patient’s record.

## Pressure Ulcer Location

The sacrum is the number one location for pressure ulcer occurrence in adults; heels are second (vanGilder, MacFarlane, Harrison, Lachenbruch, & Meyer, 2010). For the neonatal intensive care unit (NICU), pediatric intensive care unit (PICU), and pediatric patients, medical device pressure ulcers were more common (vanGilder, Amlung, Harrison, & Meyer, 2009) with the nose being the most common site (Baharestani, 2012). In specific PC patients, other sites may be at risk for pressure ulcer breakdown. For example, elders with chronic obstructive pulmonary disease who are on long-term oxygen therapy are at higher risk for device-related pressure ulcers. Skin near the ears, mouth, and nose are susceptible to tissue necroses as a result of increased pressure associated with tubing. Black et al. (2010) reported that 34.5% of hospital-acquired pressure related injuries were a result of injury from medical devices.

## Pressure Ulcer Staging

Pressure ulcers are staged based on the visible assessment of the depth of tissue that has been damaged in the wound bed. Bennet (1995) has urged clinicians to use appropriate lighting sources such as natural or halogen lighting as well as evaluating skin temperature and consistency to detect Stage I pressure ulcers in clients with darkly pigmented skin. Unlike the six stages of pressure ulcer classification by the NPUAP, the EPUAP has not adopted the unstageable and sDTI (Suspected Deep Tissue Injury) categories as separate

**TABLE 25.4 Intervals for Pressure Ulcer Risk Assessment**

<b>Acute care</b>
Initial assessment on admission
Reassessment every 24–48 hr or whenever the patient’s condition changes
<b>Long-term care</b>
Initial assessment on admission
Reassessment weekly for first 4 weeks, then monthly to quarterly or whenever the patient’s condition changes
<b>Home health care</b>
Initial assessment on admission
Reassessment with every registered nurse visit

**TABLE 25.5 Pressure Ulcer Prevention Protocol**

Inspection and care of skin
<p>Frequency of inspection—daily and document</p> <ul style="list-style-type: none"> <li>■ Check skin under medical devices</li> <li>■ Individual bathing—avoid hot water, drying soaps</li> <li>■ Use emollients to hydrate dry skin</li> <li>■ Do not massage reddened bony prominences</li> <li>■ Manage incontinence and protect skin from exposure to moisture</li> <li>■ Protect from pressure to vulnerable skin areas such as the sacrum, elbows, greater trochanters, and heels</li> </ul>
Mechanical loading and support surfaces
<ul style="list-style-type: none"> <li>■ Premedicate persons who have pain on movement at least 20 min prior to moving them.</li> <li>■ Individualize the turning and repositioning schedules based on the support surface being used and the person's wishes and choices for a position of comfort, general medical condition, activity and mobility level, care goals, and skin condition.</li> <li>■ Use transfer devices to lift the person while repositioning rather than dragging him or her.</li> <li>■ Determine what positions provide comfort; consider the 30° lateral position when in bed.</li> <li>■ Elevate heels without putting pressure on the Achilles tendon.</li> <li>■ Use pressure redistribution seat cushions for persons when sitting in a chair/wheelchair.</li> <li>■ Avoid positioning an individual on any reddened or pressure-discolored areas.</li> <li>■ Avoid using donut devices.</li> </ul>

categories. Some key points from the staging system are listed below (NPUAP- EPUAP, 2009):

- **Category/Stage I:** Intact skin with nonblanchable erythema of a localized area, usually over a bony prominence. Discoloration of the skin, warmth, edema, hardness, or pain may also be present. Darkly pigmented skin may not have visible blanching. The area may be more painful, firmer or softer, or warmer or cooler than adjacent tissue. Category I may be difficult to detect in individuals with dark skin tones. This may indicate an at-risk individual.
- **Category/Stage II:** Partial thickness loss of dermis presenting as a shallow, open ulcer with a red/pink wound bed, without slough. It may present as an intact or open/ruptured serum-filled blister or sero-sanguineous-filled blister. This stage presents as a shiny or dry shallow ulcer without slough or bruising. This category should not be used to describe skin tears, tape burns, incontinence-associated dermatitis, maceration, or excoriation.
- **Category/Stage III:** Full-thickness tissue loss. Subcutaneous fat may be visible, but bone, tendon, or muscle is *not* exposed. Some slough may be present; it *may* include undermining and tunneling. The depth of a Category III pressure ulcer varies by anatomical location. The bridge of the nose, ear, occiput, and malleolus do not have (adipose) subcutaneous tissue, and Category III ulcers can be shallow. In contrast, areas of significant adiposity can develop extremely deep Category III pressure

ulcers. Bone/tendon are not visible or directly palpable.

- **Category/Stage IV:** Full-thickness tissue loss with exposed bone, tendon, or muscle. Slough or eschar may be present. It often includes undermining and tunneling. The depth of a Category IV pressure ulcer varies by anatomical location. The bridge of the nose, ear, occiput, and malleolus do not have (adipose) subcutaneous tissue, and these ulcers can be shallow. Category IV ulcers can extend into muscle and/or supporting structures (e.g., fascia, tendon, or joint capsule), making osteomyelitis or osteitis more likely to occur. Exposed bone/muscle is visible or directly palpable.
- **Unstageable:** A full-thickness tissue loss in which actual depth of the ulcer is completely obscured by slough (yellow, tan, gray, green, or brown) and/or eschar (tan, brown, or black) in the wound bed. Until enough slough and/or eschar are removed to expose the base of the wound, the true depth cannot be determined, but it will be either a Category III or IV. Stable (dry, adherent, intact, without erythema or fluctuance) eschar on the heels serves as “the body’s natural (biological) cover” and should not be removed.
- **Suspected deep tissue injury:** Purple or maroon localized area of discolored, intact skin, or blood-filled blister due to damage of underlying soft tissue from pressure and/or shear. The area may be preceded by tissue that is painful, firm, mushy, boggy, or warmer or cooler than adjacent tissue. Deep tissue injury may be difficult to detect in



individuals with dark skin tones. Evolution may include a thick blister over a dark wound bed. The wound may further evolve and become covered by thin eschar. Evolution may be rapid, exposing additional layers of tissue even with treatment.

In May of 2013, the Center for Medicare and Medicaid Services (CMS) stated in its long-term acute care hospital (LTCH) quality reporting program manual (Version 2.0) that “skin ulcers that develop in patients who have terminal illness or are at the end of life should be assessed and staged as pressure ulcers until it is determined that the ulcer is part of the dying process (also known as Kennedy ulcers). Kennedy ulcers can develop from 6 weeks to 2 to 3 days before death. These ulcers present as pear-shaped purple areas of skin with irregular borders that are often found in the sacral-coccygeal areas. When an ulcer has been determined to be a Kennedy ulcer, it *should not be coded as a pressure ulcer*” (page M-3).

## Pressure Ulcer Treatment

The management of patients on PC with pressure ulcers is complex and should focus on a holistic approach, where the patient is assessed as a whole. The incorporation of an interprofessional team greatly enhances the provision of optimal care. Naylor (2005) outlined seven principles that should be included in the management of palliative pressure ulcers:

- Correcting or treating the cause of the wound
- Preventing the development and/or further breakdown of the wound
- Addressing symptoms related to the wound
- Having patients (and their circle of care) perform self-assessments
- Encouraging independence
- Providing psychosocial support
- Improving QOL

The EPUAP/NPUAP 2009 pressure ulcer guidelines recommend using normal saline or cleansers that are noncytotoxic to control odor and decrease trauma to the wound. Cytotoxic agents are typically not recommended for cleaning of pressure ulcers. For PC patients, the use of these solutions may be warranted, because the goal is *no longer healing*. The benefits of odor control from these solutions may make them an appropriate choice for older adults who are at the end of their lives. However, there are other methods of controlling odor and these include use of topical metronidazole, activated charcoal dressings, antimicrobial dressings, and external odor absorbers (kitty litter, coffee beans, vinegar, and vanilla; Langemo & Black, 2010).

Pressure ulcers may need ongoing debridement of necrotic tissue. Pain associated with debridement is an important component of managing a wound in a palliative patient. Autolytic debridement can be achieved by using calcium alginate, hydrogel hydrocolloid, film, or other dressings (modified from Ayello, Cuddigan, & Kerstein, 2002). Enzymatic debridement is associated with little pain and can be as effective in the PC setting. Surgical debridement may be best for infected wounds with advancing cellulitis with appropriate systemic antibiotic coverage (Kirshen, Woo, Ayello, & Sibbald, 2006). Mechanical debridement accomplished by wet-to-dry dressings is painful and traumatic to the wound bed, resulting in bleeding of the tissue and is not generally recommended for use with PC patients, when comfort is the goal.

Since the discovery of moist wound healing by Winter (1962), many new types of dressings have become available. As a result, dressing selection can be confusing for the clinician. Determination of the most appropriate dressing is a difficult task and it depends on the characteristics of the wound. In the case of palliative wounds where healing is not the goal, dressing choice should be focused toward those that are nonadherent, absorb exudate well, and require infrequent changing. For many clinicians, the key determining factor is the amount of exudate in the pressure ulcer wound. For example, wounds with low amounts of exudate can be managed by a dressing with low-absorbent capabilities. If the wound bed were dry, then using dressings that add moisture to the wound would be indicated. See Table 25.6 for a brief summary of selected dressings.

## Quality-of-Life Issues Including Pressure Ulcer-Associated Pain

Gorecki et al. (2009) concluded from a pain impact study that “pain was the most significant consequence of having a pressure ulcer and affected every aspect of patients’ lives.” Although they are few in number, some studies have provided clinicians with insights into QOL issues for patients with pressure ulcers (Langemo et al., 2000) and their caregivers (Baharestani, 1994). Themes common to both of these studies were pain, lack of knowledge, the meaning of the pressure ulcer, and lifestyle changes imposed by the pressure ulcer. A recent article by Pieper, Langemo, and Cuddigan (2009) provides extensive summary tables of pressure ulcer pain studies.

Acute pain in a person with a pressure ulcer often indicates extension of the injury or secondary complications such as infection, periwound maceration or

**TABLE 25.6 Selected Dressings****Low exudates absorption**

## Film dressings:

- Easily applied
- Can see the wound site
- Waterproof, good for incontinent patients
- Adhesive may cause skin injury during removal (stretch laterally to decrease adhesive bond before lifting off the skin)
- Generally not recommended for use with infected wounds

## Hydrogel dressings:

- Available as sheets or gels
- Effective for painful wounds
- High water content, so effective for use in wounds that are dry
- Require a secondary dressing to keep in place

## Hydrocolloid dressings:

- Available in many shapes and sizes
- Very moldable
- Some are adhesive, some are not
- Can remain in place for many days

**Moderate to high exudates absorption**

## Calcium alginate dressings:

- Made from seaweed
- Bioresorbable, excellent for absorption and autolytic debridement
- Available in sheet and rope forms
- Not effective on wounds without enough exudate to convert the fiber to a hydrogel (do not use on dry wounds)
- Be aware that the wound may have the odor of “low tide”
- Switch to another dressing if exudate diminishes, as it can dry out a wound with low exudate
- Requires a secondary dressing to hold in place

## Foam dressings:

- Very useful for wet, weepy wounds
- Effective for packing deep wounds
- Requires a secondary dressing
- Can be used underneath compression stockings and multiple layer bandaging systems
- Some have low-tac, so they do not “strip” the skin when removed
- Will give a variable amount of moisture back to the wound base and surrounding skin as part of the moisture balance mechanism. If maceration is associated, consider a superabsorbent dressing instead (e.g., ABD pads or other dressings with absorptive fluid lock dressing similar to diapers)

## Negative pressure wound therapy:

- Great for wounds with large amounts of exudate
- Requires learning the technique for placing the specialized foam/dressings into the wound, positioning the tubing, applying the specialized drape, and attaching to the vacuum source
- Some patients report pain with this therapy
- Contraindicated with untreated infection or malignancy in the wound base
- Expensive and may be noisy/disturbing to the palliative patient

## Antimicrobial dressings:

- Effective for critically colonized/ locally infected wounds
- Most requires a secondary dressing (not adhesive foams or hydrocolloids)
- No MRI if silver dressings used



friction, and shear injury. Wound-associated pain is often due to a combination of nociceptive and neuropathic components. Treatment must consider both the stimulus-dependent nociceptive (gnawing, aching, tender, or throbbing) or the spontaneous neuropathic components (burning, stinging, shooting, and stabbing) that need to be treated differently with a combination of appropriate agents. Nociceptive pain responds to the World Health Organization ladder for cancer pain including nonsteroidal anti-inflammatory drugs and aspirin progressing to weak and then strong narcotic agents. Short-acting agents should be replaced with long-acting agents with lower doses of short-acting agents for breakthrough. Neuropathic pain is best treated with second-generation tricyclics in a single low nightly dose (e.g., 10–30 mg of nortriptyline or desipramine is preferred over first-generation amitriptyline with lower levels of the critical antinoradrenalin activity for equal doses). Alternate neuropathic pain choices include antiepileptics including gabapentin, pregabalin, and carbamazepine.

The total management also requires attention to nutritional needs. Adequate nutrition may be difficult for elders experiencing anorexia from cancer or other chronic disease. It also may be inconsistent with the elder's wishes, directives, and the goals of management.

Pressure ulcers are a result of unrelieved pressure. Providing an adequate pressure-relieving support cushion, mattress, or bed may greatly decrease the older adult's pain, prevent skin breakdown, or prevent further tissue destruction in an existing pressure ulcer. Always check to see if the support surface is "bottoming out" by placing a hand under the support surface. If the patient's bottom can be felt, then the support surface is not adequate. Alternately, the examiner's hand can be placed between the patient and the surface to see if bottoming out occurs (i.e., if the hand can feel the base of the underlying pressure redistributing device). If this is the case, then deep foam pressure redistribution static or dynamic support surfaces should be obtained.

## ■ SKIN TEARS

### Scope of the Problem

Unlike chronic wounds such as pressure ulcers, skin tears are acute wounds. Skin tears were defined by an international consensus panel as "a wound caused by shear, friction and/or blunt force resulting in separation of skin layers. A tear can be partial thickness (separation of the epidermis from the dermis) or full thickness (separation of both the epidermis and dermis from underlying structures)" (LeBlanc & Baranoski, 2011, p. 6). Thomas, Goode, LaMaster,

Tennyson, and Parnell (1999) have reported that 1.5 million skin tears occur each year in institutionalized adults and more recent data are limited. In the United States, CMS data from section M of the MDS 3.0 RAI reports a rate of 4.95% in long-term care residents ([www.cms.gov](http://www.cms.gov)).

### The Aging Skin

Aging skin predisposes a patient to skin tears due to many changes that are normal aspects of the aging process. As skin ages, there is a decrease in the dermal thickness leading to a thinning of the skin, especially over the legs and forearms. With the decrease in fatty layers and subcutaneous tissues, the bony prominences are less protected. The skin's elastin fibers lose their ability to recoil. Sensation, metabolism, and sweat gland production are also diminished, resulting in dry skin that lacks some of the protection mechanisms. An important change that translates into skin tear injury risk is the decrease in the size of the rete ridges in the basement membrane of the skin. As these ridges become flatter with aging, it becomes easier to accidentally separate the epidermis from dermis (Kaminer & Gilchrest, 1994; Mason, 1997).

### Location and Cause

Most skin tears (80%) occur in the upper extremities on the arms and hands over areas of senile purpura that are most prominent on sun-damaged regions of the extensor aspect of the hands and forearms (Malone, Rozario, Gavinski, & Goodwin, 1991; McGough-Csarny & Kopac, 1998; Payne & Martin, 1990). Skin tears on the back and buttocks can be mistaken for Stage II pressure ulcers. For about half of skin tears, there is no apparent cause. When the cause is known, one fourth are from wheelchair injuries, one fourth are caused by accidentally bumping into objects, 18% from transfers, and 12.4% from falls (Malone et al., 1991). Long-term steroid use and decreased hormone levels in older females may also be risk factors for skin tears (O'Regan, 2002). Skin tears can also occur in infants and children, especially those who are critically ill or medically compromised (LeBlanc & Baranoski, 2011).

A retrospective study by White, Karam, and Cowell (1994) identified dependent patients who required total care for all activities of daily living as being most at risk for skin tears. The skin tears occurred during routine activities of dressing, bathing, positioning, and transferring. The next most common at-risk areas in independent ambulatory residents were the lower extremities. Last were those slightly impaired residents whose skin tear injuries resulted from hitting furniture or equipment such as wheelchairs (White et al., 1994).

The method of skin cleansing in routine bathing practices may affect the occurrence of skin tears. Soap increases skin pH to an alkaline level rather than the normal “acid mantle” of the skin (Mason, 1997). Mason (1997) found a lower rate of skin tears in long-term residents (34%) who were bathed every other day with emollient soap. Use of the newer no-rinse bathing products (responsible bathing) may also be advantageous (LeBlanc, Christensen, Orsted, & Keast, 2008). Birch and Coggins (2003) have reported a decline of skin tears from 23% to 3% in a long-term care facility when a no-rinse, one-step bed bath protocol rather than the traditional soap and water was used.

The Registered Nurses’ Association of Ontario (RNAO) recommends risk assessment tools using a validated tool. White et al. (1994) developed a skin integrity risk assessment tool to identify persons at risk for skin tears. The tool utilizes three groups (I, II, or III) for leveling the risk of skin tear occurrence. Implementation of a skin tear risk prevention plan of care depends on the number of criteria that a patient meets in a group or a combination of criteria in groups II or III. Additional research with this and most available assessment tools would be valuable in establishing its reliability and validity. Many authors have researched and have come to consensus on prevention strategies for skin tears (Bank & Nix, 2006; Krasner, Rodehaver, & Sibbald, 2007; LeBlanc & Baranoski, 2011; LeBlanc et al., 2008; Lloyd & Morris, 2011; O’Regan, 2002; Ratcliff & Fletcher, 2007).

In their 6-month study of residents in a Veteran’s Administration (VA) nursing home care unit and nine community nursing homes, McGough-Csarny and Kopac (1998) identified 10 risk factors for skin tears; six of these accounted for skin tears in 65% of their sample. They were advanced age, sensory loss, compromised nutrition, history of previous skin tear, cognitive impairment, and dependency. Fifty percent of the sample had bruising and poor locomotion as contributing factors. Two other factors present in 40% of the sample were polypharmacy and the use of an assistive device. Using these 10 identified risk factors, they report a plan to develop an instrument to assess skin tear risk.

## Classifying Skin Tears

Originally, the Payne-Martin Classification system for assessing skin tears (Payne & Martin, 1990, 1993) was used to identify the type of skin tear. It has three categories, two of which have subcategories (Payne & Martin, 1993). McGough-Csarny and Kopac (1998) used this system in their 6-month study. These authors reported that Category I and Category III were the easiest tears for staff to identify. Thomas

et al. (1999) utilized this system in their study comparing the healing of skin tears with foam versus transparent film dressings. Although the Payne-Martin Classification system has been used in some studies (McGough-Csarny & Kopac, 1998; Thomas et al., 1999), the tool has not been widely used in clinical practice. Most recently, an international panel proposed the use of a new validated classification system with only three types (LeBlanc & Baranoski, 2011; LeBlanc, & Holloway, 2013). This international skin tear advisory panel (ISTAP) skin tear classification is as follows: type 1, no skin loss; type 2, partial flap loss; and type 3, total flap loss (LeBlanc, & Holloway, 2013).

## Plan of Care to Prevent or Treat Skin Tears

Once a patient has been identified as being at risk for developing skin tears, a protocol to prevent skin injury should be implemented. There is no universal agreement as to the best practice to prevent or treat skin tears in the literature; one example can be found in Appendix 1. The ISTAP published its recommended protocols in the fall of 2013 (LeBlanc & Holloway, 2013).

### ■ Strategies in Preventing Skin Tears

1. Assess for risk upon admission to health care service and whenever the individual’s condition changes.
2. Implement a systematic prevention protocol.
3. Have individuals at risk wear long sleeves, long pants/trousers, or knee-high socks.
4. Provide shin guards for those individuals who experience repeat skin tears to shins.
5. Ensure safe patient handling techniques and equipment/environment.
6. Involve individuals and families in preventive strategies.
7. Educate registered and nonregistered staff and caregivers to ensure proper techniques for providing care without causing skin tears.
8. Consult dietician to ensure adequate nutrition and hydration.
9. Keep skin well lubricated by applying hypoallergenic moisturizer at least two times per day.
10. Protect individuals at high risk from trauma during routine care and from self-injury (LeBlanc & Baranoski, 2011).

### ■ Skin Tears Treatment Protocol

- Gently clean the skin tear with normal saline.
- Let the area air dry or pat dry carefully.



- Approximate the skin tear flap.
- Apply petroleum-based ointment, steri-strips, or a moist nonadherent wound dressing.
- Calcium alginate dressings facilitated closing in 7 to 10 days (Nazarko, 2005).
- Two studies reported healing with octylcyanoacrylate skin glue (LeBlanc et al., 2008; Milne & Corbett, 2005).
- Use caution if using film dressings as skin damage can occur when removing this dressing. Consider using silicone dressings with low tack to avoid tearing the skin.
- Consider putting an arrow on the dressing to indicate the direction of the skin tear to minimize any further skin injury during dressing removal.
- Always assess the size of the skin tear; consider doing a wound tracing.
- Document assessment and treatment findings. For U.S. residents in long-term care, this is documented on the MDS RAI in Section M 1040 item G for occurrence of a skin tear and on M 1200 for care interventions.

## ■ PERISTOMAL (OSTOMY) SKIN

Secondary to the original surgery or because of complications (obstruction from recurrent tumor), some patients may require urinary or fecal diversions. This is most commonly seen in patients with colon, rectal, cervical, bladder, or other pelvic malignancies (Turnbull, 2007). Once a patient develops an incontinent ostomy, protecting the skin around the stoma—the peristomal skin—and preventing its breakdown becomes an important nursing goal. A wound, ostomy, continence nurse (CWOCN, formerly ET) is an excellent resource in planning and implementing care for these elders. The Wound, Ostomy, and Continence Nurses Society (WOCN) has a website and maintains a directory of nurses by geographic area who are available for clinical consults ([www.wocn.org](http://www.wocn.org)).

## Assessing Peristomal Skin

Peristomal skin must be assessed with each pouching system change. Recently, a new tool to bring consistency to describing peristomal skin complications was published in English and three other languages. The tool contains three criteria: discoloration, erosion, and hyperplasia, or raised lesions that can be measured with size and severity for a maximum score of 5 points for each criterion (Claessens, Serrano, English, & Martins, 2008). Normal peristomal skin should be intact without discoloration and no difference between the peristomal skin and adjacent skin surfaces. Peristomal skin damage may be evidenced by erythema, maceration,

denudation, skin rash, ulceration, or blister formation. In darkly pigmented patients, the damaged skin may appear lighter or darker than the surrounding skin (Erwin-Toth, 2001).

Protecting the peristomal skin from the damaging effects of urinary or fecal effluent is paramount. The proteolytic enzymes found in the effluent from small bowel stomas can rapidly erode the skin. If the urine from a urinary diversion becomes alkaline, it is more damaging to the skin than normally acidic urine. Large amounts of liquid effluent can result in maceration if allowed to pool on the skin. The mnemonic “MINDS” can be used to remind clinicians of common peristomal complications (Woo, Sibbald, Ayello, Coutts, & Garde, 2009). MINDS stands for *M*-mechanical trauma, *I*-infection, *N*-noxious chemical and irritants, *D*-disease of the skin, and *S*-skin allergens (Woo et al., 2009).

## Maintaining Peristomal Skin Integrity

Maintaining the integrity of peristomal skin can be accomplished, in part, by observing correct pouching principles. Similarly, peristomal skin must be protected from mechanical trauma, which can occur from inappropriate cleaning. To avoid skin stripping, use adhesive removers to remove skin barriers and pouching systems. Gently peel the adhesive barriers off the skin by supporting with one hand and then using the adhesive remover as the edge of the barrier that is attached to the skin. Application of skin sealants prior to application of skin barriers of the pouching system can provide protection for the peristomal skin. Avoid too frequent or unnecessary changing of the pouch–skin barrier.

The nurse should be sure to use the correct products on peristomal skin. Alcohol-based products should never be used, especially if the peristomal skin is denuded. If solvents are used, the skin should be cleaned and the solvent removed before applying the ostomy pouch. The older adult should be assessed for sensitivity to the ostomy products prior to using the product; this includes assessing for latex sensitivity.

Skin sealants come in a variety of forms—wipes, gels, and sprays. These products, when dried, provide a thin film to the skin surface, and thus decrease the chance of skin stripping. Some skin sealants contain alcohol, so care should be taken not to use them on denuded skin because they can cause the elder additional pain or burning on application.

A variety of skin barriers can be used to protect the peristomal skin from effluent. These are available as rings, wafers, pastes, and powders. In addition to protecting the skin, they also create a level pouching surface, which can prevent leakage of effluent underneath the pouch seal in “difficult to fit” stomas. A

properly sized and applied skin barrier can protect the skin from the damaging effects of ostomy effluent. Skin barriers vary in their resistance to breakdown by urine or feces. Karaya dissolves with urine, so avoid the use of this product with urinary diversions.

Skin barriers that are powders can be “dusted” onto the denuded skin. Using a skin sealant product over this product can help provide an absorptive protective layer for the peristomal skin. Some skin barriers can cause pain when used on denuded skin. Check that the skin sealant product does not have alcohol in it, as this can be painful when applied to denuded and irritated skin. Some companies make “no sting” skin barriers that do not cause pain or “burning” when applied to irritated denuded skin.

Selecting the right ostomy pouching system for your patient may require the assistance of the CWOCN (ET) nurse. Pouching systems are provided as one or two pieces. A one-piece system has the skin barrier permanently attached to the ostomy pouch. A two-piece ostomy pouching system has the advantage of the skin barrier remaining on the skin for several days with the ease of snapping the pouch off the skin barrier for emptying of contents. Pouches can be drainable or closed end. There are also pouches specially designed for pediatric patients.

Pouches should be selected that are correct for the type of drainage coming from the ostomy. For example, fecal pouches will not work for urinary diversions. Urinary ostomy pouches have a spout on the bottom for proper emptying of the urine. For fecal pouches, the opening is wide and closed, and, in most cases, with a special ostomy clamp. Most modern day ostomy pouching systems are odor proof when correctly closed and the seal is intact. If the elder has an unusually large amount of drainage, one of the high-output pouches should be used. Treatments such as chemotherapy or radiation may affect the patient's stool consistency and amount of output. Adjustments in the size of the pouch, more frequent emptying of the pouch, and changes in ostomy irrigations may need to be implemented. It is imperative when selecting the appropriate pouch that it is the correct size for the ostomy stoma. A too large or too small pouch opening size can cause leakage and/or trauma to the stoma (Bryant & Fleischer, 2000).

## Total Ostomy Care Management

Care of the older adult patient with an ostomy involves more than just assessing the peristomal skin and pouching system. The elder's emotional and psychosocial acceptance of the stoma is important; for some people, the creation of a diverting ostomy may bring relief from the symptoms of obstruction, but it may also serve as a permanent reminder of the

progression of their disease. Supporting the patient to adjust to this change in body image, overcoming concerns about odor, learning new psychomotor self-care skills, and dietary adjustments are just some of the comprehensive care elements that the patient may need to obtain in consultation with a WOCN (ET) nurse to meet the patient's needs.

## Fistulas

Fistulas are abnormal openings between two organs or an organ and the skin. An internal fistula is inside the body while an external fistula tracts outside the body to the skin, most commonly through the gastrointestinal tract or bladder but sometimes through the vagina or rectum. Fistulas can occur with certain diseases (e.g., malignancies including obstructions, Crohn's disease, or diverticulitis) or from treatment modalities such as radiation or surgery, including postoperative adhesions. A high-output fistula has more than 200 mL/24 hr (Rolstead & Bryant, 2000). Assessment of the perifistula skin is critical because irrigation from the effluent can be caustic to the skin and result in irritation and erosion. The perifistula skin should be assessed for signs of fungal infections as well as for redness, papular rash, and satellite lesions.

Identification of the fistula to determine its origin is important for developing the plan for closure, which can be spontaneous (about 50%) or surgical. Goals of management for an older adult with a fistula should include maintaining fluid and electrolyte balance (assess for dehydration and metabolic acidosis), protection of the perifistula skin, odor control, effluent containment and measurement, nutritional management, and patient comfort. Holistic care of an elder with a fistula might include total parenteral nutrition to meet the nutritional needs, therapeutic communication to respond to the patient's emotional needs from having a foul-smelling fistula, protecting the skin from injury from the effluent, and eliminating odor.

Women who have had pelvic radiation can then develop vaginal fistulas, which are often distressing to the patient and challenging to the nurse. Containment of the feces and odor are difficult and require frequent dressing changes. For nonambulatory patients, urinary incontinence pouches, commercially available vaginal drain devices, or a breast shield or vaginal diaphragm attached to a malecot catheter may be used (Rolstead & Bryant, 2000).

## Management Options

■ **Pouching.** A pouching system may be the primary choice for management for older adults with odorous fistulas. Using a clear pouch will enable the caregiver or nurse to easily see the type and amount of effluent.



Pouching is superior to dressings because it provides better protection for the skin. A pouch with a spout on the bottom works well for fistulas with thin effluent drainage; for thicker drainage, a fecal pouch that can be closed with a clamp is a better choice. Wound management pouches come in a variety of sizes and are useful for treating abdominal fistulas (Schaffner, Hocevar, & Erwin-Toth, 1994). For patients with odorless fistulas and output (100 mL/24 hr), dressings may be used. Dressings that are absorbent such as foams, calcium alginates, or hydrocolloids (see Table 25.6 for an overview of dressings), can be selected depending on the exudate level. In these cases, use a petroleum- or zinc-based ointment to protect the peristoma skin from maceration or breakdown. Some patients have such large wounds with enterocutaneous fistulae that the usual commercially available pouches are too small and will not fit. O'Brien, Landis-Erdman, and Erwin-Toth (1998) have described the management of one such fistula and large wound using a surgical isolation bag with skin barrier while packing the wound with moistened gauze.

The more enzymes and liquidity of the fistula output, the greater the need to place additional skin barrier seals around the fistula opening prior to placing a high-output pouch. For older adults who have abdominal fistulas with irregular skin surfaces, skin barrier pastes or strips may need to be placed around the fistula opening to “build it up” so the abdominal plane can be “filled in” and then a pouch placed over it. Sometimes, a patient has two fistula openings; if they are close together, one pouch may fit over both fistula orifices. If not, “saddle bagging” two pouches may be the best option.

■ **Tubes and Suction.** Another way to manage fistulas is to use drainage tubes, with or without suction. Beitz and Caldwell (1998) have described the management of a high-output enterocutaneous fistula using a drain tube Jackson-Pratt drain (JP) connected to low-wall suction (60 mmHg of pressure) that was covered with saline-soaked gauze and a large surgical plastic drape. When using this technique, be careful in placing the catheter tube so it does not inadvertently cause injury to the tissue. Harris and Komray (1993) have also used a similar system to manage a pharyngeal-cutaneous fistula. This system should not be confused with the negative pressure wound therapy (NPWT). According to some manufacturers, NPWT can be used for management of fistulas.

■ **Trough.** Another method of managing enterocutaneous fistula is by using the trough procedure. This technique is used for fistulas that are deep within wounds (Wiltshire, 1996). It is made up of several layers of transparent dressing with an ostomy pouch on the bottom of the wound (Rolstead & Bryant, 2000).

## Patient Comfort

Promoting patient comfort is a major priority in caring for a patient with a fistula. The amount of pain or discomfort that a particular management option may cause a patient should influence the decision regarding which management option to select. The goal is to choose the method that will cause the least discomfort and disruption to the patient and caregiver. Medicating the patient prior to removal and application of fistula containment measurements is essential.

## ■ SKIN DAMAGE FROM RADIATION THERAPY

Radiation therapy damages cellular DNA, resulting in cell death. This is why rapidly dividing cells such as skin, hair, or mucosa die after being irradiated (Turnbull, 2007). Skin reactions may include erythema; desquamation, either dry (dry, flaky, scaly) skin when sweat and sebaceous glands are damaged) or moist (blistering, peeling sloughing) skin; or even ulceration (Oncology Nursing Society, 2005).

While undergoing radiation therapy, care should be taken not to remove any of the treatment field markers on the skin. Avoid activities that could cause mechanical skin damage such as vigorous rubbing, heat, or shaving of the skin in the treatment area. Use of any topical products, such as lotions, creams, or deodorants, is generally discouraged. Any product with metal components or ingredients (e.g., silver or zinc oxide) should not be used during radiation treatment (Turnbull, 2007). Patient care goals include keeping the skin intact as well as in correct moisture balance. The Oncology Nursing Society recommends products with vitamin A and E or aloe vera gels for treating erythema, although topical steroids should also be considered with the presence of a topical contact irritant dermatitis. Talcum, cornstarch, or baby powder use is controversial as they often contain heavy metals; however, if they are applied, an even layer can be obtained with a cotton ball dabbed on the affected area rather than sprinkling the powder from a container. Sprinkling often leads to local clumping.

## ■ TUMOR NECROSIS AND SKIN INJURY FROM FECAL INCONTINENCE

### Tumor Necrosis and Skin Care

In some older adults with advanced cancer, the tumor can invade the skin, which results in ulcerated fungating wounds. For example, in patients with breast cancer, the tumor can grow outward onto the skin

**TABLE 25.7** Giving Voice to Patient-Centered Concerns

Here are some comments from the patient in our case study about important aspects of her care.

*Initial approach:* "From the very beginning, the wound care team treated me with respect. You asked me if I was ok. You called me by my name. It was not just about my breasts, my illnesses or my wounds."

*What made the difference:* "You acknowledged that my feeling[s] about my body image were an important component to me. I always put on my jewelry, did my hair and dressed up nice to come to the wound clinic. Even though I have several wounds on my chest, you always remarked about my pretty necklace."

*Pain:* "When my wounds were painful, you understood that I had to work through the pain. I was addicted to the feeling of feeling better. Even something as simple as lifting the laundry can be very heavy, with the pain and these wounds on my chest."

in a blackened cauliflower-like appearance (see Table 25.7). This results in maceration of the surrounding skin as well as extensive odor from bacterial infection from organisms such as *Pseudomonas aeruginosa*, *Staphylococcus*, *Proteus*, and *Klebsiella* (Haisfield-Wolfe & Baxendale-Cox, 1999; Haisfield-Wolfe & Rund, 1997). Nodules may enlarge and erupt spontaneously through the abdominal skin in patients with carcinomatosis. While the majority of metastatic skin lesions are found on the anterior trunk, they may also be found on the pelvis, flank, head and neck, and posterior trunk (Bauer, Gerlach, & Doughty, 2000). Haisfield-Wolfe and Baxendale-Cox (1999) have suggested the use of a staging classification for assessment of malignant cutaneous wounds. Parameters to include are wound depth, color of the wound, drainage, pain, odor, and presence of tunneling or undermining.

## Management Strategies

In an effort to palliate symptoms, radiation or chemotherapy may be used to shrink the tumors that have grown onto the skin. Maida, Ennis, Kuziemy, and Trozzolo (2009) identified eight key symptoms associated with malignant wounds from a prospective series of 472 cancer patients. Approximately two thirds of the malignant wounds were associated with at least one of these symptoms: pain, mass effect, aesthetic distress, exudate, odor, pruritus, bleeding, and crusting. Management strategies suggested by Alvarez et al. (2007) include the mnemonic SPECIAL (Stabilizing the wounds, Preventing new wounds, Eliminating odor, Control pain, Infection prophylaxis, Advanced, absorbent wound dressings, Lessen dressing changes).

## ■ How Should These Wounds Be Cleansed?

Although the evidence base for management of such extensive wounds is limited, options for addressing the patient care needs are anecdotally reported. Frequent irrigation of the wound with large amounts of fluid may be important to reduce the bacterial burden on the wound surface (Bauer et al., 2000). For patients who can get into the shower, cleansing these fungating wounds may provide physical as well as psychological benefits. Instruct the patient not to aim the shower water directly at the wound, but rather above the ulcerated area so the water can trickle down over the wound without undue force. Use of a handheld shower device might be preferred by some patients (Bauer et al., 2000). For patients who cannot tolerate being showered or where the tissue is very friable, gentle cleaning with saline or commercially available wound cleansers may be substituted.

## ■ How Do You Manage Exudate From These Wounds?

Management of these wounds can be challenging and they generally have large amounts of exudate because of the tumor's hyperpermeability to fibrinogen and colloids, but primarily due to the secretion of vascular permeability factor secreted by the tumor (Bauer et al., 2000). There may also be drainage of fecal material in the case of patients with abdominal carcinomatosis. Dressings that are absorbent (foam, calcium alginate, or cotton absorbent dressing pads) should be used. Often there is much necrotic tissue in these wounds and debridement is required. Autolytic debridement techniques such as the use of calcium alginate dressings, hydrogel dressings, or other nonadherent modern dressings are advocated. Others (Bauer et al., 2000) recommend using a petroleum-impregnated gauze dressing. Picture frame the skin area around the fungating wound with protective skin barriers such as hydrocolloid dressing strips. Use of Montgomery straps to hold the secondary dressing in place will also reduce damage to skin that can be caused by the frequent removal of tape. Cutting the crotch off mesh underpants and putting this around the chest wall like a tube top can also be used to hold the bulky dressings in place (Bauer et al., 2000). Mechanical debridement, such as wet-to-dry dressings, should be avoided due to the obvious risk of causing more bleeding and increasing pain. The safety of using enzymatic debriding agents in cancer wounds is not yet known.

## ■ How Do You Control Bleeding in Friable Areas?

Bleeding commonly occurs in these types of wounds because tumor cells take over the function of platelets, and the growth and clotting factors that they secrete damage normal tissue (Bauer et al., 2000). Prevent-



ing the dressings from drying out can minimize tissue trauma from the removal of soiled dressings. Calcium alginate dressings (Haisfield-Wolf & Rund, 1997) have a hemostatic effect and are a good choice for bleeding wounds. Silver nitrate sticks can be used to control small amounts of blood.

■ **How Can Wound Pain Be Managed?** Pain also results from the tumor growing on the skin and from treatment procedures. Seaman (1995) suggests using ice packs or topical anesthetic aerosol spray (Hurricane) to alleviate wound pain. Some clinicians have reported using the NPWT dressing system solely for pain management and comfort for elders with these types of extensive wounds; however, this use is not Food and Drug Administration-approved. Topical extemporaneously compounded opioids or preparations containing amide local anesthetics (lidocaine and prilocaine including EMLA [eutectic mixture of local anesthetics]) and pramoxine have also been used to relieve wound pain (Alvarez et al., 2007).

■ **How Can Wound Odor Be Managed?** Odor may be one of the most distressing problems for the patients and their caregivers. Seaman (1995) suggests first using one of the commercially available wound gel deodorizers; however, some patients may experience burning with application of these products. The use of Metrogel (1% topical antibiotic wound deodorizing gel; Newman, Allwood, & Oakes, 1989; Rice, 1992; Seaman, 1995) to control even the most horrific odors has been reported. Metronidazole tablets can be dissolved into normal saline and used to irritate the wound (McMullen, 1992). Metronidazole tablets (250 mg or 500 mg) can be crushed and sprinkled directly onto the wound bed (Bauer et al., 2000). Health care professionals should wear a mask to avoid inhaling the particles. Taking metronidazole systemically or using the IV solution as an irrigation solution has also been recommended.

Topical application of yogurt or buttermilk has been used to combat the extensive odors from tumor necrosis (Schulte, 1993; Welch, 1981). The newer antimicrobial cadexomer iodine or silver dressings are also excellent at reducing odor with the added plus of also controlling the bacterial burden in the surface compartment wound. Another advantage is that some of these dressings can stay in place for up to 7 days, which reduces the pain from dressing change. Odor control within the patient's environment may be achieved by utilizing aromatherapy products, such as peppermint oils/sprays or charcoal under the bed (Cormier, McCann, & McKeithan, 1995).

■ **Quality-of-Life Issues.** The clinicians should be aware of their nonverbal and verbal communication to patients during dressing changes. Patients and/or family members may have difficulty coping with wound odor or appearance, and will look to the clinician to see their reaction. Seeing the extensive death of their own body, coupled with overpowering smells and weeping feces, may be extremely overwhelming to patients. The clinician's resolve to problem solve and provide the patient with the physical comfort from appropriate wound management is vital in helping these patients overcome their (sometimes self-imposed) isolation and hiding.

## Skin Care Needs From Fecal Incontinence

Changes in bowel habits may occur in older adults undergoing cancer treatments such as radiation or chemotherapy. Bliss, Larson, Burr, and Savik (2001) tested the reliability of a four-picture, word definition stool consistency classification system, and found it to be a valid tool for use by nurses and lay caregivers. Precision in describing the characteristics of the stool is important for clinicians. By understanding if a patient truly is having diarrhea or loose stools, the clinician can then develop an appropriate plan to protect the skin. For example, Grogan and Kramer (2002) have described the use of the rectal trumpet (nasopharyngeal airway) to contain fecal incontinence in critically ill and geriatric patients. This technique proved to be less traumatic than other methods of fecal containment (diapers, perineal incontinence pouches, and balloon catheters). However, there are now commercially available bowel-containment catheter devices that are available.

Educating elders about skin care is an important part of nursing interventions. Ideally, this type of teaching will occur prior to any skin injury. For example, Haisfield-Wolfe and Rund (2002) created a booklet for cancer patients with guidelines for skin care. The 30 female oncology patients who were receiving chemotherapy found the booklet helpful in doing their own self-assessment for perineal skin changes.

## CONCLUSION

Health care clinicians are often faced with a multitude of challenges when caring for palliative patients and their circle of care. Focusing on the wound etiology and classifying wounds as healable, maintenance, or palliative (nonhealable) can provide realistic expectations for patients, their family unit, and caregivers

as well as the health care professional team. Local wound care should be aimed at providing comfort, relieving pain, reducing odor, containing exudates, and improving patient's QOL, permitting them to resume as many activities of daily living as possible. Local wound care may be aimed at moisture reduction rather than moisture balance, with antibacterial activity of agents such as povidone iodine or

chlorhexidine and its derivatives viewed as more important than tissue toxicity. Debridement is often conservative to remove slough or devitalized tissue but not to create active bleeding of an acute wound within a chronic wound. It is paramount that the patient's preference be prioritized in the decision-making process and implementation of realistic treatment care plans.

### CASE STUDY Conclusion

Ms. D. L. required treatment systemically for the secondary infection, including the gram-negative and anaerobic organisms that led to the increased pain, exudates, and odor. A combination antibiotic of clavulanic acid and amoxicillin was administered, and her symptoms improved. For cleansing of the wounds, a dilute acetic acid compress was used for 10 minutes prior to dressing changes. The wounds contained slough that was autolytically debrided with hypertonic saline ribbon gauze alternating with a calcium alginate and iodine combination product. With the treatment program, the dressing changes with moist saline gauze and an antibiotic ointment that were being changed three to four times a day were reduced to daily with an improvement in pain, odor, and amount of exudate.



Psychologically, the improved management of the cutaneous lesions led to Ms. D. L. feeling an increased self-confidence and the ability to resume social relationships. She also consented to an interview for an advanced wound care program to highlight the importance of palliative wound care centered around patient concerns.

### Evidence-Based Practice

Maida, V., Ennis, M., & Corban, J. (2012). Wound outcomes in patients with advanced illness. *International Wound Journal*, 9(6), 683–692.

A prospective case series was studied to assess the potential for complete healing of wounds among patients with advanced illness referred to a regional palliative care program in Toronto, Canada. Two hundred eighty-two patients, of whom 148 were primarily diagnosed with cancer and 134 with noncancer advanced illness, were assessed and followed until their deaths. On the baseline initial referral date, 823 wounds were documented. The wound classes assessed included pressure ulcers, malignant wounds, skin tears, venous leg ulcers, diabetic foot ulcers, and arterial leg/foot ulcers. Proportions of patients showing complete healing of at least one wound were calculated and stratified by patient's survival time postbaseline (1 week, 1 month, 3 months, and 6 months).



Proportions of patients showing complete healing of at least one wound increased the longer patients lived and ranged between 12.9% and 43.5% for Stage I pressure ulcers, 0% and 60% for Stage II pressure ulcers, 2.4% and 100% for skin tears, 10% and 100% for venous leg ulcers, and 0% and 50% for diabetic foot ulcers. Only one person showed complete healing of a Stage III pressure ulcer and no complete healing was observed with Stage IV pressure ulcers, unstageable pressure ulcers, malignant wounds, and arterial leg/foot ulcers.

## Evidence-Based Practice

White-Chu, E. F., & Reddy, M. (2013). Daily baths: Pressure ulcer prevention in patients with advanced illness. *Current Opinion in Supportive & Palliative Care*, 7(1), 111–115.

Through a MEDLINE and CINAHL database search from January 1, 2011, to June 1, 2012, a total of 14 abstracts were found addressing the prevention of pressure ulcers in persons with advanced illness. Search terms included pressure ulcer, prevention, and control. Advanced illness was defined as patients transitioning from curative to supportive and palliative care. Ten original studies and four review articles specifically addressed pressure ulcer prevention. There were four articles that specifically addressed patients with advanced illness. The studies varied in quality. One systematic review, one randomized controlled trial, three prospective trials, two retrospective trials, one cost-effectiveness analysis, one quality improvement project, one comparative descriptive design, and four review articles were found. The interventions for pressure ulcer prevention were risk assessment, repositioning, surface selection, nutritional support, and maintenance of skin integrity with or without incontinence.

### Summary

The quality of pressure ulcer prevention studies in persons with advanced illness is poor. Increased number and higher quality studies are needed to further investigate this important topic for these fragile patients.

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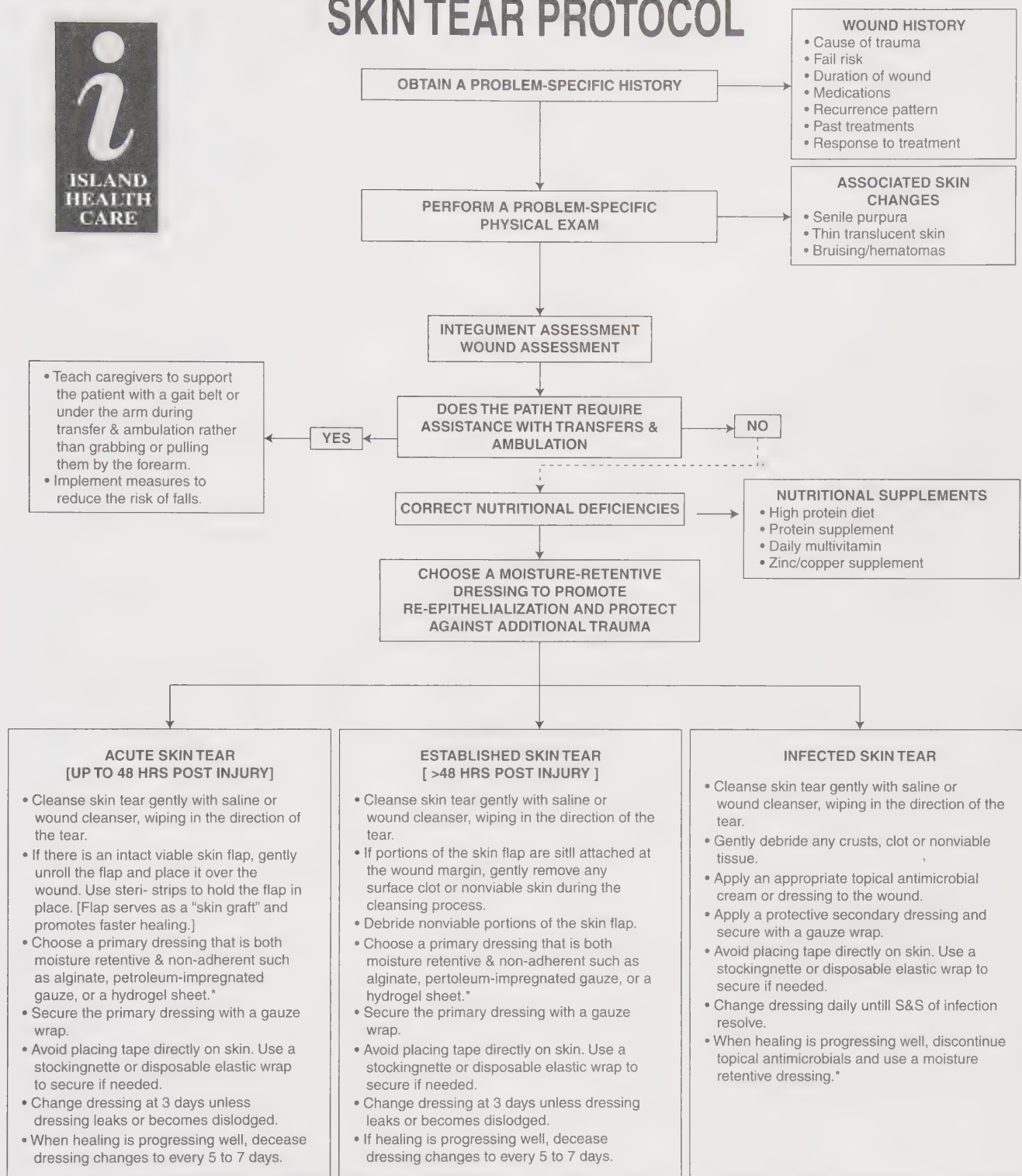
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## ■ APPENDIX 1



# SKIN TEAR PROTOCOL



Note: Some patients may benefit from the use of an adhesive product [transparent film, thin hydrocolloid, adhesive foam] to maintain dressing integrity. Adhesive dressings can cause reinjury and should be used with caution.

Source: From Cuzzell, J. (2002). Wound care assessment and evaluation: Skin tear protocol. *Island Health Care. Dermatology Nursing*, 14(6), 405.





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# Peri-Death Nursing Care

## C H A P T E R

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### KEY POINTS

- Nurses caring for a patient who is near death should be aware of the patient's and family's physical and emotional experiences during the dying experience.
  - Special considerations for children and elderly patients who cannot make their own decisions should be addressed with the family.
  - Families should be informed of the physical processes that occur during the dying process and the nursing interventions and activities that occur after death.
  - Nurses should engage in a discussion with families about the options for organ donation, autopsy, and various postmortem responsibilities, rights, and rituals appropriate to the culture, and assist them with accessing resources.
  - Nursing interventions do not terminate with a patient's death and should include bereavement care and assistance with accessing appropriate resources.
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### CASE STUDY

I was a fairly new hospice nurse when I walked into Mr. Clement's room at the nursing home. There were 10 people around his bed, including family members and a priest administering Prayers for the Sick. I stood there quietly, but was welcomed into the service as the priest continued. Mr. Clement, who was diagnosed with Lewy body dementia, had just been released from the hospital earlier that day. He had stopped drinking and taking nutrition during the past 3 days. He was a tall, thin man whose eyes were closed, but he did not look uncomfortable. He was really quite peaceful.

One of the daughters-in-law was a nurse and seemed to gently guide the family. The family had opted not to place a PEG tube in this 77-year-old patient in advanced stages of dementia. After the priest was finished, she encouraged Mr. Clement's daughter to lean next to his face, say his name, and he would kiss her. She knew his hearing was still intact. As his daughter leaned down and said "Dad," his lips puckered and she received that last kiss from her father. When I spoke to the family, they all agreed hospice was the right choice for their father. While they seemed to find comfort in that decision, I was also comforted in how they seemed at peace with their father's impending death.

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As an experiential process, dying and death for the individual, his or her family, and the health care practitioner can be one of the most profound and significant events experienced in one's lifetime. The last hours of life are conceptualized as the peri-death period, which specifically encompasses the symptoms and experiences right before death occurs, the actual death, and the care of the body after death. This time requires intensive holistic nursing care.

The purpose of this chapter is to relate the role of the nurse during the peri-death period and convey the core knowledge necessary for nurses to help facilitate a "good" death. The information in this chapter should be considered a requirement for nurses educated at a basic level. The role of the advanced practice nurse regarding peri-death nursing includes mentoring and modeling appropriate behaviors for the novice nurse, as well as directing symptom management. Additionally, the role includes supporting the novice nurse through the dying experience, and support of the family during the decision-making process regarding autopsy and funeral arrangements.

## ■ PERI-DEATH 1: SYMPTOMS AND EXPERIENCES BEFORE DEATH

The peri-death period begins with a preparation phase, the hallmark of which is the realization or acknowledgment that death is inevitable and temporally near. The patient and family members begin to prepare for the death. Similarly, the preparation phase for the terminally ill person is also a time when patients and families have many decisions to make regarding home or hospital care, hospice referral, advance directives, and do-not-resuscitate orders.

The patient may be so uncomfortable with the physical (e.g., pain, dyspnea, fatigue) and emotional (e.g., depression, dependency) aspects of dying that he or she may feel ready for life to end. This sense of readiness may be in tension with a reluctance to die based on fear of the unknown and concern for how the family will cope after the death. Family members are confronted with their role in the dying process, the prospect of losing their loved one, and the conflicts that arise from these and other issues. The patient's role within the family may change as the family learns how to provide care.

The peri-death period brings the surrogate decision maker's role to the forefront when decisions for the dying patient must be accomplished. Conflicts exist between health care providers and surrogates related to the health care decisions for the dying patient frequently. Tan and Manca (2013) believe this conflict

can contribute to a "bad death" experience that can include uncontrolled management of the symptoms listed here.

Any, all, or none of the following symptoms may occur during the final stages of the dying process. In-depth nursing interventions for the person with advanced disease can be found in the previous chapters of this book. The focus here is on the physiological changes that occur as death is imminent and the nursing interventions that are appropriate at this time.

## Pain

Pain is thought to have a major negative effect on quality of life (QOL) within the peri-death experience (Smith et al., 2010). As the body begins to shut down and die, the need for pain medication may change or decrease. World Health Organization's pain ladder (2013) is a simple tool to determine what medications should be used. The liver conjugates these drugs and active metabolites remain in the body, exerting a pharmacological effect until they are cleared by the kidneys. As the body is dying, renal and hepatic function is compromised and the drugs are cleared from the system very slowly. This results in an increase in serum opioid concentrations, which results in increased drowsiness or mild confusion. A nursing priority should be to keep the patient pain free and comfortable but with the understanding that the dosage to accomplish this may be considerably less than what had been previously needed for effective pain management. Parenteral ketamine, the only available form in the United States, can be mixed in orange juice and administered orally, and has been used by palliative care (PC) providers when pain is difficult to manage (McPherson, Kim, & Walker, 2012).

Patients, health care providers, and family need an understanding of the importance and value of pain management during the dying process. Pain management has improved; the prevalence of inadequate pain management at the end of life (EOL) remains a key issue (Bailey et al., 2012). The patient may seek pain relief or may view pain as a way to atone for sins and refuse to be medicated. Health care professionals may worry about determining the appropriate dose that will either offer relief of pain and suffering or hasten death (Rushton, 2008). Identifying the appropriate dose and frequency can be challenging and may require creativity (McPherson et al., 2012). Like the nurse, the family may fear being the person to give the "last dose" of morphine before the patient dies. Not adequately medicating for pain, though, can interfere with the memories that the family will carry with them for the rest of their lives. They will remember the death of their loved one as a time of agony and pain rather than a time that could have



been used for conversations that are more meaningful and memorable.

The role of the nurse in management of pain and other distressing symptoms is to assess the level of pain the patient is having and the patient and family's attitudes toward pain. The assessment must be based on an informed understanding of the patient's values and goals, and assure patients and families that comfort and alleviation of pain is a priority. Encouraging patients to report their pain before it becomes intense will prevent unbearable suffering. Determining the adequacy of the pain control and its duration are important assessment data so that those dosages can be appropriately adjusted. Pain relief is an attainable goal, but may require sedation to achieve adequate control (Patel, Gorawara-Bhat, Levine, & Shega, 2012).

Given that pain medications typically cause constipation, nurses must be vigilant in assessing for constipation. Caregivers should be encouraged to continue prophylaxis bowel regimens to prevent or alleviate its associated discomfort. Additionally, there are medications available to minimize opioid-induced constipation (OIC). Other nonpharmacological interventions that alleviate pain are a calm environment, soothing music, and aromatherapy. Simple human touch or therapeutically intended touch, such as Reiki or therapeutic touch, can relieve stress, be a source of comfort or support, and overcome fear of abandonment.

## Anorexia and Dehydration

As patients approach the EOL, they may say they are not hungry, which is a normal predeath finding. Decreased eating results in a metabolic imbalance whereby the energy a patient takes in does not cover the energy he or she expends, resulting in a state of dehydration. Although healthy people who are experiencing dehydration will report pain, abdominal cramps, nausea, vomiting, and dry mouth, patients who are terminally ill do not report such symptoms. At the EOL, patients typically only complain of having a dry mouth, which is often unrelated to hydration status and most often is the result of medication side effects, increased respiration, or mouth breathing.

Food represents more than nutrition to many families and may have symbolic importance. It can have a vital role in helping them to maintain hope and providing comfort to the patient (Hospice and Palliative Nursing Association [HPNA], 2012). It is regrettable that attempts to feed the dying patient are not only frustrating for everyone involved, but can also add to the patient's suffering (Danis, 2011). Danis (2011) also indicates artificial nutrition and hydration are not warranted. In many cases, artificial hydration and

nutrition provide an opportunity to "do something" at a time when the mistaken perception is that there is little else the nurse can do for them. A patient's right to refuse nutrition has been supported with legal opinions (Soriano & Lagman, 2012), but the family's choice to provide food should be respected (Danis, 2011) and balanced with the patient's autonomy (HPNA, 2012).

IV fluids are sometimes given to reverse delirium for a person who is actively dying (Emanuel, Ferris, von Gutten, & von Roenn, 2008). While IV fluids may alleviate symptoms, HPNA (2012) recommends a time-limited trial for IV fluid infusions. IV fluids increase urinary output, which may require a Foley catheter. It may increase respiratory secretions and increase cough as well as increasing gastrointestinal fluids, leading to abdominal distention, nausea, or vomiting. Increasing the intravascular volume in the presence of decreasing renal function can further result in peripheral edema and increase the incidence of decubitus ulcers. Pain can result from the IV site and restraints may become necessary to prevent the patient from removing the tubing. The presence of the IV may act as a physical barrier to the family and may be a cause of anxiety to them. In essence, artificial nutrition and hydration at this stage may lead to symptoms of congestive heart failure, increased tracheal and bronchial secretions, pleural effusions, nausea and vomiting, painful edema, and diarrhea rather than improving symptoms or prolonging life (HPNA, 2012).

Clinicians should recognize that a legal or ethical distinction between withholding and withdrawing treatment does not exist (Danis, 2011). A patient's right to refuse nutrition has been supported with legal opinions (Soriano & Lagman, 2012) and the Patient Self-Determination Act. There are many benefits to the patient in not utilizing artificial food and fluids as death nears. With calorie deprivation comes an increased production of ketones, which results in an elevation of naturally occurring opioid peptides or endorphins that provide analgesia. An electrolyte imbalance, if present, will also result in increased analgesia. Decreased fluid intake will result in fewer pulmonary fluids, which ease respiration, lessens coughing, and reduces the drowning sensations. If a tumor is present, dehydration may make it smaller in size by reducing the edematous layer around the tumor, resulting in less pressure and pain. Discontinuing total parenteral nutrition can reduce the burden of sepsis, while stopping tube feedings can reduce diarrhea (American Academy of Hospice and Palliative Medicine, 2006). While IV fluids may alleviate symptoms, time-limited trials are recommended. Whatever the decision, nurses should discuss EOL choices related to patient goals and values (HPNA, 2012).

Nursing interventions focus on meticulous mouth, nasal, and conjunctival care to alleviate mouth dryness and prevent sores, dental problems, infections, and discomfort. Scrupulous cleaning and moistening of the mouth can be one of the most important interventions to prevent suffering in a patient nearing death. The benefits are doubled in preserving a patient's dignity with fresh breath and communication with family members during the process (CroyÃre, Belloir, Chantier, & McEvan, 2012; Emanuel et al., 2008; Field & Cassel, 1997). The mouth and teeth can be cleaned with a soft-bristled toothbrush or sponge-covered oral swabs. To maintain moisture in mucosal membranes, the mouth should be rinsed frequently with water. A spray bottle can be used to mist the mouth often; a room humidifier is also very helpful. Commercial salivary substitutes or supplements such as Salivart, Oral Balance, Salagen, and MoiStir, or a baking soda mouthwash (one teaspoon salt, one teaspoon baking soda, and one quart tepid water), can also help keep the patient comfortable. Chamomile tea is also very soothing and can be used to clean the mouth or offered to the patient to sip on. EOL halitosis is a frequent phenomenon. Two drops of essential peppermint oil in one ounce of purified drinking water can be used on a toothette when providing oral care. It is not an immediate cure for halitosis, but with multiple uses can refresh breath and leave a pleasant taste and aroma for the patient (K.T. Young, personal communication, September 8, 2008). Generously applying lip lubricant can prevent dry, chapped lips and alleviate associated discomfort. Avoid petroleum-based products if the patient is on oxygen. Ophthalmic lubricating gel or artificial tears can be used to hydrate conjunctiva.

Family members should be shown how to give good mouth, nasal, and conjunctival care and be supported by the nurse in their efforts. It is essential for everyone involved in the care of the patient to realize that not providing food and fluids is not the same as not caring for the patient, only that the concentration of care is on meeting the needs of the dying person and providing comprehensive symptom management (Emanuel et al., 2008).

If the patient is experiencing oral pain, morphine or morphine elixir can be used if the pain is severe or during mouth care and meals. Topical agents for mouth pain include Viscous Xylocaine 2% solution, 5 to 15 mL, swish and spit every 2 to 4 hours as needed. KBX solution (Kaopectate, Benadryl, Xylocaine viscous in equal parts), 5 to 15 mL, swish for 1 minute, then spit or swallow every 2 to 4 hours as needed, may also be ordered. The Xylocaine provides topical anesthesia; the Benadryl is a short-acting anesthetic; and the Kaopectate (Mylanta may be substituted) serves as an alkalizing agent (Gates & Fink, 1997; Schaefer, 2008).

If the patient is still sipping fluids, encourage those fluids that contain salt to help prevent electrolyte imbalance. Fluids such as bullion soup, tomato juice, or sport drinks such as Gatorade may be well tolerated. Avoid citrus juices or foods that may irritate the mouth, as well as temperature extremes of foods. It is important not to force food or fluids at this point and to support the family, who may have a difficult time accepting the patient's refusal to eat or drink. Families can be reminded that even in the case of acute illness, such as the flu, food and fluids can create additional distress.

As death approaches, patients often lose their ability to swallow due to weakness or a decrease in neurological function. The gag reflex may diminish and secretions will tend to accumulate in the tracheobronchial tree. Positioning is important to prevent the accumulation of secretions in the back of the throat and upper airways (Ferrell, Virani, & Grant, 1999). This phenomenon, known as a death rattle, occurs in 23% to 92% of dying patients, and is present in 76% of patients within 48 hours before death (Wee & Hillier, 2008). Anticholinergic interventions such as Atropine 1% ophthalmic solution can be administered sublingually and has a response time of 30 minutes. Scopolamine transdermal patches have an onset of 12 hours, reach a steady state in 24 hours, and can be used to decrease secretion production and decrease the occurrence of the "death rattle." Although not distressing to the patient, this sound can be very upsetting to the family (McPherson et al., 2012). Oropharyngeal suctioning is not recommended as it is frequently ineffective and may stimulate the patient and distress the family even more (Emanuel et al., 2008).

## Weakness and Fatigue

Fatigue is a primary complaint of patients in the last hours and days of life. The tiredness may be a result of both the disease and the treatment for the disease, as well as malnutrition and disrupted sleep patterns. Fatigue may interfere with a person's ability to move, bathe, or toilet (Emanuel et al., 2008; Field & Cassel, 1997).

The nurse should be aware that while the patient is at high risk for a pressure ulcer, turning and positioning should be done as frequently as possible but only as often as comfort permits. Bony prominences should be padded and supported if this is comfortable for the patient. If any of these interventions result in increased pain or suffering, they should not be implemented. Initially, this may be difficult for the novice nurse to support, as it is contrary to the basic nursing skills they have been taught. When a patient is actively dying, intervention goals should focus on comfort; any intervention that compromises this goal should be discontinued.



## Dyspnea

Dyspnea is common, and can be the most distressing symptom experienced at the EOL. It results from the lungs' inability to function in proportion to the metabolic demands of the body and may be indicative of significant neurological compromise. Dyspnea is considered a subjective experience and is difficult to measure at the EOL when patients are not able to report symptoms (Campbell, 2012). When a person has trouble breathing, there must be either an increase in ventilation or a decrease in activity. Terminal dyspnea occurs in as many as 75% of patients in the peri-death period. Changes in respiration are normal and should be anticipated prior to death. Physiologically increased carbon dioxide in the blood stimulates respiration. During the peri-death period, increased pulmonary congestion and poor gas exchange results in a rise in carbon dioxide levels, but the brain is less responsive to this signal (Pitorak, 2003). The breathing pattern can become irregular and include shallow breathing altered with apnea lasting 5 to 60 seconds (Cheyne-Stokes breathing; Emanuel et al., 2008).

Families should be warned that dyspnea and loud respirations are a possibility during the peri-death period. Patients may fear they will suffocate while they are dying and families fear they will have to watch their loved one struggle to breathe. Nurses should educate the patient and family regarding what they can expect and give assurances that medications will be used to effectively palliate these symptoms (D'Arcy, 2012; Emanuel et al., 2008).

Nursing interventions include positioning the patient on his or her side, semiprone or in brief Trendelenburg, to prevent the accumulation of secretions in the back of the throat and upper airways. For opioid-naïve patients, low-dose opiates, such as morphine 5 mg PO every 4 hours, can alleviate the sensation of breathlessness. If morphine is already being used for pain, an increase of 2.5 mg times the regular dose is generally effective. Oxygen is typically only effective if the dyspnea is secondary to hypoxia (e.g., COPD, pulmonary fibrosis), although it may provide a placebo effect (D'Arcy, 2012). A fan blowing a gentle breeze toward the patient's face can also be very effective. Suctioning is usually not recommended as it may incidentally increase secretion production. Emotion-focused interventions such as relaxation techniques, prayer and meditation, and distraction may alleviate the anxiety often associated with dyspnea (Horn, 1992; Spector, Connolly, & Carlson, 2007).

## Multisystem Failure

As the body is shutting down, there is a decrease in blood perfusion and a resulting shutdown of the

major organs (e.g., renal and hepatic). Decreased cardiac output and intravascular volume result in tachycardia and hypotension. Additionally, the body will conserve blood volume for vital organs, which results in peripheral cooling (as the body conserves heat) and peripheral and central cyanosis. The skin may therefore become mottled and discolored, which is normal before death and a sign that it is imminent. Mottling is typically seen on the earlobes and the soles of the feet before other areas.

Urine output is greatly diminished and there can be a loss of sphincter control resulting in urinary or fecal incontinence. It may be a good idea to insert a urinary catheter to reduce the need for frequent bedding changes and to prevent skin breakdown. The catheter also helps the continent patient conserve energy by removing the need to use a bedpan or urinal.

Neurological dysfunction is a result of multiple, concurrent, and nonreversible organ failure as a result of infections, nutritional deficits, neurological disorders, electrolyte imbalances, and medications (Chirco, Dunn, & Robinson, 2011). Consequently, the patient may experience reduced cerebral perfusion, hypoxemia, metabolic imbalances, acidosis, accumulation of toxins from renal and hepatic failure, and sepsis (Ferrell et al., 1999). The net effect of these changes may be a decreased level of consciousness or terminal delirium.

## Terminal Delirium

Individuals at the EOL can experience a disturbance of fluctuating consciousness, cognition, and perception known as delirium, but it is often underdiagnosed in the terminally ill (Candy et al., 2012). Terminal delirium can also be manifested as confusion, anxiety, agitation, or restlessness; restlessness and delirium are typical symptoms that are indicative that the patient is close to death. Chirco et al. (2011) indicate the most commonly occurring symptoms include somnolence, followed by communication difficulties, memory disturbances, thinking difficulties, and disorientation. These can be distressing symptoms for patients and their families and are estimated to occur in up to 88% of patients who develop delirium in the last 24 to 48 hours of life (Macleod, 2006). Confusion is a mental state in which a person reacts inappropriately to his or her environment because he or she is confounded or disoriented. It may be the side effect of medications or caused by the dying process itself (Chirco et al., 2011; Field & Cassel, 1997). Anxiety is the biological and emotional reaction to stressful situations, including the approach of death.

The patient may experience dread, danger, or tension with somatic complaints that include shortness

of breath, nausea, or diarrhea (Field & Cassel, 1997). Moaning and grimacing can accompany agitation and restlessness and may be misinterpreted by the nurse as pain (Ferrell et al., 1999). Uncontrollable pain is not likely to develop during the last hours of life if not previously present (Emanuel et al., 2008). The patient may be restless and make repetitive motions (e.g., pulling on clothing or the sheets). The underlying cause of the restlessness may be opioid toxicity, metabolic disorders and lowered seizure threshold, or full bladder or bowel (Candy et al., 2012).

Nursing interventions to manage terminal delirium should focus on the treatment of the underlying physical cause if it is practical and possible. Nonpharmacological interventions are preferred, but are not always possible. Antianxiety agents such as benzodiazepines (lorazepam, diazepam, alprazolam) and neuroleptics (Haldol) for drug toxicity can help to quiet distressing symptoms. Barbiturates or propofol have been suggested, as have other antiepileptics such as IV phenytoin, phenobarbital, or carbamazepine (Candy et al., 2012; Emanuel et al., 2008).

The family is in need of education and support regarding the cause and the irreversible nature of the behavior. Maintaining a calm environment, spiritual comfort, and emotional support are vital at this time. The family can be advised to continue to talk to the patient and calm the patient with their words. Light massage of the arms, back, or forehead can be very soothing. Soft music and low lights can also be effective. It may be suggested that the number of people in the room be decreased if there is a lot of activity. Refraining from asking the patient many questions can diminish agitation.

Eventually the patient's level of consciousness will decrease and he or she may even become unable to be aroused. This is a very upsetting time for families because the patient may seem unresponsive and withdrawn, but it is a normal aspect of the dying process. At this time, the patient is starting to "let go" in preparation for death and is detaching from relationships and the physical environment. A patient may ask to be with only one person toward the end or seem distracted from the family. Reassure the family that this is not a personal rejection, only another aspect of the dying process. A dying person may talk about seeing people who have already died or talk about taking a trip with a long-deceased relative. Patients may describe feeling separate from their body. This is a normal experience and is not considered a hallucination.

Even if the patient is unresponsive, encourage family members to talk with him or her. Assume that the patient hears everything; this is the time for loved ones to say "Good-bye," "I'm sorry," "I love you," or "Thank you." The patient may have difficulty letting go and the nurse may need to encourage the family to

give the patient permission to die. Encourage the family to show affection to the patient, touch the patient, and let the patient know he or she will be missed.

## Affirming Life and Maintaining Hope

Two very important goals of PC nursing are to help patients live until they die, and to encourage hope. First, the nurse can help patients live until they die by encouraging socialization, listening, being honest, and helping them finish any unfinished business. The nurse can also help families find meaning in the situation. Dialogues about death with health care professionals, families, and friends can benefit all involved (Revier, Meiers, & Herth, 2012; Wasserman, 2008). By offering patients choices regarding routines, food, and activities, nurses promote continued independence and the ability to help maintain control over their lives. Of course, the degree of independence depends on patients' energy level and ability (Birchenall & Streight, 1997; Zerwekh, 2006). Furthermore, patients' wishes should be respected even if those wishes are inconsistent with the family's or health care provider's values.

Second, hope is an important component of the emotional stages of dying and death. It has been a factor in helping the patient and family continue through the difficult months and years leading up to the death. Hope is what maintains a person's spirit and helps the person to go on; as the person is dying, *what* he or she hopes for may change, but it does not go away. There may be hope for the miracle of a complete cure; it is not acceptable for the nurse to take this hope away or to tell the patient and family to be realistic. It may be dying a good death that has different meaning for each client (Tan & Manca, 2013). Their hopes may change from that of cure to the hope for a full night's sleep, a visit from an important person, or for less pain. Persons with hope have been found to live longer and have a greater QOL than those who are hopeless (Birchenall & Streight, 1997). Benzein and Saveman (2008) posit that patients who told their story were able to relieve an unrecognized burden. What is important for the nurse is to be present for the patient and family wherever he or she is in this process and support the feelings that are experienced. The rights of the dying can be found in Table 26.1. Listening and caring for their needs are important nursing functions at this time of life.

## Palliative Care for the Aged and Individuals With Dementia

In the 21st century, the needs of health care will continue to change. It is predicted that by 2022 the Medicare population will approach 67 million



**TABLE 26.1 The Dying Person's Bill of Rights**

■ I have the right to be treated as a living human being until I die.
■ I have the right to maintain a sense of hopefulness, however changing its focus may be.
■ I have the right to be cared for by those who can maintain a sense of hopefulness, however challenging this might be.
■ I have the right to express my feelings and emotions about my approaching death, in my own way.
■ I have the right to participate in decisions concerning my care.
■ I have the right to expect continuing medical and nursing attention even though "cure" goals must be changed to "comfort" goals.
■ I have the right not to die alone.
■ I have the right to be free from pain.
■ I have the right to have my questions answered honestly.
■ I have the right not to be deceived.
■ I have the right to have help from and for my family accepting my death.
■ I have the right to die in peace and dignity.
■ I have the right to retain my individuality and not be judged for my decisions, which may be contrary to the beliefs of others.
■ I have the right to discuss and enlarge my religious and/or spiritual experiences, regardless of what they may mean to others.
■ I have the right to expect that the sanctity of the human body will be respected after death.
■ I have the right to be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face my death.

Note: This Bill of Rights was created at a workshop on "the terminally ill patient and the helping person" in Lansing, Michigan, sponsored by the Southwestern Michigan In-service Education Council and conducted by Amelia J. Barbus, Associate Professor of Nursing, Wayne State University, in 1975.

Source: Reproduced with permission from Sorrentino, 1999.

Americans, and estimates costs of providing care will reach \$1 trillion (Antos, Capretta, Coulam, Feldman, & Dowd, 2013). This will create a significant challenge for current hospice, PC, and EOL care practices and providers.

Although the body of research regarding EOL care continues to grow, information about the very old or individuals with dementia is more in its infancy. These individuals have unique issues in that they may lose some of their capacity to make decisions or choose to designate surrogates to make those decisions for them. Research indicates surrogate decision making encourages the surrogate to "exercise considerable discretion in the decision making" (Berger, DeRenzo, & Schwartz, 2008, p. 48).

Individuals with dementia often enter an EOL stage without acknowledgment by the family or caregivers, which may lead to inappropriate care during the end stages of dementia (Peacock, 2012). A patient with progressive dementia has the potential for an extended life unless complicating conditions develop (Zerwekh, 2006). One effort to enhance end-of life practices for individuals with dementia includes the *Palliative Excellence in Alzheimer Care Efforts* (PEACE) program offered by the University of Chicago (promotingexcellence.org/).

Decision making for family members can be compounded by ambivalence, struggles with opposing beliefs, and moral issues. Family members may require additional conversations, and interventions by health care workers to help resolve those conflicts (Peacock, 2012). Advance directives and living wills may create as many problems as they solve as the patient's priorities in the context of aging rather than a specific illness may be more tenuous (Berger, DeRenzo, & Schwartz, 2008).

### Special Considerations Related to the Dying Child

PC for the child encompasses a holistic approach to physical, psychological, and spiritual care. Consideration for both the dying child and his or her family supporting optimal functioning until the time of death is a vital role for the nurse (National Hospice and Palliative Care Organization [NHPCO], 2009). Ethical considerations have a significant role in decisions related to a dying child. Identifying if, when, and how much to tell a child about his or her impending death is an important decision for the family. Talking with children about impending death

demands an understanding of the child's perception of death based on previous experiences and developmental stage (NHPCO, 2009).

Children are often very perceptive and may know far more than adults assume. Offering time for discussion related to death and the dying process helps the child recognize that he or she will not be alone in the process and will be loved and remembered. EOL communication will not typically send a dying child into a deep depression. Attempts to protect children from knowledge about their impending death places barriers between them and the people who can best help them understand and deal with their experience. Honest and accurate information about a child's impending death can address separation issues in young children, fears, phobias, and regression in school-age children; emotional lability in preadolescents; and anger, insecurity, and body image in older adolescents (NHPCO, 2009).

Children experience a variety of symptoms in the dying process that may be similar or different from those of adults, but discomfort, seizure management, pain in nonverbal patients, and feeding issues are most common (Sumner, 2006). These symptoms may be a result of the disease process, previous treatment history, or side effects of palliative medication. It is important to assess the onset of those symptoms, severity, duration, and the impact those symptoms have on the child's comfort. This requires extensive investigation and developmentally appropriate interventions and strategies to identify and manage those symptoms. Physical signs and symptoms that occur in children as death approaches include sleeping more, decreased appetite, and less fluid intake. The urine frequency and output will diminish and breathing may become slow and shallow, with occasional deep sighs. There may be some gasping and periods of apnea. The skin may be cool to the touch and appear pale, grayish-blue.

Nurses should help families understand what they see may be different from what the child experiences. If the families are given the opportunity to care for the child, utilizing what they feel is best for the child, a gift of confidence is given to the family. Basic caring—bathing, holding, dressing—becomes significantly important during the peri-death period (Emanuel et al., 2008). Caring for the child does not stop at the time of death. Families may choose to engage in the same activities as if the child were alive and should be encouraged if cultural and religious values allow it (IOM, 2003).

### **Family Support During the Last Hours of Life**

Supporting the family during the last hours of the patient's life is an important nursing role. When

possible, one nurse should be assigned to be with the family through the last phase of life. Enough time with the dying person should be given to the family so that they have the opportunity to resolve any final interpersonal issues. If the death is occurring at home the family should have access to a symptom relief kit with detailed, easy to understand instructions for its use (Appendix 1). Depending on cultural and religious considerations, the family should be afforded privacy and clergy support. The primary nurse should communicate with the family regarding what they can expect the dying process to be like and how they will know when the person has died.

Many people have not been with someone who is actively dying and do not know what to expect. Even though no two deaths are alike, it helps to give significant others an idea of what the final stage of life may be like and the symptoms they may see during this period. Table 26.2, which shows the final stages of dying, is an information sheet written for the general population regarding the dying process and is a good handout for students.

### **Palliative Sedation**

Sedation for the imminently dying is an intervention to relieve intractable symptoms of patients who are suffering at the end of their life. It involves medical use of sedative medications to relieve suffering from refractory symptoms when other therapies do not relieve those symptoms (Maltoni, Scarpi, & Nanni, 2013), by reducing the level of consciousness, but not to intentionally end life. This intervention should only occur when the symptoms or suffering cannot be relieved in any other way. Maltoni et al. (2013) posit palliative sedation as a gradual process of titrating medications to obtain symptom relief. One of the forms of palliative sedation includes deep continuous sedation (DCS), which is generally used to manage refractory symptoms in late stages of disease. This should not be confused with euthanasia.

Indications for terminal sedation are uncontrolled physical suffering such as intractable pain, dyspnea, seizures, or delirium. Table 26.3 offers general guidelines for terminal sedation and Table 26.4 lists medications and guidelines for their use in sedating an imminently dying patient. The level of sedation that eliminates objective signs of discomfort is maintained until the elder dies; death will typically occur within hours or days of the initiation of sedation (Quill & Byock, 2000). There is no literature to support the belief that imminently dying patients die quicker when sedated to control intractable symptoms (Maltoni et al., 2013). Panke (2003) suggests that patients with unrelieved symptoms may die sooner secondary to "increased physiologic stress,



**TABLE 26.2 Final Stages: The Dying Process**

When a person enters the final stage of the dying process, two different dynamics are at work. Physically, the body begins the final process of shutting down, which will end when all the physical systems cease to function. Usually this is an orderly, progressive series of physical changes—the ways the body prepares itself to stop. The most appropriate kinds of responses are comfort-enhancing measures.

The other dynamic of the dying process is emotional and spiritual. The “spirit” of the dying person begins the final process of release from the body, its immediate environment and all attachments. This release follows its own priorities, which may include the resolution of whatever is *unfinished* of a practical nature and exercising permission from family members to “let go.” The most appropriate kinds of responses are those that support and encourage this release and transition.

When a person’s body is ready and wanting to stop, but the person is still unresolved or not reconciled about an important issue or relationship, the person may linger in order to finish whatever needs finishing. On the other hand, when a person is emotionally/spiritually resolved and ready for this release, but his/her body has not completed its final physical process, the person will continue to live until the physical shutdown is completed.

The experience we call “death” occurs when the body and the spirit complete the process of shutting down, reconciling, and finishing. These processes need to happen in a way appropriate and unique to the values, beliefs, and lifestyle of the dying person. The following are offered to help you understand the natural kinds of things that may happen and how you can respond appropriately. Not all these signs and symptoms occur with every person, nor do they occur in this particular sequence. Each person is unique and needs full acceptance, support, and comfort. The following signs and symptoms are indicative of how the body prepares itself for the final stage of life:

*Coolness:* The hands, arms, feet, and legs may be increasingly cool. The color of the skin may change. The underside of the body may become darker and the skin mottled or discolored, a normal indication that the circulation of blood is decreasing to the body’s extremities and being reserved for the most vital organs. Keep the person warm with a nonelectric blanket.

*Sleeping:* The person may spend an increasing amount of time sleeping and appear to be uncommunicative or unresponsive and, at times difficult to arouse. This is due in part to changes in the metabolism. Sit with your loved one and speak softly and naturally. Plan to spend time when the person seems most alert and awake. Try not to talk as if the person were not there. Speak directly as you normally would, even though there may be no response. Never assume the person cannot hear; hearing is the last of the senses to be lost.

*Fluid and food decrease:* The person may have a decrease in appetite and thirst, wanting little or no food or fluid. The body will naturally begin to conserve energy that would be expended on these tasks. Do not try to force food or drink into the person. If the person is able to swallow, fluids may be given in small amounts by syringe. Glycerin swabs may help keep the mouth and lips moist and comfortable. A cool, moist washcloth on the forehead may also increase physical comfort.

*Incontinence:* Control of urine and/or bowels may be lost as the muscles in that area begin to relax. Discuss with your hospice nurse what can be done to keep your loved one clean and comfortable. If it would make the person more comfortable, the nurse may suggest a catheter to drain the bladder. The person’s normal urine output may decrease and become dark due to the decrease in circulation through the kidneys.

*Congestion:* The person may have gurgling sounds coming from the chest. These sounds may become very loud. This is due to the decrease of fluid intake and the inability to cough up normal secretions. The sound of the congestion does not indicate the onset of severe or new pain. Suctioning usually increases the secretions. The nurse or home health aide can show you how to keep the mouth clean with “touthettes.”

*Breathing Pattern Change:* The person’s regular breathing pattern may change and become irregular—shallow breaths with periods of no breathing for a few seconds up to a full minute. This is called Cheyne-Stokes breathing. The person may also experience periods of rapid shallow panting. Elevating the head and/or turning on one side may bring comfort.

*Disorientation:* The person may seem to be confused about the time, place, and identity of people, including those close and familiar. This is due in part to metabolism changes. Identify yourself by name before you speak; speak softly, clearly, and truthfully when you need to communicate.

*Restlessness:* The person may make restless and repetitive motions, such as pulling at bed linen or clothing. This is due to the decrease in oxygen circulation to the brain and to metabolism changes. Do not interfere with or try to restrain such motions. To have a calming effect, speak in a quiet, natural way; lightly massage the forehead, back, or arms; read to the person, or play some soothing music. Try to decrease the number of people around the person.

(continued)

**TABLE 26.2 Final Stages: The Dying Process (continued)**

*Withdrawal:* The person may seem unresponsive, withdrawn, or in a comatose-like state. This indicates preparation for release, a detaching from surroundings and relationships and a beginning of letting go. Because hearing remains almost all the way to the end, now is the time to say whatever you need to say that will help the person let go. The person may only want to be with a very few or even just one person. If you are not part of this inner circle at the end, it means you have already fulfilled your tasks, and it is time for you to say good-bye.

*Vision-like experiences:* The person may speak or claim to have spoken to persons who have already died, or to see places not presently accessible or visible. This means the person is beginning to detach from this life and is preparing for the transition. Do not contradict, explain, or argue about what the person claims to have seen or heard. Affirm the experiences. They are normal and natural.

*Letting go:* The person may continue to perform repetitive and restless tasks. This may indicate that something is still unresolved or unfinished. The hospice team can assist you in identifying what may be happening and help the person find release from tension or fear. As hard as it might be, you need to give the person permission to let go.

*Saying good-bye:* When the person is ready to die, and you are able to let go, saying good-bye is your final gift of love. It achieves closure and makes the final release possible. It may be helpful to hold or touch and say the things you want to say. It may be as simple (or as complicated) as saying "I love you." It may include saying "I'm sorry for whatever I've done to cause any tensions or difficulty." You may also want to say "Thank you." Tears are a normal and natural part of saying good-bye. They are a natural expression of your sadness and loss. It is all right to say "I will miss you so much."

Although you may be prepared for the dying process, you may not be prepared for the actual moment. It may be helpful for you and your family to think about and discuss what you would do if you were alone when the death occurs. The death of a hospice patient is expected and is not an emergency. Nothing must be done immediately. The signs of death include:

- No heartbeat
- Release of bowel and bladder
- No response
- Eyelids slightly open
- Pupils enlarged
- Eyes fixed on a certain spot
- No blinking
- Jaw relaxed and mouth slightly open

You may now notify a hospice nurse or the on-call nurse of the death. The nurse will make the pronouncement and notify the physician. The body does not have to be moved until you are ready. The nurse can call the funeral home, but you or a member of your family will probably need to speak with the funeral director.

Source: Adapted from the Visiting Nurses Association of Manchester and Southern New Hampshire, Manchester, NH.

diminished immunocompetence, decreased mobility, increased risk of thromboembolism and pneumonia, increased difficulty breathing, and greater myocardial oxygen requirements" (p. 31).

Terminal sedation requires participation of the entire health care team for monitoring the patient and the support of his or her family. The sedation is maintained by continuous subcutaneous or IV infusion. Opioids that have already been initiated for pain and other symptoms should be continued to prevent unobservable pain or opioid withdrawal, but opioids should not be used to maintain the sedation itself (Quill & Byock, 2000).

## Ventilator Release

Withdrawal of mechanical ventilation and removal of the endotracheal (ET) tube (terminal extubation)

occurs in clinical situations where prior attempts to wean the patient have not been successful, in cases of futility, when the family decides that continued intubation is a burden and source of suffering for the patient, and when the QOL is unacceptable. The "best" protocol for release from the ventilator in the case of terminal extubation is unclear. There is a paucity of research evidence to guide terminal extubation so clinicians are often left with only their personal values and beliefs, family preferences, and staff input to guide clinical practice (Billings, 2012). In the case of terminal extubation where the patient is not expected to survive, the clinical obligation and priority should be comfort and to prevent suffering for the patient and their family (Matzo & Orwig, 2013).

Campbell (2007) conducted a systematic review of the literature regarding the withdrawing of mechanical ventilation and concluded that there is a lack of evidence



**TABLE 26.3 General Guidelines for Terminal Sedation**

Guideline Domain	Terminal Sedation
Palliative care	Must be available, in place, and unable to adequately relieve current suffering.
Usual patient characteristics	Severe, immediate, or otherwise unrelievable symptoms (e.g., pain, shortness of breath, nausea, vomiting, seizures, delirium) or to prevent severe suffering (e.g., suffocation sensation when mechanical ventilation is discontinued).
Terminal prognosis	Usually days to weeks
Patient-informed consent	Patient should be competent and fully informed or noncompetent with severe, otherwise irreversible suffering (clinician should use advance directive or consensus about patient wishes and best interests).
Family participation in decision	Clinician should strongly encourage input from and consensus of immediate family members.
Incompetent patient	Can be used for severe, persistent suffering with the informed consent of the patient's designated proxy and family members. If no surrogate is available, team members and consultants should agree that no other acceptable palliative therapies are available.
Second opinion(s)	Should be obtained from an expert in palliative care and a mental health expert (if uncertainty exists about patient's mental capacity).
Health care practitioner participation in decision	Input from staff involved in immediate patient care activities is encouraged; physician and staff consent is required for their own participation.

Source: Adapted from Quill & Byock, 2000.

**TABLE 26.4 Medications Used in Terminal Sedation**

Medication	Type	Usual Starting Dosage	Usual Maintenance Dosage	Route
Midazolam	Rapid, short-acting benzodiazepine	0.5–1.5 mg/hr after bolus of 0.5 mg	30–100 mg/day	Intravenous or subcutaneous
Lorazepam	Benzodiazepine	1–4 mg every 4–6 hr orally or dissolved buccally; infusion of 0.5–1.0 mg/hr intravenously	4–40 mg/day	Oral, buccal, subcutaneous, or intravenous
Propofol	General anesthetic; ultrarapid onset and elimination	5–10 mg/hr; bolus doses of 20–50 mg may be administered for urgent sedation, but continuous infusion is required	10–200 mg/day	Intravenous
Thiopental	Ultrashort-acting barbiturate	5–7 mg/kg of body weight to induce unconsciousness	Initial rate may range from 20–80 mg/hr; average maintenance rates range between 70 and 180 mg/hr	Intravenous
Pentobarbital	Long-acting barbiturate	2–3 mg/kg, slow infusion, to induce unconsciousness	1 mg/hr, increasing as needed to maintain sedation	Intravenous
Phenobarbital	Long-acting barbiturate	200 mg loading dose, repeated every 10–15 min until patient is comfortable	Approximately 50 mg/hr	Intravenous or subcutaneous

*Note:* Goal of treatment is to relieve suffering by inducing sedation. Dosage should be increased by approximately 30% every hour until sedation is achieved. Once desired level of sedation is achieved, infusion is usually maintained at that level as long as the patient seems comfortable. If symptoms return, dosages should be increased in 30% increments until sedation is achieved. The ranges above are representative. Individual patients may require lower or higher doses to achieve the desired goal. Previous doses of opioids and other symptom-relieving medications should be continued.

Source: Adapted from Quill & Byock, 2000.

to predict the best method for ventilator withdrawal and that procedures should be determined within the clinical context (i.e., degree of respiratory distress, premedication with opioids and benzodiazepines), and “every attempt should be made to extubate patients after ceasing mechanical ventilation because the ET tube is a source of iatrogenic discomfort. However, in some cases, particularly when the patient is unresponsive, it may be best to keep the ET tube, such as when the tongue is swollen, when gag and cough reflexes are absent, or when there is a large volume of pulmonary secretions” (Campbell, 2007, p. 402).

Postextubation stridor (PES) has been documented as occurring in 22% of patients who have been intubated for more than 24 hours, likely secondary to airway inflammation and edema (Cheng et al., 2011). One study documented that the incidence of PES can be reduced with one dose (40 mg) of methylprednisolone (Cheng et al., 2011). An observational study documented that in cases of withdrawal of life support in the ICU, extubating intubated patients before death was associated with higher family satisfaction with care ( $p = .009$ ; Gerstel, Engelberg, Koepsell, & Curtis, 2008) but did not test protocols for extubation.

Billings (2012) proposed that the humane response in this situation is to offer “preemptive high doses of opioids and sedatives for anesthesia, or at least deep sedations to assure comfort” (p. 628). We suggest that in addition to premedication and in the absence of clinical indicators to the contrary (i.e., in the case of burns, airway trauma, or intubation for greater than 14 days, all of which increase the risk of stridor) that extubation be included as part of a humane response. It must be emphasized that discontinuation of mechanical ventilation with or without removal of the ET tube can and should be done in a way that optimizes symptom management, respects patient and family desires, and acknowledges local culture and practice (Matzo & Orwig, 2013). Table 26.5 offers an order set to guide terminal extubation.

## ■ PERI-DEATH 2: DEATH

### Signs of Death

Signs of death include cessation of a heartbeat and respiration, release of bowel and bladder, eyelids slightly open and not blinking, the eyes glaze, and pupils are fixed and dilated. There is a drop in body temperature and, as the blood settles, the body color turns to a waxy pallor, the jaw is relaxed and slightly open, and there is no response from the patient. These signs do not occur in sequence and it may take a few minutes for the body to completely stop (Ferrell et al., 1999; Green & Green, 2006). If the death occurs at

home, the family should be told that it is not considered an emergency but be given a number to call to inform hospice staff or their physician of the death. The body does not have to be moved immediately so the family should not feel rushed or pressured to act.

### When Death Has Occurred

Postdeath nursing care involves preparing the body for the morgue or funeral home and helping the family through decisions regarding autopsy and burial. When death has occurred, the blood will begin to pool in the areas of the body closest to the ground; if the corpse was supine this would be the back and buttocks. A purple-red discoloration of the skin is evident and results from the blood accumulating in the dependent vessels; this is called *livor mortis*. The body begins to cool and this fall in body temperature after death is called *algor mortis* (Kastenbaum & Kastenbaum, 1989; Pattison, 2008). Initially, at the time of death, the muscles in the body relax, but within 2 to 6 hours, *rigor mortis* begins. Rigor mortis is the stiffening of all muscle groups beginning with the eyelids, neck, and jaw. During the next 4 to 6 hours, it will spread to the other muscles including the internal organs. Rigor mortis will usually last between 24 and 48 hours depending on the ambient temperature. After this time, the muscles relax and secondary flaccidity develops (Beattie, 2006; Iserson, 2001).

Care of the body by the nurse should include closing the eyes, inserting dentures and closing the mouth, and elevating the head of the bed so that the blood does not drain into the face and discolor it. Any IV or catheter can be removed at this time, and the physical environment should be straightened. Removal of tubes and equipment is dependent on institutional protocol. Follow the agency protocol regarding jewelry; if there is a wedding ring, secure it on the finger with tape. The body should be bathed in plain water and dried; a bed protector should be placed under the body. If there are dressings on wounds, they should be replaced with clean ones. The hair should be combed, the extremities straightened, and the right great toe tied with an identification tag (Pattison, 2008; Sorrentino, 1999).

If the family wants to participate in the preparation of the deceased for the funeral home, they should be encouraged to do so. The family should also be offered the opportunity to bathe and dress the body if they wish. Some people find comfort in giving the last bath and it helps them to believe that no one else will touch the body in this way again.

When the body and the room have been prepared, family and those close to the patient can be encouraged to say a final good-bye. Within the



**TABLE 26.5 Extubation Orders**

Date/time:
1. Diagnosis:
2. Code status:
3. Lab/radiology:
<input type="checkbox"/> Discontinue all previous routine and daily orders <input type="checkbox"/> Other: _____
4. Respiratory therapy:
<input type="checkbox"/> Notify respiratory therapist for extubation and/or discontinuation of ventilator or BiPAP at date/time: _____ <input type="checkbox"/> ET tube and oral/pharyngeal suctioning prior to extubation Following extubation or discontinuation of ventilator/BiPAP: <input type="checkbox"/> Room air <input type="checkbox"/> O <sub>2</sub> at _____ liters/minute via _____ <input type="checkbox"/> Titrate to comfort
<b>**If patient has implanted defibrillator, notify Cardiac Cath Lab for deactivation prior to extubation (may also use magnet to deactivate)</b>
5. Nursing:
<input type="checkbox"/> Notify chaplain and social work/case manager of extubation date/time <input type="checkbox"/> Discontinue continuous monitoring just prior to extubation: <input type="checkbox"/> Cardiac <input type="checkbox"/> Pulse oximetry <input type="checkbox"/> Arterial line <input type="checkbox"/> Swan-Ganz catheter <input type="checkbox"/> Discontinue routine vital signs <input type="checkbox"/> Vital signs PRN per family request <input type="checkbox"/> Vital signs every _____ hours <input type="checkbox"/> Comfort level check and documentation every 15 min for the first hour after extubation and then every hour (pain, dyspnea, nausea, coping, fears, mental/spiritual status, etc.) <input type="checkbox"/> Discontinue sequential stockings <input type="checkbox"/> Place NG to suction <input type="checkbox"/> Discontinue NG/Dobhoff and remove tubing <input type="checkbox"/> Discontinue tube feeding and/or TPN <input type="checkbox"/> Wash face and hands, comb hair, put glasses on if available <input type="checkbox"/> Change top sheet and remove all soiled pads and linens
6. Current medications:
<input type="checkbox"/> Discontinue the following medications: _____ _____ _____ _____
7. Premedications: Give 15 min prior to extubation.
<input type="checkbox"/> Lorazepam (Ativan) _____ mg IV × 1 <input type="checkbox"/> Morphine sulfate _____ mg IV × 1
8. Opioids:
<input type="checkbox"/> Morphine sulfate _____ mg <input type="checkbox"/> IV or for pain or dyspnea
9. Anxiety:
<input type="checkbox"/> Lorazepam (Ativan) 1–2 mg IV every 15 min for anxiety/restlessness

(continued)

TABLE 26.5 Extubation Orders (*continued*)

10. Secretions:
Choose one:
<input type="checkbox"/> Scopolamine transdermally 1.5 mg patch(es); apply _____ patch(es) now and change every 72 hr <input type="checkbox"/> Hyoscyamine 0.125 mg orally/sublingually every _____ hour(s)
11. IV fluids:
<input type="checkbox"/> Change IV maintenance fluid rate to TKO <input type="checkbox"/> Discontinue IV fluids <input type="checkbox"/> Other: _____
12. If patient is in critical care unit and survives postextubation/discontinuation of ventilator/BiPAP for greater than 2 hr, notify palliative care team and arrange transfer to palliative care unit.
13. Notification:
<input type="checkbox"/> Notify attending and all consultants of change in plan of care.

NG, nasogastric; TPN, total parenteral nutrition; TKO, to keep open.

confines of cultural, personal, and religious practices, the family can be invited to touch or hold the person's body and to take the time they need. This time spent with the deceased can help to promote the transition from acute grief to a new stage of the grieving process (Ferrell et al., 1999; Pattison, 2008). Accepting the reality of the death is considered one of the first tasks of mourning necessary for working through the grief (Worden, 1992). Seeing the dead body helps the bereaved see the reality of the death and to say good-bye. The body should not be transported to the morgue or mortuary until the family is prepared and they have given their permission. The family's wishes should be respected regarding their presence during the removal of the body (Beattie, 2006).

When the family has given permission for the body to be moved, the nurse should follow the institutional protocol regarding shrouding the body. If a person has died at home and it is an expected death, the undertaker is called and they remove the body as it is. In a hospital or nursing home setting, the body is wrapped in a shroud or body bag. The shroud should be secured with safety pins or ties and a second identification tag attached to the shroud or body bag. The body is then taken to the morgue (Beattie, 2006; Sorrentino, 1999).

The nurse can offer help with making personal phone calls to give the family time to become accustomed to the immediate loss. The physician should be notified of the death and the nurse should be certain to follow agency protocol regarding the removal of medications and equipment. If the family wishes, support from their clergy or bereavement professionals can be offered.

In many states, the nurse can sign the death certificate if the death occurs in the hospital or nursing home or at the family home if hospice is involved. Once the death certificate is signed, the family can contact the mortuary and the body can be transported to the funeral home or crematorium. If the nurse or physician is unwilling to sign the death certificate because of a suspicious nature of the death, the medical examiner is called and he or she assumes responsibility for the body (Iserson, 2001). If the death is sudden and unexpected or if it occurs at home, the medical examiner must be notified and he or she will decide if an autopsy is required.

The next of kin may request an autopsy even if the medical examiner declines to do one. The nurse should be available to educate the family about the autopsy and assist them in their decision-making process. An autopsy will help determine the cause of death but the family may be charged a fee for this service (as much as \$2,000). Autopsies also serve other purposes, as shown in Table 26.6.

The word autopsy comes from the Greek *autopsia*, which means seeing with one's own eyes. Pathologists, who are physicians who have specialized in human anatomy, perform them. Organs are removed and inspected, and body fluids are analyzed. There are three degrees of autopsy: complete, limited, and selective. A complete autopsy exposes all body cavities (including the head) for examination; limited autopsy usually excludes the head; and selective autopsy involves examination of only one or more organs specific to the nature of the illness (Iserson, 2001).

If the deceased has requested that his or her organs be donated, the nurse is often the person responsible



**TABLE 26.6 The Benefits of Autopsies**

■ Discover new or elucidate uncommon diseases
■ Help explain unknown or unanticipated medical complications
■ Assist in the development and quality assurance of technology, procedures, and therapies
■ Help educate medical students and help continue physician education
■ A source of organs and tissues for medical and scientific purposes
■ Classify and help explain sudden, unexpected, and/or unnatural deaths
■ Identify infectious and contagious diseases
■ Identify and help monitor occupational and environmental health hazards
■ Help with quality control and risk assessment in hospital practices
■ Provide materials and hypotheses for research
■ Help improve accuracy and usefulness of vital statistics
■ Assist in the grieving process
■ Provide a vehicle for organ or tissue contribution
■ Help discover contagious diseases within the family
■ Assist in genetic counseling and identification of family health risks
■ Provide information for insurance/death benefits

Source: Adapted from Iserson, 2001.

for notifying the proper agencies for organ and tissue harvesting. Organ donation is the practice of giving a part of the deceased body for transplantation into another person. Persons designate this wish to donate organs by signing the back of their driver's license, indicating their preferences; by specifying organ donation in an advance directive; or by filling out an organ donor card. Organ donor cards can be ordered from the United Network for Organ Sharing (UNOS; 804-782-4800 or [www.unos.org](http://www.unos.org)). Persons younger than 18 years of age generally must have the consent of parents or guardians to sign an organ donor card. The Anatomical Gift Act of 2006 has been adopted by many states. Specifics of the act can be found at [http://uniformlaws.org/Act.aspx?title=Anatomical+Gift+Act+\(2006\)](http://uniformlaws.org/Act.aspx?title=Anatomical+Gift+Act+(2006)). Some states will record the intent to donate an organ in a donor registry, which is a central repository of information regarding the intent to donate. When a potential donor is identified, the

donor registry is contacted to determine the person's intent (Office of the Inspector General, 2002). Complete information on organ donation and times required for specific organ removal can be found at the *Organ Procurement and Transplantation Network* (OPTN) web page at [optn.transplant.hrsa.gov](http://optn.transplant.hrsa.gov) (OPTN, 2013). Based on data retrieved in June 2013, the OPTN indicates that there are more than 110,000 individuals registered for transplants in the United States. Depending on what organ is being donated, the time for organ removal varies.

Once the organs are removed from the body, it is ready for embalming or cremation. Embalming is the process by which the corpse is preserved and prepared for viewing; it is common for health reasons and protects mourners from being in the presence of a decaying body, but is not legally required, even if it is to be viewed (Shannon, 2006). "Basically, the embalmer is a creator of illusions—of pleasant illusions which banish the traces of suffering and death and present the deceased in an attitude of normal, restful sleep. In the practice of embalming this illusion is called a 'memory picture'" (Strub & Frederick, 1967, p. 133). There are four embalming methods that all involve the injection of chemicals to preserve the body. Arterial embalming injects the chemicals into the blood vessels; cavity embalming injects the chest and abdomen; hypodermic embalming injects under the skin; and surface embalming is the application of chemicals in gel or liquid form to the body surface (Iserson, 2001; Mayer & Taylor, 2005). The size of the body, age, water content, temperature, decomposition, condition of the body's blood vessels, and pre-mortem medication regime (e.g., gentamycin inactivates embalming fluid) will dictate the types, solution strengths, and injection rates of the embalming chemicals.

Primarily formaldehyde and methyl alcohol are used as preservative chemicals because they change the cell proteins to prevent putrefaction. Embalmers inject these chemicals into the body using a centrifugal pump that pushes the fluids into the body with 5 to 10 psi of pressure. At the same time, blood and fluid are drained from the body by gravity or electrical aspirators. The embalmer will look for evidence that the chemicals have reached the hands and face and facilitate this process by massaging and repositioning the corpse. When the embalming fluid reaches the hands, they are placed in their final position over the chest or abdomen and the fingers are held together by using cyanoacrylate (e.g., Super-Glue). The muscles will gradually harden over the 8- to 12-hour period following the embalming; once they are set, the body's position will not be able to be moved.

If there is going to be a viewing at the funeral home, the body is prepared with the use of cosmetics.

The hair is styled and the deceased is dressed. The body is then “casketed” in the coffin; typically, the right shoulder is lower than the left so the body does not look like it is flat on its back. Cost of these services is approximately \$8,000 with prices increasing depending on the type of casket purchased.

Cremation is a popular, less-expensive (approximately \$3,000) alternative to embalming and burial that dates back to prehistoric times. Our primitive ancestors believed they could return to their bodies and harm the living and therefore feared the dead; destroying the corpse removed that danger. Ancient civilizations believed that cremation would provide the dead with heat and warmth in the next world and protected the body from mutilation by animals or other humans. Native Americans believe that souls are conveyed to paradise by means of fire.

Cremation is a process to reduce the “corpse and its container to ashes and small bone fragments” (Iserson, 2001, p. 236). The first crematory was built in the United States in 1876 in Pennsylvania. At that time, decomposing bodies were leaking into the water systems and the thought was that there could be a more sanitary way to manage the dead.

Temperatures between 1,400°F and 1,800°F are used to burn the body, which evaporates water (70%–80% of nonbone tissue), burns soft tissue, and reduces the average-sized adult to 4 to 8 pounds of ash (cremains). It takes about 2 to 3 hours to cremate a body and what is left are grey ash and bone fragments. The cremains are then processed through an electric grinder to pulverize the bone fragments into an even consistency.

Prosthetic devices do not burn (e.g., dental gold, metal plates, and screws) and are removed with a magnet from the ashes. Pacemakers with lithium batteries will explode when burned and are removed before cremation. The body does not have to be embalmed before cremation nor does the family need to purchase a coffin. The only requirement is that the body be burned in a combustible container (e.g., cardboard or particleboard). Typically, there is a 24- to 48-hour waiting period after the death before cremation can legally take place.

Crematories are the facilities that contain the oven or retorts where the cremation will take place. It is becoming increasingly common for funeral homes to build crematories on the site and to offer a wide range of disposal options. There are no local, state, or federal laws that require a body to be cremated in a casket, but some facilities may require a container of some sort (Harris, 2007). Cremation has become increasingly popular this century; the highest cremation rate is in the state of Oregon (70%).

A newer method of cremation (available since 2003) is water-based cremation called alkaline hydrolysis,

which was originally used by the Mayo Clinic as an environmentally friendly way to dispose of bodies that had been used for research. This cremation process takes place in a Resomator, a stainless-steel chamber that holds a combination of water, potassium hydroxide, and heat. The Resomator dissolves the body to white fragments that are then pulverized into a fine powder and the water waste is discarded into the wastewater treatment system. The cost is approximately the same as cremation by fire.

Some cemeteries will have a columbarium for the interment of the urn containing the cremains. Memorial gardens are also available for the ashes to be scattered or buried and give visitors a place to visit or place a marker. Some people will divide the cremains to bury, scatter, keep in an urn, share among family members, or even wear in specially designed jewelry. The cremains can be made into a diamond or sent up in a rocket.

## ■ PERI-DEATH RELIGIOUS AND CULTURAL RITUALS

Nursing care does not stop when a patient dies. There is tremendous variability around the world regarding the care of dead bodies and funeral practices. In India, there are funeral pyres; there are second burial rites by Indonesian hill tribes; and there is a pervasiveness of embalming practices in the United States (Quested & Rudge, 2003). Throughout the dying process, and particularly at the very EOL, the nurse must be aware of cultural and religious values, practices, and traditions of the patient and the family. Customs and rituals have tremendous significance in the healing process following death, and the grief response is often structured by these rituals. The nurse’s role is to help the family carry out the rites and practices that provide solace and support. The nurse should be open-minded and understanding of the physical, psychosocial, and spiritual needs of the dying patient and his or her family and offer them respect and privacy (Purnell & Paulanka, 2008).

Rituals and customs vary based on a person’s faith background or culture. For those of the Roman Catholic faith, priests will offer the Sacrament of the Anointing of the Sick, which in the past was called Extreme Unction or the Last Rites. The sacrament is for those who are seriously ill. The family, friends, and priest gather at the bedside to pray for healing. If it is God’s will that the person not recover from his or her illness, then the prayer is that God will accompany the dying person toward the rewards of heaven (Green & Green, 2006; Miller, 1993). The nurse can ask the family if they would like the priest to be called. The priest would hear the patient’s



confession of sins, absolve the individual, and offer the Sacrament of the Sick. The comfort this ritual can bring to the dying Catholic and his or her family cannot be underestimated.

The preference of the Catholic Church is that the body of the deceased be present for the funeral rites; masses with cremated remains present can be performed. When cremated remains are present, they must be contained in a “worthy vessel,” placed on a table, or in the place normally occupied by the casket, and must be covered with a pall, that is, a heavy drape or cloth. The prayer of committal would read “earthly remains” in place of “body” (Archdiocese of San Antonio, 2002; Green & Green, 2006).

Catholic burial practice calls for the cremains to be buried in an urn within a consecrated grave or placed inside a mausoleum. Keeping ashes at home or scattering them on land or sea, even where legal, is inappropriate to the Church’s deep reverence for the body as a place where the soul has resided (Jacquet, 2013). The Catholic Church recommends burial or inurnment (placing the cremains in an urn) in a Catholic cemetery. Throughout the history of the Church, the Catholic cemetery has served as a visible sign of the faith community: a statement of continued belief in that everlasting life, even in death (Archdiocese of Chicago, 2008).

In the Church of Jesus Christ of Latter-Day Saints (Mormons), church members of the same gender who have permission to be admitted into the temple are the ones who dress deceased members. The body is dressed in white undergarments that are covered by a robe, cap, and apron. Prior to burial, a white cap is placed on a deceased man, and a deceased woman’s face is veiled (Green & Green, 2006; Iserson, 2001).

A Hindu who is dying may also request holy rites before death; readings and hymns from holy books are also comforting. Some may wish to lie on the floor to symbolize their closeness to the earth. A Hindu priest would administer the holy rites, which may include tying a thread around the wrists or neck of the dying person, sprinkling blessed water from the Ganges, or placing a sacred *tulsi* leaf in the dying person’s mouth. Some Hindus may wish to return to India to die, especially to the holy city of Banaras. Many believe that to die in Banaras ensures a rebirth in heaven or even a release from continued rebirth. At a minimum, a Hindu will request to die at home because death in the hospital is very distressing. Only another Hindu should touch the dead body; if it is necessary for a non-Hindu to touch it, disposable gloves should be worn. Sacred threads, jewelry, and other religious objects should not be removed. The body should not be washed but only wrapped in a plain sheet. Washing of the body is a part of the funeral rite

and is typically carried out only by family members; a mixture of milk and yogurt is used to cleanse the body. In India, a funeral takes place within 24 hours; adult Hindus are cremated, although young children and infants may be buried (Green, 1989a, 1989b, 1989c; Green & Green, 2006).

The dying person of the Muslim faith may wish to lie or sit facing Mecca. If it is possible, the bed should be positioned to accommodate this wish. Those of Islamic faith believe the body belongs to God, so reasons for autopsies must be clear and legitimate. Likewise, organ donation and cremation are not acceptable. In Iran, embalming is not practiced, and a person is immediately placed in a casket if he or she has died during the day. If death occurs at night, a copy of the Qur’an should be placed on the chest of the deceased and a lighted candle at the head (Iserson, 2001; Purnell & Paulanka, 2008); the body is watched during the night by a person reading the Qur’an (Green, 1989d).

Following the death, non-Muslims should wear gloves when touching the body. If there is no family available to carry out postmortem care, the nurse should wear gloves in administering care of the body. However, the body is not washed and hair and nails are not cut; the eyes are closed. According to Green and Green (2006), the normal Muslim procedure is that the body is straightened immediately after death. This is done by flexing the elbows, shoulders, knees, and hips first, before straightening them. This is thought to ensure that the body does not stiffen, thus facilitating its washing and shrouding. Turn the head toward the right shoulder. This is so the body can be buried with the face toward Mecca.

The body is then covered with a sheet that cloaks the whole body until a Muslim is available to perform the ritual bath. The ritual bath includes washing the body three times, first with lotus water, and then camphor water, and last with plain water (Iserson, 2001). This bathing is done from head to toe and front to back. All body orifices are closed and packed with cotton (to prevent body-fluid leakage that is considered unclean). Prayers from the Qur’an are read (especially verses of hope and acceptance) and the body is wrapped in a special cotton shroud. This shroud is made from three pieces of white unsewn cloth, 9 yards long, which are wrapped above, below, and around the midsection. Muslims are buried in a brick- or cement-lined grave with the head facing east toward Mecca. In Iran, the body is buried directly in the earth with the shroud removed from the face and one side of the face turned to be in contact with the earth (Purnell & Paulanka, 2008).

When those of the Jewish faith are dying, they may want to hear or recite special prayers, such as the *Shema*, which confirms one’s belief in one God;

or psalms, in particular Psalm 23 ("The Lord is my Shepherd"). Jews also have a personal confession prayer called *Viddui*, which is said by the dying person or by another individual when death is imminent (Purnell & Paulanka, 2008). Observant Jews are often buried in shrouds called *takhrikhim*. These are plain white cotton garments that are generally hand-sewn and made without buttons, zippers, or fasteners of any kind and cover the entire body (Hill & Daniels, 2007).

The person may also wish to hold the written prayer in his or her hand (Green, 1989e). A relative remains with the dying person to ensure the soul does not leave the body when she or he is alone; it is a sign of disrespect to leave the body alone. Even after death, the body is not left alone until the funeral, so that the body is not left defenseless (Purnell & Paulanka, 2008). The eyes should be closed after death, preferably by a child of the deceased; the body should be covered and left untouched (Green, 1989e). Autopsies are not permitted, although organ transplants are. The body should be handled as little as possible by non-Jews, and burial should take place within 24 hours. Burial is usually only delayed for the Sabbath. Embalming and cosmetics are not part of traditional practice. Orthodox Jews are always buried, although Jews who are more liberal may select cremation. The body is wrapped in a shroud and a prayer shawl. The casket is made of wood, so that the body and the casket decay at the same rate. There is no wake or viewing of the body. At the funeral, the *Kaddish*, the *prayer* for the dead, is said, which praises God and reaffirms faith (Purnell & Paulanka, 2008).

For those who are Buddhist, an important consideration is the state of mind at the time of death; dying thoughts and desires are crucial in determining the next rebirth of the deceased. A Buddhist monk or minister should be notified at the time of death to offer chant verses to the dead and the family. Buddhists may be cremated because Buddha was cremated (Purnell & Paulanka, 2008). The length of time between death and burial can vary between 3 and 7 days depending on the Buddhist tradition. Family members plan the burial; the tradition is to wear white to the funeral.

In terms of differences based on cultural backgrounds, Cuban Americans who are dying are usually attended by large groups of family and friends. Depending on their religious affiliation, a Catholic priest, Protestant minister, rabbi, or *santero* may be called to perform death rites. For followers of *santero*, these rites may include animal sacrifice, ceremonial displays, and chants (Purnell & Paulanka, 2008). After the death, candles are lit to light the path of the spirit to the afterlife. Burial is

the common custom although there is no restriction to cremation.

African Americans generally prefer to have people with terminal illness cared for in the home, but prefer death to occur in the hospital for fear of bad luck being brought to the home. Family members and extended family stay by the bedside of the dying patient as they believe God is ultimately in control of outcomes. Grief is expressed openly and publicly. Autopsy is acceptable, although organ donation is not typical. Death does not end the connection to the family (American Geriatrics Society, 2004; Purnell & Paulanka, 2008).

Mexican Americans may take turns sitting vigil over the dying person; dying in a hospital is not desirable because the spirit may become lost. Spiritual amulets, rosary beads, or other religious artifacts are kept near the patient. Typically, organ donation or autopsy is not allowed. When death occurs, family and friends will often come long distances for the funeral. A *velorio* is a festive watch of the deceased body before burial. Traditional families may exhibit hyperkinetic shaking and seizure-like activity called *ataque de nervios*, which is a way to release emotions related to grieving. The family may erect altars in their homes in honor of the anniversary of their relative's death and may include candles, decorations, and having the deceased's favorite meal at a graveside picnic (Purnell & Paulanka, 1998).

Native Americans have different traditions in each tribe. There is a belief that the spirit of the deceased remains where the person has died; therefore, family may not want the person to die at home. At the same time, it is considered inappropriate for the person to die alone. If the person dies at home, the house must be abandoned or a ceremony is held to cleanse it. Families gather together at the time of death and material possessions are dispersed. When a person dies, a cleansing ceremony is performed or else the spirit of the deceased may try to take over someone else's spirit. Those who work with the dead also must have a ceremonial cleansing to protect themselves from the dead person's spirit. No embalming is done; the deceased are buried in sacred ground with their shoes on the wrong feet, rings on their index fingers, and with many gifts surrounding them; or the body is cremated (Purnell & Paulanka, 2008).

For Appalachians, a death is an important event, even for extended family. The funeral is a significant social occasion and family and friends will come great distances to attend. The body is displayed for long periods of time so that all can see the body who wish to. The deceased is buried in his or her best clothes and some people have custom-made clothes



for burial. At the funeral home, personal possessions are displayed and it is common to bury these items with the person. Gravesites are typically on hillsides because of the fear they will be flooded out in low-lying areas (Purnell & Paulanka, 2008).

Subgroups from China, Vietnam, Laos, Thailand, and Burma together are called the Hmong. The Hmong believe that proper burial and worship of the dead and other ancestors directly affects the safety, health, and prosperity of the family. The belief is that the spiritual world coexists with the physical world and that the spirits are able to influence human life. The preference is to die at home because they believe their soul will wander for all of eternity without a resting place if they were to die elsewhere. Some groups believe that death should take place in the hospital so as not to bring bad luck into the home. Autopsy and cremation are acceptable practices to some families. For these groups, burial occurs in the afternoon.

The Chinese will place a coin in the deceased's mouth so that the deceased has money to pay anyone who interferes in the journey. Additionally, symbolic money may be burned to signify the transmission of wealth to the celestial bank, and has recently translated to burning symbolic paper items, which includes houses, cell phones, and cars (Chung & Wegars, 2005). In northern China, the body is placed in burial clothes, and an unpadded quilt is used as a shroud. The face is covered with cloth or paper and the feet are tied with colored string. The wife or oldest son wipes the eyes of the deceased with cotton floss before the coffin is closed. Instead of being buried immediately after the funeral, the body may be stored so that a husband and wife can be buried together (Iserson, 2001).

The Japanese bathe their dead, shave some of the hair, and dress the person in white. The deceased wears a ceremonial hat or triangular piece of white paper tied to the forehead and may also include white socks and white gloves. Special favorite items may be placed in the coffin (Green & Green, 2006). Koreans use perfume to wash the body and dress the body in silk or hemp clothes tied in seven places that correlate with the seven stars in the Ursa Major constellation (Iserson, 2001).

Literature related to Wiccans, Pagans, and Nature Spiritualists (WPNS) and EOL preferences is extremely limited. The passage from this life is generally referred to as "into the Summerland." It is important to include priests, priestesses, and death midwives in the dying process to provide herbal therapies and complementary care. In preparation for death, Pagans may perform rituals or prayers in a circle surrounding the patient. Individuals may sing, pray, or chant,

focusing energy on the patient. Alternative healing methods include the use of crystals and stones, Reiki, sound healing, massage, music, and color therapy. Generally, the patient's coven, priest, priestess, or chosen family member will administer last rites. The death midwife may help the family with cleansing, anointing, and dressing the body (Smith-Stoner & Young, 2007).

### ■ PERI-DEATH 3: FUNERALS AS A CEREMONY OF DEATH

Across cultures, people accept a responsibility to care for, respect, and honor their dead. The funeral can serve to dispose of the dead body, transmit the body to the afterlife, and enable the bereaved community and family to adjust to their new role in society (Brooks-Gordon, Ebete Haj, Herring, Johnson, & Richards, 2007). For most ethnic groups and religious groups, the process of physically preparing the body for the funeral and burial are handled by persons outside the family, but includes some form of preparation for the afterlife. The undertaker—a person who "undertook" the responsibility to keep the body safe and make the funeral arrangements—has been a part of society since ancient times. The general public interchangeably refers to the person who prepares the body for burial and conducts all aspects of the funeral service as the undertaker, mortician, embalmer, or funeral director (Green & Green, 2006; Iserson, 2001).

In modern society, funeral directors may coordinate all the details of the funeral for the family, but are also expected to manage the survivors' distress. They supervise preparation of the body for viewing or burial, oversee embalming procedures if embalming is desired, coordinate cremation planning, instruct and support the pallbearers, arrange the transportation of the family and the deceased to the cemetery, place death notices in the newspaper, and otherwise facilitate the family's burial decisions (Habenstein & Lamers, 2007; Iserson, 2001; National Funeral Directors Association [NFDA], 2008).

The funeral director may orchestrate all aspects of the funeral, but it is not mandated (NFDA, 2008). Those who work in the funeral industry know that the funeral must be perfectly organized and executed because they will not get a second chance to make things right. It was originally believed that the funeral held merely theological value, but for many people the funeral is one of the first steps of successful grieving. The funeral is "of the person who has died.... It is *for* those who survive" (Raether, 1993, p. 211).

For families that have a wake, this is the first component of postdeath ritual. It may be one of the few times the entire family will reassemble for an event. It is a time for family and friends to view the dead body and to pay their final respects. Seeing the dead body emphasizes the fact that the person is dead; declining to see the body may delay grieving. "I was recently again reminded of how valuable and legitimate a funeral service can be. I accompanied a friend to the funeral of his mother. She had died of a chronic and wasting illness and I had been present at her deathbed. My friend experienced a deep and profound consolation seeing his mother with the lines of suffering erased from her face and lying at peace" (Raether, 1993, p. 211).

The second component of postdeath rituals is the funeral. It is a ceremonial service typically consisting of music, prayers, poetry, eulogies, and it may be part of a funeral Mass where Communion is celebrated. Some people will plan their funerals before they die, which can be comforting to those who are dying as well as their families (Raether, 1993; Shannon, 2006).

The committal service is the concluding funeral rite. It is the final act of caring for the deceased and is celebrated at the grave, tomb, or crematorium and has seen little change during the past century. The changes that have occurred reflect compassion for the bereaved (Habenstein & Lamers, 2007). This service is a "symbolic demonstration that the kind of relationship which has existed between the mourner and the deceased is now at an end" (Raether, 1993, p. 212).

Seven specific therapeutic values have been assigned to the funeral process as delineated by Raether (1993, p. 209). First, the "therapy of direct expression" denotes that the funeral furnishes the setting and opportunity for the bereaved to express their grief physically. Funerals offer "therapy of language" by providing the bereaved an opportunity to talk about what has happened, voice their feelings, and begin to feel relief in the telling.

The "therapy of sharing" is the coming together of the family and significant others to provide emotional and physical support to each other. Time spent with the bereaved is an important aspect of burying the dead. Immersion in the many aspects of the funeral process also encompasses the "therapy of activity." The routine of greeting mourners at the funeral home or interacting with those who offer their sympathy prevents the bereaved from withdrawing and focuses their energy in the immediate postdeath period. The funeral also provides the "therapy of ceremony" that is both glorifying and ennobling. The liturgical aspect of the funeral ceremony encompasses the views of the

meaning of life and the nature of life hereafter. Given that accepting the reality of the death is difficult for many people, the "therapy of viewing" establishes a final and amended view of the deceased. This revised image replaces those composed during the illness or at the time of death and may bring comfort to the mourner. Finally, the "therapy of suffering" addresses the guilt that mourners may be experiencing and provides the occasion to verbalize what had been left unsaid previously.

Another important aspect of the postdeath experience for the bereaved is the formation of a new identity within their community. The role of widow, of no longer having a child, or of one who has lost a parent brings with it a change in how the bereaved interact and correspond to society at large. Social groups may shrink, volunteer opportunities may be lost, and favorite activities may be forfeited due to the loss of the deceased. Nurses need to be aware of the difficulties inherent in these role shifts and offer alternatives and community-support referrals during this transitional stage.

## Analyses of the Peri-Death Experience

As with any application of the nursing process, the nurse should evaluate the effectiveness of the interventions that have been utilized. In the case of peri-death nursing, there is no way to obtain objective data from the older adult who has just died to determine the efficacy of care. Although family members can be surveyed regarding their experiences, they can truly only report their perceptions as viewed through their own lens. In reality, guilt, remorse, or grief may cloud this lens.

Ternstedt, Andershed, Eriksson, and Johansson (2002) propose seven questions that the nurse can use to perform a retrospective analysis of the quality of patient care given at the EOL. These questions are:

1. Did the patient receive adequate symptom relief and was the care adequate?
2. Could the patient make his or her own decisions during the final phase of his or her life?
3. Could the patient maintain important social relationships to the end of his or her life?
4. Could the patient maintain an acceptable self-image and feeling of personal worth during the final phase of his or her life?
5. Were there signs of conflict resolution and did the patient sum up his or her life?
6. Did the patient accept the fact that death was near, or did he or she struggle against death?



7. Did the patient have a very good death? A good death? A bad death? (Ternstedt et al., 2002, p. 157)

These questions should be asked by the health care practitioners after each person has died to attain knowledge about the care of dying older adults and determine areas where improvement can be made.

## ■ CONCLUSION

When the nurse is providing EOL care, the focus of care is the patient and his or her family. Family-

centered care continues after the death of the patient. The goal of postdeath nursing care is to promote optimal adjustment and to help the family and significant others with the tasks of bereavement (see Chapter 10). Bereavement is an important developmental stage; the nurse should provide interventions that offer the opportunity for healing and growth, a redefinition of self, and opportunities to make new plans. Follow-up with the family is important during the bereavement period. The nurse should encourage memorial rituals commemorating the deceased's life and death. Unique opportunities exist in peri-death nursing to support the dying patient and the patient's family in making what is a painful and difficult process one that is also priceless.

## CASE STUDY Conclusion

After I assessed Mr. Clement, I spoke with the family and discovered his wife had died suddenly of pulmonary emboli. He had been diagnosed with dementia prior to her death, but she had not shared that with her children. For them, his declining health lasted only 18 months, with the most recent decline occurring within the past 5 days. Each of his children, as well as other family members, had fond and funny stories. His humor was dry, but his laughter, contagious. They were happy with the decision to not prolong life with additional interventions. Mr. Clement died the next day and the family called to say thank you after his death, though I had done little in their journey to his death.

## Evidence-Based Practice

Walling, A. M., Fineberg, I. C., Brown-Saltzman, K., & Wenger, N. S. (2011). An interdisciplinary program to improve knowledge and attitudes about an end-of-life symptom management protocol. *Journal of Hospice and Palliative Nursing*, 5(13), 309–315.

### Objectives

Development and implementation of “a practical, targeted, interdisciplinary, and interactive intervention to change the attitudes of clinicians working in the inpatient setting to improve knowledge in using a palliative care order set for dying inpatients during a period when the institution had limited access to formal palliative care consultation” (Walling, Fineberg, Brown-Saltzman, & Wenger, 2011, p. 310).

### Methods

“The educational program was developed as part of the dissemination plan for the end-stage symptom management order (ESMO) protocol, an order set designed to help guide clinicians without palliative care specialty training in their care of dying inpatients. The educational program aimed to be practical and brief, fitting into the inpatient setting's continuing education framework” (Walling et al., 2011, p. 310).

### Setting

A nurse, social worker, and physician working together within a hospital environment developed a practicum for decision making, family discussion, and order writing.

### Participants

There were 297 clinicians of multiple faiths, including nurses, attending physicians, residents, social workers, spiritual care workers, respiratory, and others.

### Measurements

“Knowledge questions were asked about clinical and patient issues related to use of the ESMO protocol. Seven core knowledge items were summed into an index with a score range of 0–7, the higher score indicating greater levels of knowledge. The second set of knowledge items tested understanding of the goals of the ESMO protocol. Clinician’s attitudes toward caring for dying patients were explored by asking about their comfort with caring for dying patients and the use of opiates at the end of life” (Walling et al., 2011, p. 311).

### Results

“All clinicians reported that they found the educational program to be at least ‘somewhat helpful’ and 85% of clinicians found the program to be ‘very helpful.’ Knowledge regarding use of the ESMO protocol improved after the educational intervention. The 7-item knowledge index increased from a mean of 5.2 before the intervention to 5.8 afterward ( $p < .001$ ). After the educational program, more clinicians correctly reported that a no-CPR order must be in place to implement the ESMO protocol (86% pre vs. 97% post:  $p < .001$ )” (Walling et al., 2011, p. 311). Knowledge and attitudes improved across all disciplines (p. 312).

### Conclusions

“This study shows that a practical, targeted, interdisciplinary, and interactive educational program can increase knowledge and improve attitudes of clinicians concerning use of an EOL symptom management protocol. This is important because prior work has shown that inadequate knowledge and misconceptions of EOL treatment are important barriers to adequate palliation” (Walling et al., 2011, p. 313).

## Evidence-Based Practice

Bailey, F. A., Williams, B. R., Goode, P. S., Woodby, L. L., Redden, D. T., Johnson I., ...Burgio, K. L. (2012). Opioid pain medication orders and administration in the last days of life. *Journal of Pain and Symptom Management*, 44(5), 681–691.

### Objectives

“To describe baseline pain management practices for imminently dying patients in Veterans Administration Medical Centers (VAMCs) and examine factors associated with these processes, including presence of opioid orders at the time of death and



medication administration in the last seven days, 48 hours, and 24 hours of life" (Bailey et al., 2012, p. 681).

### Methods, Settings, and Participants

"Data on orders and administration of opioid pain medication at the end of life were abstracted from the medical records of veterans who died in six VAMC hospitals in 2005" (Bailey et al., 2012, p. 681).

### Results

"Of 1068 patient records, 686 (64.2%) had an active order for an opioid medication at the time of death. Of these, 69.8% of patients had received the medication at some time within the last seven days of life, 61.2% within the last 48 hours, and 47.0% within the last 24 hours. In multivariable models, presence of an order for opioid pain medication at the time of death and administration within the last 24 hours were both significantly associated with having a Do Not Resuscitate (DNR) order ( $p < 0.0001/0.0002$ ), terminal condition ( $p < 0.0001/0.0001$ ), family presence ( $p < 0.0001/0.0023$ ), location of death ( $p = 0.003/0.0005$ ), and having pain noted in the care plan ( $p = 0.0073/0.0007$ )" (Bailey et al., 2012, p. 681).

### Conclusions

"Findings indicate a need for improving availability of opioids for end-of-life care in the inpatient setting. Modifiable factors, such as family presence and goals-of-care discussions, suggest potential targets for intervention to improve recognition of the dying process and proactive planning for pain control" (Bailey et al., 2012, p. 681).

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## ■ APPENDIX 1: SYMPTOM RELIEF KIT

### INFORMATION FOR HEALTH CARE PROVIDER:

- For *pain or dyspnea*: Morphine solution: 0.25 to 0.5 mL (20 mg/mL solution) PO/SL q 2 PRN. May increase up to 1 to 2 mL q 1 to 2 hours, PRN as directed by the health care provider.
- For loud, *wet respirations or excessive secretions*: Hyoscyamine (Levsin) 0.125 mg (one to two tablets) PO/SL q 6 hours PRN.
- For *unrelieved respiratory fluid accumulation*: Furosemide (Lasix) 40 mg IV/IM/PO/SC. May repeat.
- For *nausea or vomiting*: Prochlorperazine 25 mg suppository PR q 8 hours PRN. If not effective, give ABH<sup>a</sup> suppository PR q 8 hours PRN.
- For severe agitation or restlessness:
  - If client is in pain, treat accordingly
  - If client is constipated or having urinary retention, take appropriate action
  - If agitation persists, administer Pentobarbital suppository PR q 6 hours PRN.
- **Liquid morphine**: For pain or difficulty breathing. Given by mouth.
- Four kinds of suppositories in four differently labeled bags:
  - **Prochlorperazine** (the active ingredient in Compazine): For nausea with or without vomiting.
  - **ABH** (stands for Ativan, Benadryl, and Haldol): For severe nausea and vomiting. May also be used if the patient is very restless or anxious; may cause the patient to become very sleepy.
  - **Pentobarbital**: For severe agitation or seizures; will make the patient very sleepy.
  - **Acetaminophen**: For high fevers.
- **Levsin tablets**: For noisy, wet, “gurgly” breathing sounds. Can help to dry up secretions.
- **Furosemide (Lasix)**: For severe difficulty breathing because of fluid build up. The nurse will visit and give this medicine to the patient if you have not been taught how to give “shots.”

### INFORMATION FOR PATIENTS AND FAMILIES

The Symptom Relief Kit is designed to help you cope with physical problems that might unexpectedly arise. If you feel that you need to use this kit, call the hospice nurse first.

Symptom	Drug	How to Use It
Unrelieved pain	Morphine solution	1–2 mL in the mouth, under the tongue, every 2–3 hr as needed.
Unrelieved shortness of breath	Morphine solution	0.25–0.5 mL in the mouth, under the tongue, every 2 hr as needed.
Nausea and vomiting	Prochlorperazine suppository	One suppository inserted into the rectum every 8 hr as needed.
Unrelieved nausea and vomiting or restlessness and anxiety	ABH suppository	One suppository inserted into the rectum every 8 hr as needed.
Severe agitation and restlessness	Pentobarbital suppository	One suppository inserted into the rectum every 4–6 hr as needed.
Wet, “gurgly” breathing	Levsin tablets	One or two in the mouth or under the tongue every 4–6 hr as needed.
Unrelieved accumulation and respiratory distress	Furosemide injection	Inject 40–80 mg as instructed by the nurse.
Fever	Acetaminophen suppository	One suppository inserted into the rectum every 4 hr as needed.

Note: Clients taking opioids for pain will need to increase their usual morphine dose (for breakthrough pain) for effective treatment of dyspnea.

<sup>a</sup>ABH suppository: Ativan (Lorazepam), Benadryl (Diphenhydramine), and Haldol (Haloperidol). Reglan (Metoclopramide) may be added by the pharmacist for severe nausea/vomiting; this would become an ABHR suppository.

Source: Adapted from the VNA Home Health and Hospice Services, Manchester, NH.



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# Palliative Care Nursing

FOURTH EDITION

## Quality Care to the End of Life

MARIANNE MATZO, PhD, APRN-CNP, FPCN, FAAN

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