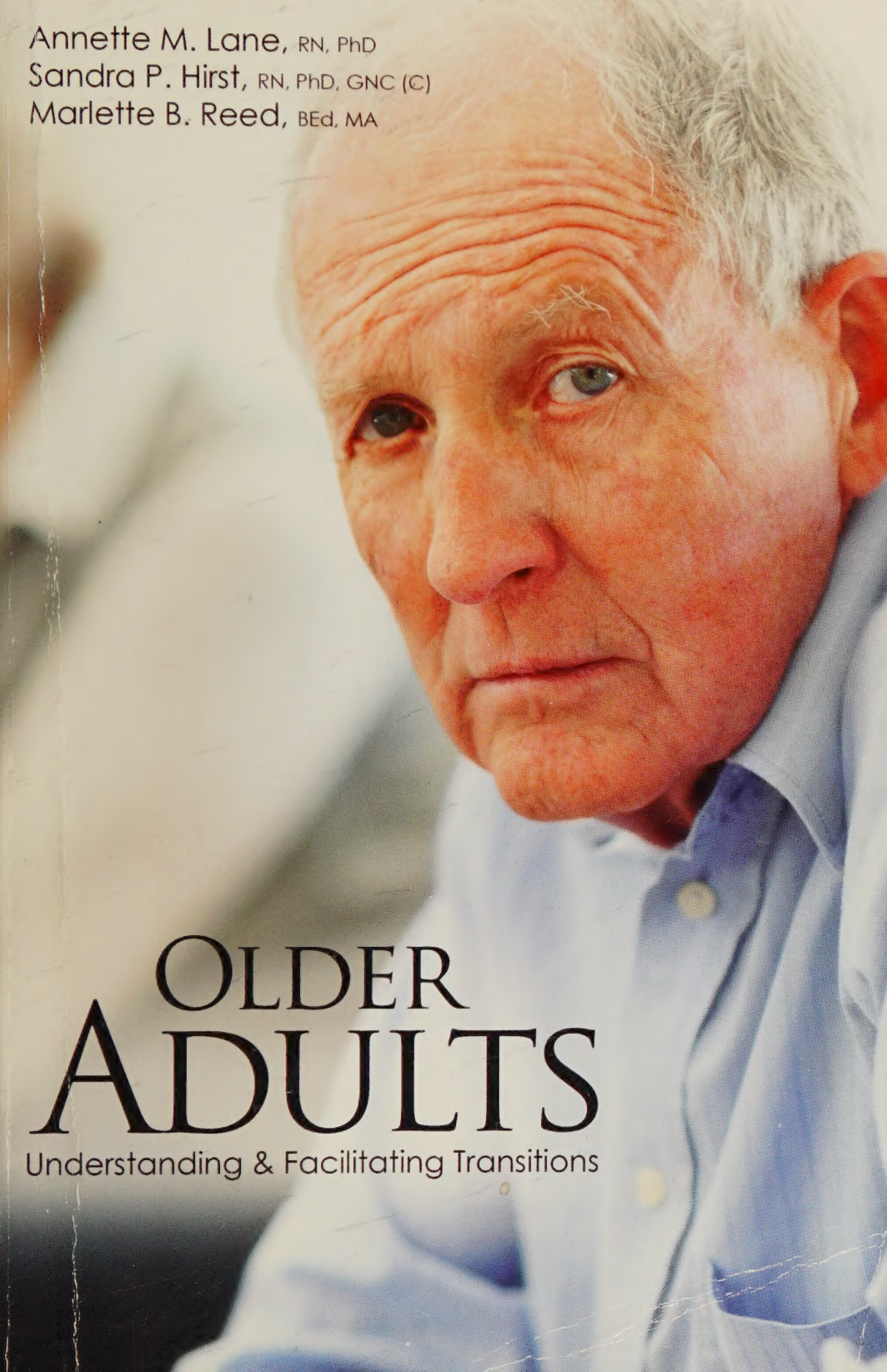
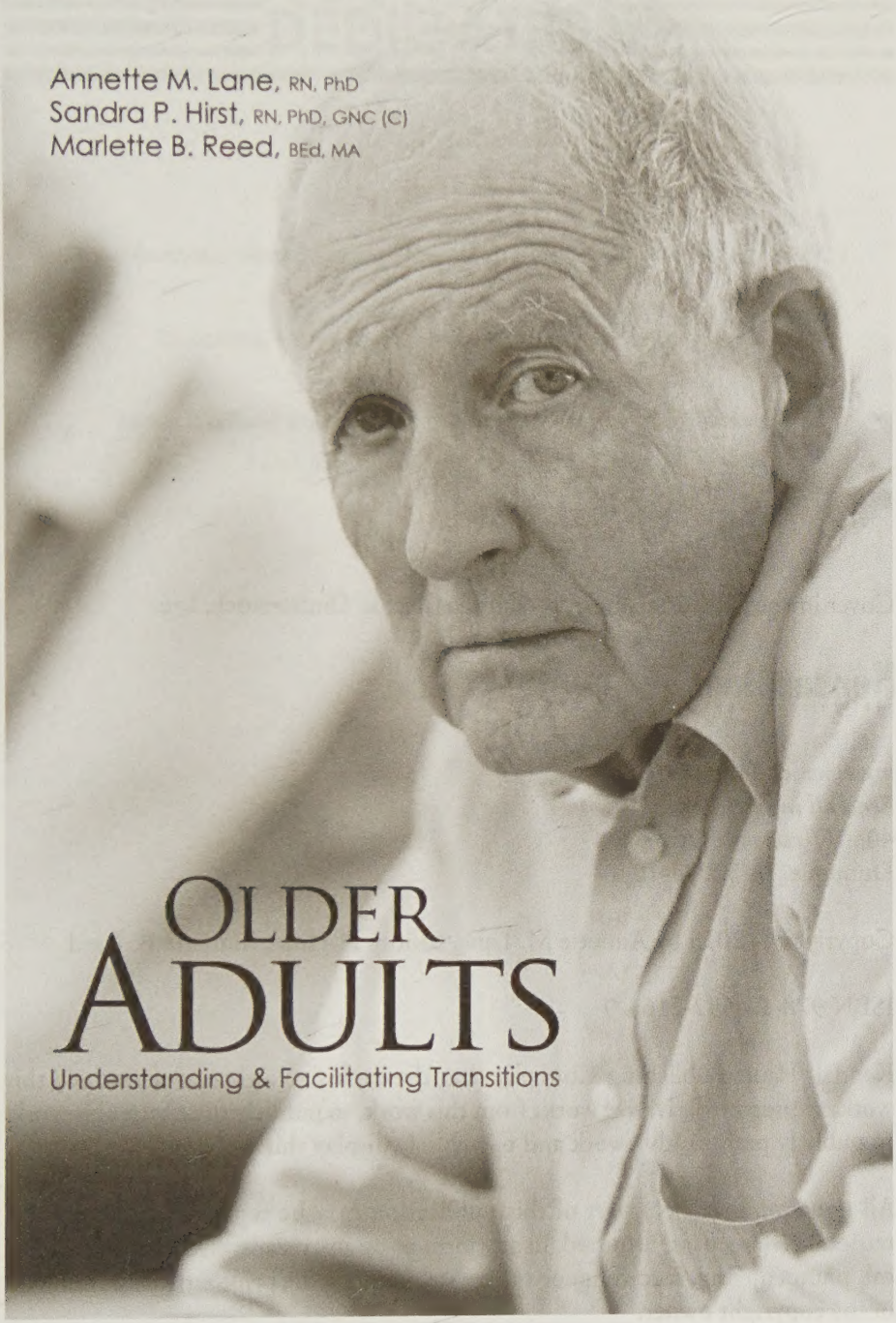
Annette M. Lane, RN, PhD
Sandra P. Hirst, RN, PhD, GNC (C)
Marlette B. Reed, BEd, MA



OLDER ADULTS

Understanding & Facilitating Transitions

Annette M. Lane, RN, PhD
Sandra P. Hirst, RN, PhD, GNC (C)
Marlette B. Reed, BEd, MA



Older Adults

Understanding & Facilitating Transitions

Kendall Hunt
publishing company

Cover image © Shutterstock. Used under license Shutterstock, Inc.

Kendall Hunt
publishing company

www.kendallhunt.com
Send all inquiries to:
4050 Westmark Drive
Dubuque, IA 52004-1840

Copyright © 2013 by Annette M. Lane, Sandra P. Hirst, Marlette B. Reed

ISBN 978-1-4652-2165-0

Kendall Hunt Publishing Company has the exclusive rights to reproduce this work, to prepare derivative works from this work, to publicly distribute this work, to publicly perform this work and to publicly display this work.

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted, in any form or by any means, electronic, mechanical, photocopying, recording, or otherwise, without the prior written permission of the copyright owner.

Printed in Canada
10 9 8 7 6 5 4 3 2

DEDICATION

To my husband, David R. Lane: You are the absolute love of my life (AML)

To Martin, Rebecca, and Brittany: Love is a voyage (SPH)

To my husband Brian and son Jonathan, the two men in my life:
I love you more than I could say (MBR)



Digitized by the Internet Archive
in 2022 with funding from
Kahle/Austin Foundation

https://archive.org/details/olderadultsunder0000lane

CONTENTS

Preface _____ *vii*

Chapter 1 Introduction _____ *1*

Our Changing Understanding of Human Transition *2*
How Transitions are Conceptualized *4*
Domains of Transition *6*
Coping with Transitions *17*
Factors That Influence the Transition Experience *18*
Assessment and Interventions during Transitions *22*

Chapter 2 Transitions and Older Adults: An Overview _____ *33*

Why this is an Important Topic *34*
What are the Transitions Faced by Older Adults? *37*
The Complexities of Transitions in Older Adulthood *41*
Underlying Assumptions in Working with Older Adults *44*
Challenges for Nurses and Other Professionals *47*

Chapter 3 Health Transitions in Older Adults _____ *63*

Physical Illness: Chronic *64*
Chronic or Persistent Pain *67*
Mental Illness *68*
Medication Usage and Addictions *73*
Frameworks within which to Understand Illness *75*
Assessment and Intervention *78*

Chapter 4 Housing Transitions _____ *91*

The Concept of Home *93*
Global Perspective *95*
Housing Options in Later Life *96*
Theory and Research That Underlies Our Understanding of Transitions *104*
Interventions to Promote Positive Transition Experiences *111*

Chapter 5 Existential Transitions _____ *122*

Development of Personhood *123*
Existential Transitions in Older Adults *127*

Interventions to Address Existential Issues in Older Adults *139*
Existential Work for Professionals *151*

Chapter 6 Death: The Final Transition *161*
Myths about Dying in Advancing Years *162*
Issues Related to Dying for Older Adults *169*
Issues for Family Members *183*
Ethical Issues *193*

Chapter 7 The Family *204*
Definition of the Family *205*
Developmental Tasks of an Aging Family *206*
Challenges in Working with the Family *207*
Principles in Assessment and Intervention with Families *224*

Chapter 8 Future Directions *237*
Education for Current and Future Health and Human Service Professionals *240*
Services in the Community *243*
Housing Options *253*
Support for Families (Caregivers) *265*
Advocacy: By Older Adults for Older Adults and the Vulnerable *265*

Afterword *275*

PREFACE

We all face transitions in life. Some are expected, others are not. Some transitions may be relatively smooth and painless, and others are extremely arduous. This can be in part due to the nature of the transition, but also, the ability of the individual to weather the situation.

Writing about transitions experienced by older adults has not been easy, perhaps in part, because of their enormous impact upon aging individuals. Transitions are complex, often one transition leads to several, transitions may evoke issues of meaning and purpose in life, and their impact affects families in challenging ways, including exacerbating old issues in how family members relate and problem-solve.

As such, we structured this text in such a way that each chapter builds upon the previous one. In the first chapter, we lay the foundation by discussing transitions in general: What are transitions and how are they conceptualized? What are some examples of transitions across the lifespan? What does the literature reveal about how children, adolescents, and adults progress through transitions? In Chapter 2, we address background information of why transitions are so difficult for older adults; in particular, we discuss demographic trends such as the aging of populations in developed countries, specific types of transitions faced by older adults, and we suggest why transitions can be so life changing for aging individuals. In Chapter 3, we discuss health transitions and how they impact the lives of older adults. We purposely focus on health transitions first, as they often precipitate other transitions, such as relocation to other living arrangements. Next, we concentrate on relocation transitions, including various options for older adults, as well as the impact of relocating upon aging adults. In Chapters 5 and 6, we discuss existential issues (those pertaining to meaning and purpose) and death and dying, respectively. If the reader is perusing various chapters out of order, we suggest that these chapters be read together, as existential issues related to transitions of life and dying/death often coincide. In Chapter 8, we offer future directions for research and practice that may assist older adults and their family members experiencing transitions.

In terms of technicalities, a few points about how the chapters are configured may be helpful to the reader. For some chapters, we have added a case example in order to illustrate the challenges of transitions, as well as how nurses and other professionals can assess and intervene. When we offer examples throughout the text (in addition to the case examples), we use pseudonyms to protect the identity of individuals. We also often change identifying information to further

ensure anonymity of the situations described. At times, we use the acronyms AML (Annette Lane), SPH (Sandra Hirst), and MBR (Marlette Reed) to refer to personal situations that one of us has encountered. These acronyms distinguish which author is referring to herself within the examples. We also use the term *nurses and other professionals* to refer to a wide range of professionals besides registered nurses, such as social workers, chaplains, therapists, psychologists, and occupational and recreational therapists.

We want to stress that the purpose of this text is to illustrate the complexities of transitions faced by older adults and their family members and to offer some ideas for nurses, social workers, chaplains, and other health and human service professionals in working with vulnerable aging individuals. This is not a medical/surgical nursing text, a psychiatric/mental health text, a book on religion, or a volume addressing ethics. If readers want to delve more into the various health problems described, glean specifics on how to conduct a suicide risk assessment, or access greater detail on religion or ethical principles, we encourage you to seek out appropriate references.

So how did we come to be interested in how older adults process and progress through transitions? Our interest in and commitment to working with older adults spans many years and many different sites, including community agencies, hospitals, and hospice. And, for two of us (AML and SPH), we have spent years teaching gerontological and mental health nursing to baccalaureate students. MBR is palliative care chaplain and has worked for years with dying individuals and their families across the lifespan, including older adults. Within our work, we have observed that transitions, including those related to health, relocations (moves), and dying and death, evoke strong reactions in older adults and may trigger issues related to meaning and purpose (also known as existential issues). They also can result in great fear, frustration, anger, pain, and grief in family members. Our work as professionals, as well as our experiences in helping parents who faced transitions, including dying and death, have sensitized us to the tremendous difficulties that older adults confront, often at their most vulnerable times of life.

Understanding how traumatic transitions can be for aging adults, we jumped at the chance to write this text. We have endeavored to write this book in a way that is pertinent not just for nurses, but for many health and human service professionals. It is a privilege to impart our experience and knowledge about working with older adults experiencing transitions and hope that this text is useful for students, as well as practicing professionals.

In closing, we wish to thank the team at Kendall-Hunt for their gracious support and guidance throughout this process. We are grateful for their ongoing assistance, as well as their expressed interest in the care and well-being of older adults.

Chapter 1

INTRODUCTION

Nothing is secure but life, transition, the energizing spirit.
(Ralph Waldo Emerson, American essayist and poet)
Not in his goals, but in his transitions is man great.
(Ralph Waldo Emerson)

Reflective Questions

- What is the experience of human transition?
- How do stages of the life course influence and shape the experience of transition for nurses and other healthcare and human service professionals?[1]
- How does the care transition process shape my professional role?

By their very nature, transitions are enigmatic. They are composed of multiple facets, may be expected or totally unexpected, may confuse or frighten some, but are critical in progressing successfully through life. While transitions are sometimes conceptualized as life's changes, they involve much more than that. They are those "in-between" stages that link the past to the future and determine that life will never be quite the same. However, the ability to navigate transitions depends upon more than the specifics of the various passages, but also is determined by the coping skills of the individuals negotiating them. And, as noted in the first cited quote from the American essayist Ralph Waldo Emerson, transitions are inescapable. Even if individuals try gamely to avoid transitions, by the very process of attempting to escape them, they will still be changed. In the second cited quote of Emerson, he hinted at what transitions require of persons, but also how transitions may reveal individuals' characteristics. In other words, transitions may require

[1] This book is intended for nurses and other health and human service professionals who work with older adults. This grouping of professionals includes registered nurses, social workers, psychologists, recreational and occupational therapists, chaplains, therapists, etc. Some of these professionals will work in healthcare contexts and others may work outside of these contexts, such as community chaplains or community therapists. As the usage of "nurses and other health and human service professionals" is cumbersome and can seem unwieldy, hereafter in this book, we will refer to this broad category of professionals as "nurses and other professionals."

much out of individuals and tax their coping abilities, and yet they also manifest the strength and mettle of those experiencing them.

Our main focus within this text is to examine the various transitions that older adults and their family members may face, as well as how nurses and other professionals can understand and facilitate these transitions. Because of the number and types of transitions encountered, as well as the degree of physical and mental health challenges experienced by some older adults, transitions can be particularly problematic in advancing years. Thus, the bulk of this text will entail an explication of the various transitions faced by aging individuals and their family members, as well as the big questions about meaning that arise from these transitions.

In order to set the context for this book, we begin with basic information about transitions within the first chapter. We address what transitions are and several frameworks within which to conceptualize them. We examine common life transitions across the life course and factors that facilitate and hinder movement through these passages. We then offer a case example and conclude with a brief discussion on interventions to assist individuals moving through transitions.

Within the subsequent chapters, we narrow our focus to transitions experienced by older adults. They include transitions related to physical and mental health challenges, moves from the family home to other facilities, existential issues (concerns about meaning and purpose in life) arising from advancing years, and death and dying. Understanding the importance of families in the transitional experiences of older adults, we have included a chapter on working with families. Finally, we conclude by contemplating future directions to help expand knowledge of the experience of transition. Specifically, we examine some important areas in practice, research, and policy that need development.

OUR CHANGING UNDERSTANDING OF HUMAN TRANSITION

Etymologically, the word transition is derived from the Latin *transitio(n-)*, *transire* "go across." As a noun, the word *transition* refers to the process or a period of changing from one state or condition to another; as an example, *the students were **in transition** from one program to another* (Oxford dictionary, http://oxforddictionaries.com). As a verb, it means "to undergo or cause to undergo a process or period of transition" (Oxford dictionary, http://oxforddictionaries.com). Using the above example, but as a verb rather than a noun, the example would be, *the students **transitioned** from one program to another.* A perusal of a thesaurus reveals no adequate synonym for the depth of meaning found in the word, as the explanation below will reveal. Hence, we will use the term *transition* consistently in this text—avoiding synonyms such as "alteration" or "change"

unless they appropriately convey our intent in representing that aspect of meaning in the word *transition.*

The term *transition* is used in diverse ways in the literature and is found in a number of disciplines, including molecular biology, sociology, anthropology, healthcare, and immigration planning. Within the literature, the word *transition* is used frequently to describe a process of change in life's developmental stages, or alterations in health and social circumstances, rather than individuals' responses to change. However, Bridges (2004) suggested that the term *transition* is not just another word for change, but rather connotes the psychological processes involved in *adapting to* the change event or disruption. Similarly, transitions may be described as the ongoing processes characterized by changes *for* individuals during which a new situation or circumstance is incorporated into their lives (Kralik, Visentin, & van Loon, 2006). As such, transitions are not just changes *per se*, or even changes that occur over time, but are processes that require individuals to incorporate new knowledge and change behaviors, thus resulting in an alteration in how individuals define themselves within the new context. Additionally, we posit that even when persons fail to confront the change event, such as commencing employment after post-secondary education, they are changed through the avoidance of the transition.

Transitions are often multiple and complex in nature; typically, they do not occur in isolation. Given the complexity and interrelatedness of transitions, individuals may experience different transitions simultaneously or experience transitions in rapid succession one after another, like a domino effect. This can greatly complicate how individuals process the transition; specifically, they may need to untangle what is the most pressing transition and how best to address it. Attending to even one transition can take time, however, as transitions may be lengthy when they involve a period of anticipation and movement over time through states of instability, confusion, and distress, and end with a period of stability (Meleis, Sawyer, Im, Messias, & Schumacher, 2000). The periods of instability and confusion are particularly unsettling. In his seminal work on transition, Bridges (1980) began his commentary with the following passage from *Alice in Wonderland:*

> "Who are you?" asked the caterpillar . . .
>
> "I – I hardly know, Sir, just at present." Alice replied rather shyly, "at least I know who I was when I got up this morning, but I think I must have changed several times since then." (Carroll, 1967, p. 47)

Through Alice, this quotation reveals how transitions can leave individuals feeling a disorienting state of flux; the change in circumstances results in individuals not knowing who they are. As noted by Bridges (1980), transitions leave individuals in a "confusing nowhere of in-betweenness" (p. 47).

While some transitions can be anticipated, others cannot be foreseen. These can occur suddenly and concurrently and can be confusing and traumatic to individuals and their families. In catastrophic situations, such as a major car accident that occur suddenly, individuals' lives can change abruptly and permanently, with no time to foresee or prepare for a new and different future. Health and functional abilities can be greatly compromised, affecting the ability of those injured to work and perform regular activities of daily living. These kinds of transitions can be especially challenging for persons to face, as life is forever changed in a brief moment, and individuals have not had time to prepare for an altered body image or to develop mechanisms by which they can cope with their new life circumstances.

HOW TRANSITIONS ARE CONCEPTUALIZED

Our understanding of transitions can be broadly categorized or organized into different frameworks. These frameworks include understanding transitions as specific types of changes (Meleis et al., 2000), transitions as involving not just events, but also individuals' responses to these events (Blair, 2000), as well as conceptualizing transitions through the lens of the life course perspective. Each of these frameworks can shed light on how transitions impact individuals, and why similar transitions can impact individuals very differently. As such, we briefly discuss each framework below.

Transitions as Types of Changes

Meleis and colleagues (2000) utilized an understanding of transitions that focuses on specific kinds of changes. Within this conceptualization, they identified four specific types of transitions. These transitions include health/illness transitions, developmental transitions, situational transitions, and organizational transitions. Health/illness transitions refer to changes in the health status of individuals; examples of this kind of transition include adapting to a chronic illness, returning home from hospitalization, or recovering from surgery. Developmental transitions occur due to standard or usual changes in developmental stages of life, such as adolescence, parenthood, or aging. Situational transitions pertain to environmental, contextual, and social changes, and examples include adjustments such as changing educational or professional roles, or undergoing alterations in family situations, such as a divorce. Organizational transitions reflect changes in leadership, policies, or organizational structures, affecting both personnel and clients of an organization (Meleis et al., 2000). An example may be a change in administrative personnel or the introduction of a new policy regarding sick leave. Conceptualizing transitions according to the aforementioned types has been used by numerous authors and researchers.

Transitions as Events and Individuals' Responses to the Events

Another framework for categorizing transitions focuses upon events, including their predictability, as well as individuals' sense of control of the events (Blair, 2000). Within this framework, four primary types of events/responses are outlined. First, there are transitions that are predictable-voluntary. In these situations, the event is predictable and under the control of individuals, for example, moving to another house. Second, the predictable-involuntary type refers to transitions that are predictable, but over which individuals have no control. Mandatory retirement is an example of this type of event; while retirement is predictable, the choice and control over when to end employment is removed. Third, individuals may experience a type of transition that is unpredictable-voluntary. In these situations, the event may not have been predicted, but individuals may choose how they respond, for example, whether to apply for or accept a new job opportunity. The fourth category is labeled unpredictable-involuntary. These events are not predictable and individuals do not have control or choice in the event. Accidents are examples of this kind of event. This framework describes transitions as more than events, but also as how individuals conceptualize these events and respond to them; it has a focus upon coping strategies that may be available, including advance planning, to gain a sense of control over the situation that the individual is undergoing (Blair, 2000).

Transitions within the Life Course Perspective

Another framework within which to conceptualize transitions is the life course perspective.[2] This perspective extends the element of time in considering transitions, and includes the interaction of individuals' lives, historical events and the interdependence of humans' lives (Hutchison, 2008). Traditionally, transitions were conceptualized as occurring with the onset of certain discrete events, such as the birth of a child, the first day of school, marriage, or retirement. As such, there were limitations in how long transitions lasted. Within the life course perspective, however, *current* transitions are located within the *larger historical context* of individuals' lives. Thus, transitional experiences in childhood and adolescence may impact how individuals face into transitions in the future. As an example, if an aging woman—Mary[3]—experienced childhood transitions in two orphanages as frightening and traumatic, she may feel a similar sense of dread and fear in an

[2] Glen Elder, a sociologist, was one of the first authors to write about a life course perspective (Hutchison, 2008).

[3] Mary is a pseudonym. All names within this text are pseudonyms. When examples are given that are based upon factual circumstances, details of the situations have been altered, as well as names, in order to protect the identity of individuals.

upcoming move to an assisted living facility. This feeling of foreboding may be present, even though this woman has chosen to move to the new accommodations and finds the residents friendly and the surroundings aesthetically pleasing. She may express pure befuddlement as to why she should feel so terrified by the move. The answer, in part, may be found within the life course perspective. When Mary was born (in the United Kingdom prior to 1950), she was considered "illegitimate," because her mother was not married. As Mary was not adopted into a family, she spent her first five years in an orphanage near her birth location. However, it was decided that the orphanage would be closed, and so at 7 years of age, Mary was relocated to another facility. At 14 years of age, she left the orphanage and spent several years working for various families in a nearby community. Although the first facility was not pleasant, she realized in hindsight that it was better than the subsequent orphanage. She never felt safe in her childhood, did not know who she could trust, and had little chance to make decisions or exercise some degree of choice.

Understanding Mary's previous transitional history sheds light on why the current transition is so difficult for her. Not only did her previous experiences of transitions impact her current sense of dread, but her past transitions were shaped by trends and practices of that historical era, such as placing children of unwed mothers into orphanages. The life course perspective also emphasizes the interdependence of individuals (Hutchison, 2008). Although Mary never knew her parents, her entire life history is inextricably tied to the parents she never knew, as the *lack of familial support* impacted how she formed relationships with others. Despite an emphasis on historical events and interdependence of human lives upon individuals' behaviors, the life course perspective also emphasizes human agency (Hutchison, 2008). Thus, within reason, Mary was able to make some choices when she left the orphanage, such as working hard all of her adult life and being responsible to others around her. Despite her childhood trauma, Mary has constructed her life as best as she could, and even now, is trying to exercise some good decision making in the current transition.

DOMAINS OF TRANSITION

In addition to the aforementioned frameworks within which to understand transitions, literature in this area covers specific domains within which transitions occur, irrespective of the framework used. The primary domains identified in the literature include age-specific stages, education, employment, marriage and parenthood, retirement, healthcare system, family caregiving, and death and dying. Within this chapter, we will not specifically address death and dying as a domain, because this will be explored in depth within Chapter 6 of this book.

Age-Specific Stages

Within the literature on age-specific stages, work is conducted on *normal* (expected) transitions as well as *traumatic* (unexpected) experiences within particular age groupings. The literature on expected transitions that involve age-specific stages address changes within the individual, such as the onset of menstruation, or changes in living circumstances, such as a move out of the parental home.

Expected Transitions

Literature on expected changes within age-specific stages commonly focuses on transitions particular to adolescence. This is understandable, because adolescence is a period in life marked by multiple transitions. Not only is this the stage in which biological changes transform a child into an adult, it is also a period of transition in terms of emotional development, growth in cognitive skills, and further development of social roles and personal identity (Kaufman, 2006). And, as many parents can attest to, it can be a stage in which adolescents express their need for personal growth and identity in ways that may be contrary to their parents' wishes.

Another age-specific expected transition involves the transition from adolescence into adulthood. Arnett (2004) described the transition to adulthood in Western society as involving processes of both exploration and identity consolidation. It is also a period marked by relative freedom from clearly defined roles and responsibilities. Beyond the physical, psychological, and spiritual growth that adolescents experience, they also gain some sense of who they are in relation to others within the world. These multiple transitions are inherently stressful, challenging the adolescent's ability to solve problems and cope (Rasmussen, Ward, Jenkins, King, & Dunning, 2011).

An age-specific transition that is expected in early adulthood involves the move out of the parents' home. With an assumption that adolescent transitions impact relationships between parents and children, a Dutch longitudinal study followed 1064 adolescents and young adults over a six-year period (Bucx & van Wel, 2008). The researchers found that adolescents reported a close bond with their parents; however, after leaving their parents' home, this bond weakened. The authors noted that their findings are consistent with theories about individualization, whereby the need for autonomy in young adult children causes some distancing in the parent–child relationship (Bucx & van Wel, 2008).

The transition into the larger adult world is particularly complex for adolescents transitioning out of foster care situations. They are at risk for homelessness, economic challenges, physical and mental health problems, and they may only achieve minimal post-secondary education (Osterling & Hines, 2006). In these situations, the childhood transition into foster care now influences how these

adolescents transition into adulthood. With recognition of the perilous situations some of these young adults face, research is now examining how to support the transition through mentoring programs (Greeson, Usher, & Grinstein-Weiss, 2010; Osterling & Hines, 2006) or supporting resilience, knowledge, and skill building (Keller, Cusick, & Courtney, 2007; Scannapieco, Connell-Carrick, & Painter, 2007).

An example of this concept—although differing in particulars—is an acquaintance of mine (MBR). She grew up attending international boarding schools. When she got married, she stated that she had little understanding of how to set up a home and create a nurturing environment, hence the transitions into being a wife and a mother were difficult. Consistent with the life course perspective, she was resilient and did learn. For many years she and her husband provided an especially nurturing environment in their home for foster kids (as she knew what it was like to be "homeless"); now, as a mother with adult children, she develops curriculum for Canada's aboriginal population (some of whom were raised in residential schools).

Other age-specific expected transitions for women in midlife involve menopause and the "empty nest" syndrome. Historically, both transitions were considered to be difficult and even traumatic for some middle-aged women. However, Dare (2011) interviewed forty Australian women between the ages of 45 and 55 years. She found that most of the women interviewed managed menopause and the launching of children quite well; in contrast, these women noted that transitions related to divorce, as well as the aging and death of older parents, were much tougher to handle. These women reported that divorce resulted in a poorer financial state and had a negative impact on their social network. Caregiving for one or more aging parents resulted in feelings of great responsibility and guilt over not being able to help enough, and when parents died, painful grief (Dare, 2011).

Similarly, Lim and Mackey (2012) interviewed fourteen menopausal and postmenopausal Chinese Singaporean women to understand the meaning they attach to menopause. The women interviewed spoke of the symptoms they experienced, such as abnormal bleeding, hot flushes, and emotional changes. Like Dare's study (2011), most participants described their transition to be uneventful and a normal process of aging: ordinary. The women utilized both Western and Chinese strategies to manage their symptoms and sought support from family and friends. Even though the findings of this study are similar to some other studies, the significance of this research is that the meaning of the transition of menopause is examined in women who are from a different ethnicity than those in Western cultures. It is important that research examining transitions includes individuals from varied ethnic backgrounds. Nurses and other professionals need to be aware that findings from research conducted with participants from Western countries do not necessarily apply to individuals from other regions of the world.

Traumatic Transitions

Researchers examining age-specific stages often explore the impact of unexpected, often difficult traumatic experiences within childhood and how these transitions influence the life course. One example is childhood trauma related to the death of a parent. In a classic study, Brown and Harris (1979) traced the impact of parental loss during childhood on adult outcomes. Using data from a sample of working-class women in London, England, they found that parental loss during childhood was associated with increased risk of clinical depression, lower socioeconomic achievements, and poorer quality marriages during adulthood. Additional analysis suggested that the effects of parental loss were mediated by the quality of care the child received after parental loss. Fewer negative outcomes were observed among women who as children received high-quality care from parental substitutes.

Not only can traumatic childhood transitions result in difficulties navigating future transitions, but such experiences may trigger psychological challenges for children. In an interesting study by van Wesel, Boeije, Alisic, and Drost (2012), children who had experienced trauma, such as death of a sibling, witnessing war, being a victim of abuse or of an accident, all had the need to process the event; some engaged in the psychological work of understanding the meaning of the transition (also termed *existential work*) and how this impacted their sense of identity. With a lens of the life course perspective, we suggest that how children process traumatic transitions in childhood impacts how they manage transitions in the future, whether the transitions are expected and desired (such as marriage), or whether they are unexpected and traumatic (such as a serious accident).

Education

The education domain includes the diversity of transitional experiences across the academic years. Transitions within the educational system are influenced by the structure of the available academic facilities and how the school system is organized: for example, when students transition from grade school to junior high school. The transition from high school into further educational experiences may be positive and even exciting, but is often stressful (Suldo, Shaunessy, Thalji, Michalowski, & Shaffer, 2009). Stresses include leaving home and friends, the need to develop new friends, discovering how to learn and study in a different way (university expectations as opposed to those in high school), as well as increased responsibility and autonomy coupled with decreased parental supervision. These combined stresses can lead to mental health problems, or exacerbate pre-existing ones (Cleary, Walter, & Jackson, 2011). Writers now address the importance of starting transition planning and services for students early within their high school experience, because the services provided are free and accessible, and youth have time to participate in these opportunities (Izzo & Lamb, 2003).

Employment

Within the employment domain, most of the literature is focused upon the transition from academic institutions to formal work. School-to-work transition generally refers to the period between approximately 18 to 24 years of age. O'Regan (2010), in her work on the employment transition, commented that there were two key questions often asked by those in transition: "Who am I?" and "What do I want to do?" Twenty-two undergraduate students were interviewed just prior to graduation. O'Regan (2010) categorized the participants into four categories. One year later, she re-interviewed the participants. The participants that found employment commensurate with their education were those who fit within her instrumental category. These former students were goal-oriented, strategic, and motivated to learn for the specific purpose of their upcoming career. Students who were placed in other categories, such as those who were oriented to learning for the sake of learning, or who were hesitant or introspective (e.g., anxious) about their university experience, were less likely to have found work associated with their university degree. Along a similar vein, Brown and Hesketh (2004) argued that with the rising numbers of university students, the number of employment opportunities that match the level of education are limited, thus resulting in student struggle and angst to secure the best of colleges and employment.

It is understandable that the transition from school to work is challenging because many young people begin employment while in school, migrate out of their communities, work in low-paying and minimal hour situations, and may perhaps be discouraged by unsuccessful job searching. Some of the most immediate considerations of this period in a young person's life include issues related to adequacy of existing education and skills development, job search, labor market entry, occupational matches, stable employment, and adequate income.

Marriage and Parenthood

Although marriage is usually a desired transition, it is inherently stressful. On the classic Holmes and Rahe (1967) stress scale, which rates life stressors with a point system so that individuals can add up their points to see if they are at risk for illness, experiencing the death of a spouse scores 100 points, serving jail time scores 63 points, and getting married scores 50 points. The transition to marriage is stressful because during the first several years of marriage, the spouses are getting to know each other's habits, their rhythms of how they do things around the house, their moods, patterns in handling finances, and other such parameters. However, studies generally show that married men and women are happier than their single counterparts. Stack and Eshleman (1998) examined national surveys from seventeen countries. They found that within sixteen of seventeen countries, being married was associated with greater happiness. They concluded that men and women may be happier in marriage because this bond facilitates two processes:

financial stability and health. Similarly, in an analysis of twenty-seven countries, Lee and Ono (2012) compared ratings of happiness among married individuals, those who cohabit, and individuals who are single. They found that married individuals are happier than couples who cohabit, and couples who cohabit are happier than single individuals.

Better health experienced by married individuals may be in part related to marriage, which often results in a reduction in risky health behaviors, including problem drinking, drug use, and smoking (Bachman et al., 2002). Studies reveal that, in general, the married engage in less risky health behaviors compared with the unmarried. This generalization does not hold true for weight gain, however. Studies show that married individuals weigh more and exercise less than their unmarried counterparts. Interestingly, in one study it was found that having an obese spouse increased's one's own obesity risk by 37 percent (Smith & Christakis, 2008).

Transition into parenthood, the process that consists in discovering and assuming the parenting role after the birth of a child, can be a very stressful time. Mothers and fathers have to review their lifestyles and redefine their relationships to work and daily life. In general, this transition is characterized by a decrease in relationship satisfaction, a lack of couple time, fewer leisure activities, reduced sexual relations, and a reorganization of the tasks of every member of the new family (Lawrence, Rothman, Cobb, Rothman, & Bradbury, 2008; Mortensen, Torsheim, Melkevik, & Thuen, 2012). The parenthood transition involves the acquisition of new knowledge. As suggested by Goodman (2005), in order for fathers to have a sense of parenting efficacy, they need to attain new knowledge and skills. They also need to be involved in the parenting role in order to perceive themselves as competent with their children (de Montigny, Lacharité, & Devault, 2012).

Couples who adopt children undergo unique transitions to parenthood. Each adoption is different, and each comes with a full spectrum of emotions, from elation to grief (Baldo & Baldo, 2003). While adoption can build strong family ties, numerous challenges can develop both during and after the adoption process. Parents and adopted children face a variety of challenges within the newly formed family unit. Parents struggle with the adoption process, while adoptees from various backgrounds often wrestle with identity development. For adopted children, the process of wrestling with and working through identity development can become particularly problematic during adolescence. The challenges of developing an identity in adolescence is magnified by being raised by non-biological parents, and parents may be bewildered as to how to help their adopted child.

Retirement

Retirement is another transitional experience. This transition brings the loss of a work role and often a substantial drop in income. Retirement is especially

hard in Western societies, in which great value is placed upon one's productivity. When work is a person's primary interest, activity, and source of social support, its loss can leave a significant void in life. In the past, retirement, with its benefits and challenges, was the domain of men; today, with more and more women working throughout their adult years, the transition is now impacting them. "I've always looked forward to retirement," stated one such woman. "But I could not have imagined how this would impact my life, how I fill my days, and how I feel about myself!"

Although retirement has been extensively studied, we know relatively little about what predicts different retirement transitions and adjustment patterns. Some researchers have found that retirees, in comparison with workers, often report poorer physical health, greater depression and loneliness, lower life satisfaction, a less positive view about retirement, and lower activity levels (Kim & Moen, 2002). In contrast, others have found retirement to have a positive impact on life satisfaction, health, and stress level (Calasanti, 1996). Wang (2007) found that retirees do not follow a uniform adjustment pattern during the retirement process. Similar findings were found in the work of Potocnik, Tordera, and Perio (2013). They examined retirement satisfaction using the dynamic model of job satisfaction (Bussing, Bissels, Fuchs, & Perrar, 1999). Instead of examining job satisfaction with three criteria—degree, changes in level of aspiration, and problem-solving behavior—they applied these criteria to examine satisfaction with retirement. In the job satisfaction model, degree refers to the degree of satisfaction or dissatisfaction with a job; this satisfaction is contingent upon how a person's expectations and needs correspond to the actual work situation. The changes in level of aspiration pertain to three types of job satisfaction: progressive satisfaction, stabilized satisfaction, and resigned satisfaction. Last, an individual's problem-solving behavior is categorized as constructive dissatisfaction or fixated dissatisfaction (Bussing et al., 1999).

Using the dynamic job satisfaction model, Potocnik and colleagues (2013) applied the concept of satisfaction to retirement. They postulated that an individual develops a degree of retirement satisfaction or dissatisfaction contingent upon her[4] expectations of retirement and the actual retirement situation. Additionally, an individual's level of aspirations regarding retirement, as well as his problem-solving abilities can influence the level of satisfaction he experiences in retirement. As such, they proposed five types of retirement satisfaction, including progressive satisfaction (an individual is satisfied with retirement and endeavors to increase levels of aspirations and satisfaction), stabilized retirement (individual is satisfied with retirement and is determined to sustain satisfaction), resigned retirement satisfaction (individual is ambiguous about retirement and

[4] Throughout this text, we will utilize "her" or "his" interchangeably in order to avoid the awkward juxtapositions of "she/he" or "his/her" in reference to an individual.

lowers his level of aspirations to adapt to the unpleasant facets of retirement), constructive retirement dissatisfaction (individual is dissatisfied with retirement but tries to maintain his level of aspirations and problem-solve), and fixated retirement dissatisfaction (the individual is dissatisfied with retirement and sustains her level of aspirations, but does not try to problem-solve to improve her experience (Potocnik et al., 2013).

The researchers administered questionnaires to 270 Spanish retirees. They found that 41 percent of their sample could be categorized as stabilized-progressive retirement satisfaction, 27 percent as resigned-stabilized retirement satisfaction, 14 percent as resigned retirement satisfaction and almost 18 percent as constructive-fixated retirement dissatisfaction. A good number of their sample were satisfied with retirement and maintained their level of aspirations and even reached for personal growth. They found, however, that involuntary retirement negatively impacted retirement satisfaction, as did gender. While men may be more likely to fall in the resigned retirement satisfaction, women were more likely to be dissatisfied with retirement (constructive-fixated retirement satisfaction) (Potocnik et al., 2013).

We would like to suggest several more points regarding the retirement transition. First, the process of retirement is often not linear. Thus, it is often not an abrupt transition, whereby an individual moves from a full-time work position or career one day to no employment the next day. Increasingly today, perhaps due to lengthening life spans, as well as economic downturns in developed countries, many individuals return to some form of employment after retirement. Second, retirement is broader than the cessation of work. Individuals can also "retire" from other activities that were key to their identity in adulthood. For instance, some individuals need to give up driving; this form of retirement is very difficult for older adults and has been found to result in feelings of loss of control and independence (Choi, Adams, & Mezuk, 2012; Fonda, Wallace, & Herzog, 2001). Further, retiring from volunteer positions or church attendance due to poor health is another form of retirement that can cause much grief in some aging adults.

Healthcare Systems

Literature on healthcare/medical service transitions (transfer of care) abounds in a number of countries (Bell, 2007; Binks, Barden, Burke, & Young, 2007; Freed & Hudson, 2006; Kaufman & Pinzon, 2007; Kingsnorth, Healy, & Macarthur, 2007; Radovick & DiVall, 2007). Healthcare transitions are particularly precarious due to the *number and variance* in kinds of transitions within the healthcare system itself (for example, an individual may transition from the emergency department to a hospital unit, and then to another unit within the same hospital and perhaps again to a rehabilitation facility), the critical nature of

some transitions (such as moving from hospital to live permanently in a continuing care facility[5]), as well as the significant vulnerability of some patients (for example, older adults may have numerous health problems, be taking multiple medications, and have cognitive or sensory deficits).

Furthermore, transitions are complicated by how healthcare services are structured. Healthcare systems are often configured according to discrete loci of care that function in isolation from each other (Coleman & Williams, 2007). This *silo effect* contributes to poor communication between professionals working in different specialties, yet for the benefit of the same individual. The lack of communication can have a serious impact upon the health of vulnerable individuals. In the following section, we will address transitions between medical services (e.g., adult to geriatric services), between home and facilities (e.g., home to hospital and hospital to home; home to continuing care facility), between facilities (e.g., hospital to continuing care facility and continuing care facility to hospital), and the role of transition professionals who aid clients and families with healthcare transitions.

Transitions Between Medical Services

Transitioning between medical services can be difficult for some individuals, particularly if they have received healthcare for years from one primary service. Often, the transition across services is due to changing age groupings, rather than significant changes in needs: for instance, the transition of young adults with special healthcare needs from pediatric-oriented care to adult care. In a qualitative study, Reiss, Gibson, and Walker (2005) examined the process of healthcare transition for youths and young adults with disabilities and special healthcare needs, family members, and healthcare providers. Using both interviews and focus groups, they discovered that important reciprocal relationships, based on mutual trust between providers and families, are developed in the process of caring for these children. This finding was noteworthy, as pediatric- and adult-oriented services represent two different medical subcultures; therefore, how care is delivered to children with special healthcare needs may differ from how care is delivered to these same individuals within the adult system (e.g., professionals working in adult services often expect greater autonomy out of youth than those who provide care in pediatric services). Additionally, Reiss and colleagues (2005) found that a lack of preparation for entry into the adult system contributed to transition problems.

---

[5] We will use the term *continuing care facility* to refer to facilities, such as nursing homes, auxiliary hospitals, and veteran hospitals that provide long-term care. We recognize that this term is used in particular geographical regions, while in other locations, the term *long-term care* is favored. These terms are explained in greater depth in Chapter 4.

For individuals with mental illness, transitioning from adult to geriatric mental health services, just because they have turned 65 years of age, may not be a welcomed transition. Some of these individuals may have been seen by the same psychiatrist or community mental health nurse for years and feel comfortable and safe within those relationships. The transition to the new care provider is perceived as a loss, and it may take some time for the client to adjust and to forge new relationships.

Similarly, one study examined the transition of adolescents with HIV (who were infected in utero) from pediatrics to adult services (internal medicine) (Vijayan, Benin, Wagner, Romano, & Andiman, 2009). The researchers interviewed 18 adolescents with HIV, 15 of their parents and 9 pediatric health care professionals about their concerns regarding the transition. In addition to concerns about adolescent sexuality and compliance with medication regimes, adolescents, parents and health care providers expressed concern about letting go of their relationships. Those interviewed described a familial quality to their health focused relationships and experienced anxiety in anticipating termination (Vijavan et al., 2009).

Transitions Between Facilities

There is much literature that examines transitions between various kinds of healthcare facilities. Individuals can transition between hospital units (Beach et al., 2012), between hospitals and continuing care facilities (Callahan et al., 2012) or off-site rehabilitation units, and between acute care hospitals and hospices. Depending upon the vulnerability of the population, such as older adults with dementia, as well as the number of moves, transitions between facilities can be enormously stressful for older adults and family members and have deleterious effects upon the well-being and health of older adults (Naylor & Keating, 2008).

Transitions between healthcare facilities, such as transitioning from hospital to a continuing care facility, can be precarious. Not only do older adults experience psychological difficulty adjusting to transitions between facilities, the period of transition represents a time where medication errors may be made (Desai, Williams, Greene, Pierson, & Hansen, 2011), which can result in serious health consequences. Or, important healthcare information, which should have been passed from nurses or other healthcare professionals on to staff in the receiving continuing care facility, may be unwittingly omitted.

Another transition event is discharge from hospital to home. Even though the transition from hospital to home is usually eagerly anticipated by patients and family members, like other transitions between facilities, the nature of the transition experience is disruptive and can have negative consequences. Despite the abundance of research studies related to hospital discharge planning, transition care from hospital to home remains problematic. Problems include lapses in

quality and patient safety, gaps in communication between hospital and professional home care providers, ill-prepared family members, and confusion regarding coordination of care (Coleman & Williams, 2007). It is understandable then, that family caregivers often feel a tremendous burden of responsibility for the care of their relative (Plank, Mazzoni, & Cavada, 2012).

Transition Facilitator

With an understanding that navigating through the healthcare system can be difficult, particularly for individuals with cognitive impairment, developmental disabilities or extreme frailty, the value of the role of a transition facilitator is increasingly being discussed. The transition facilitator usually helps patients moving from hospital to home (Newbold, Schneidermann, & Horton, 2012), but may also help individuals navigate the healthcare system from the community (Boult et al., 2008). Although the transition facilitator is usually a registered nurse, the facilitator may also be a social worker (Manderson, McMurray, Piraino, & Stolee, 2012). The transition facilitator can help individuals and their families to connect with needed healthcare services within the community, as sometimes, despite the best intents of healthcare professionals across services, linkages on behalf of individuals fail.

How effective is a transition facilitator? Although the role of the transition facilitator is relatively new, early research results generally prove the efficacy of this role to assist vulnerable individuals transitioning from hospital to home (Manderson et al., 2012). Results show that the use of a facilitator results in an increased adherence with taking medications at home (Newbold et al., 2012), greater patient and physician satisfaction (Boult et al., 2008), and in some cases, decreased length of hospital stay and fewer visits to the emergency department and hospital readmission (Cameron, Birnie, Dharma-Wardene, Raivio, & Marriott, 2007). It can be argued that the use of a transition facilitator encourages and empowers patients and family members to take responsibility for their care thereby achieving better health outcomes.

Family Caregiving

It is only recently that the concept of transition has emerged in the caregiving literature (Seltzer & Li, 1996). The term *caregiver* is often used to describe the unpaid relatives or friends of a disabled individual who help that individual with his activities of daily living. For some, the transition into the caregiver role becomes all-consuming and other aspects of their lives, such as social events and leisure activities, are sacrificed for the benefit of the family member. Becoming a caregiver is a *transition in and of itself*; however, another aspect of caregiving involves helping a family member through various health and healthcare transitions.

Family caregivers encounter numerous difficulties supporting older adults during and through care transitions, such as moves from acute care to home and from home or hospital into continuing care facilities. They report not feeling prepared for the transition and describe frustration over a lack of communication with healthcare providers, as well as difficulty obtaining needed information and access to resources (Davies & Nolan, 2004; Grimmer & Moss, 2001). These difficulties contribute to family caregivers' negative experiences of care transitions. The experiences of caregivers during a transition from home or hospital to a continuing care facility (such as a nursing home), may, unfortunately, spill over into the early months of placement in the institution. The helplessness, anger, guilt, and frustration that may have been experienced during the transfer to the continuing care facility may now be expressed by caregivers to staff in the facility. Caregivers may communicate these emotions through their hypervigilance about the care of their older adult, and through their verbal expressions of displeasure over the care their older member receives.

Current approaches to transitional care focus primarily on patients' and families' experiences of moving between an array of healthcare settings. However, Shyu, Chen, Chen, Wang, and Shao (2008) examined the outcomes of a caregiver-oriented care transition intervention for family caregivers of individuals who had suffered a stroke. They found that their intervention resulted in higher self-evaluations of preparation and better satisfaction of discharge needs, in comparison to a control group who received only routine care.

As stated earlier in this chapter, we will not explore the transitional domain of death and dying until Chapter 6. However, before we examine how individuals cope with transitions, we would like to mention an important caveat. That is, although reasonable predictions can be formulated about the impact of expected events, the reality of the effect of change is *different for each individual.* What one individual considers impactful, whether in a positive or negative sense, another may experience as relatively inconsequential. To illustrate, in one study, individuals were asked to reflect upon their lives and name the major occurrences that changed the course of their lives. Some of the events frequently recognized in the transition literature as important were not identified by participants (Ronka, Oravala, & Pulkkinen, 2003), thus indicating that some individuals find particular transition experiences relatively unremarkable.

COPING WITH TRANSITIONS

Because life course transitions can vary greatly, broad frameworks have been developed to describe the ways in which individuals cope with changes. Bridges (1980) developed a framework to explain the emotions that accompany transitions; each transition is composed of three stages: (1) "endings," which produce sadness, anger, and remorse; (2) "neutral zone," which brings fear and

confusion accompanied by a potential for creativity; and (3) "new beginning," a mixture of confidence over what has been gained and anxiety about slipping backwards.

The first stage begins with the acknowledgment that the change is real; "the way things were" is no longer possible. There is a sense of loss that is accompanied by mourning. An ending in the present may bring back memories from past losses and the resulting surge in feelings can overwhelm a person and trigger behaviors that are hard for others, or the individual in transition, to understand and accept. Eventually, ending means letting go and saying goodbye to both the old identity and the old way of doing things.

In the second stage, an individual is confused, anxious, and perhaps defensive. People around the individual in this stage of transition may become impatient; they might express such comments as "you need to move on"or "get over it." While the neutral zone creates space for creativity and growth, the loss of familiar boundaries and supports creates the temptation to return to that which feels familiar. An individual needs to get through this uncomfortable in-between zone, when the old way is gone but the new way does not as yet feel truly comfortable. Even when the change seemed good initially, an individual may feel lost and confused at times. Yet, by experiencing fear and confusion, an individual may do her best problem solving. She may be able to explore a variety of paths to new beginnings (Bridges, 1980).

The third stage of Bridges' model (1980) of coping with transitions is "new beginning." In this stage, an individual is emotionally ready to do things in an entirely new way. The new beginning is reached after an individual has parted with the old and crossed the neutral zone. The past is not forgotten or discarded, but is understood as part of the individual, only in a new way. Interestingly, an individual may believe that a new beginning can happen when he wants it to, but in actuality, the new beginning will happen when the person is inwardly ready.

FACTORS THAT INFLUENCE THE TRANSITION EXPERIENCE

The literature offers a great deal of evidence about the different factors that influence the transition process. Any one factor can be perceived as either a barrier or support, depending on the situation. However, further study is required to determine the extent of the influence of these factors upon the transition process and outcomes, and how they interact with each other.

Individual Factors

There are a number of factors specific to individuals, which may influence successful navigation through the transition experience. Hopwood and colleagues

(2011) noted that genetic factors are important for understanding personality stability and changes during the transition to adulthood. As such, a person's genetic makeup influences how she responds to the transition from adolescence into adulthood. Additionally, O'Regan (2010) stated that how an individual copes with a new identity is influenced by how secure he is in the epicenter of his identity. Presumably, the security of identity is related not just to genetic factors, but also to the individual's past history of learning to cope with difficulties and transitions.

Physical or Mental Disabilities

As an individual factor, physical, mental, behavioral, sensory, developmental, and learning disabilities are strongly correlated with school non-completion and other negative outcomes of transition (Binks et al., 2007; Learning Disabilities Association of Canada, 2007; Vander Stoep et al., 2000). The influence of the type of disability has been reported in several published studies, and statistical evidence indicates that type of disability can affect the process and outcomes of adult transitions (Caton & Kagan, 2007; Van Naarden Braun, Yeargin-Allsopp, & Lollar, 2006). Some literature reports increased risk of negative outcomes with a high level of severity of different types of disability (Bowe, 2003; Caton & Kagan, 2007; Wong, 2004). However, it should be recognized that some believe that disability is only one factor in a complex process. Disabilities can greatly impact how individuals move through transitions, but the evidence to date seems inconclusive about the influences of specific types of disabilities.

That being said, disabilities can be compounded with other factors that increase the challenges in successfully moving through transitions. Literature about Aboriginal, Hispanic, and African American youth with disabilities speaks to the "double jeopardy": risk factors of disability *and* ethnicity (Blacher, 2001; Hussain, 2003). As an example, we know of an Aboriginal family that moved from one district to another in a large city. One of the teenage children had a debilitating disease and went to a special school. The arrangement for permanent transportation had not yet been established, and so the family arranged for a taxi to pick this boy up from home, take him to school, and then pick him up from school again and bring him home. In this transition, the taxi driver took advantage of this young man, both verbally abusing him and taking the long route home (running up the costs). In his vulnerabilities, this young man's transition from one home to another, and from one mode of transportation to another (no matter how short the duration), was difficult.

In understanding the impact of disabilities upon transitioning, some researchers have found that disabilities, in conjunction with gender, may influence *how* individuals cope with transitions, as well as *how well* they cope (Berge, Patterson, Goetz, & Milla, 2007; Powers, Hogansen, Geenen, Powers, & Gil-Kashiwabara, 2008). For instance, in an interesting study by Berge and colleagues

(2007), adolescents with cystic fibrosis (CF) who were transitioning into adulthood were interviewed. The researchers identified that females coped with the transition differently than males. As an example, the female participants wanted others to hold them accountable for following their CF treatment regimes, while the males felt they needed to be responsible. Further, while both females and males reported the importance of a positive outlook, the males spoke of how the illness had developed their character, while the females took a more passive role and noted that they just had to accept the illness. Berge and colleagues (2007) concluded that this coping style may have influenced the mental health of the participants, because the female participants experienced greater mental health difficulties.

Environmental Factors

There is some discussion in the literature that specifically addresses environmental factors and their influence upon the transition experience. For illustration, recent studies have found that some youth with disabilities may become involved in criminal behavior and substance abuse (Baltodano, Mathur, & Rutherford, 2005). The influence of others (as an environmental factor) upon these youth in encouraging substance abuse and criminal behaviors increases the complexity of their situations, and may result in negative outcomes of school failure and unemployment.

Maddalena, Kearney, and Adams' (2012) qualitative study examined factors influencing the quality of work life of Canadian novice nurses (less than two years' experience). In transitioning to their new role, they encountered numerous sources of environmental stress, including "difficult personalities," inadequate orientation and mentoring, and horizontal violence from nursing and medical colleagues. These stressors were compounded by staffing shortages and heavy workloads. Addressing the environmental factors by offering supportive mentoring and adequate orientation helped these beginning nurses transition into their new role.

Nalder and colleagues (2012) investigated perceived success of the transition from hospital to home after traumatic brain injury. Among participants, sentinel events such as returning to work and independent community access, as well as changing life situations, were associated with greater perceived success; financial strain and difficulty accessing therapy services were associated with less perceived success. These findings were consistent with the earlier work of Cornwell et al. (2009) who reported that restricted access to community services, as well as organizational issues such as poor communication, limited funding, and inadequate availability of staff, influenced the transition experience for a similar client group.

Case Example

In order to illustrate some of the concepts previously discussed within this chapter, as well as to link into the following topic of interventions during transitions, we now present a case example.

Dwayne is a 20-year-old young man. He recently left his home in a large urban center in Eastern Canada to go to university in the United States. His adjustment thus far into university life has been difficult. Although his marks are very good, he is hardly eating, is cutting himself again, and is isolating himself from others. Dwayne did not want to go to university, despite his great interest in the biological sciences, because he worried that he would find this transition difficult. His parents, worried about how Dwayne would "make it in life," strongly encouraged him and even pushed him to apply.

For weeks, Dwayne has sat alone in his dorm room on campus, ruminating on how he ended up in this situation. In his mind, he repeatedly thinks back on his junior and senior high school days. School was always a bitter experience for him, despite, and maybe in part, because of his stellar marks. His fellow students never liked him and repeatedly taunted him, first for being too heavy, then for being too skinny (his weight fluctuated greatly). He felt like he never fit in with his peers, or even his family, because he could not come to grips with his biological mother's giving him up for adoption. Off and on throughout his school career he cut himself in order to deal with the stresses of being disliked and lonely.

Over the course of some weeks, Dwayne decided that he needed to do something. In speaking with a kind professor, he was directed to go to Student Counseling. The student counselor talked with Dwayne about his transition to university life, as well as other concurrent transitions. She questioned Dwayne about the self-harming behavior and purposefully inquired if the self-harming was related to suicidal ideation, was done to relieve stress, or was caused by self-loathing. She examined Dwayne's coping methods, as well as who he has for support, both at home and on campus. Together they constructed a plan to help him, including ongoing appointments for counseling, as well as arranging an appointment with a doctor in the university health clinic to get a thorough checkup, as well be assessed regarding whether he should receive medication. Although still feeling worried about his ability to get through the semester, Dwayne feels less alone and a little more hopeful that he can continue.

ASSESSMENT AND INTERVENTIONS DURING TRANSITIONS

Transitions are difficult, in part, because of unknowns in *how they unfold*, as well as because of the uncertainties of how *individuals will react* throughout the transitional experiences. This may produce wariness and even fear in individuals as they approach transitions; the concern may even be extended to family members as they watch a member face into a transition and wonder how best to support the individual. Nurses and other professionals need to recognize the importance of addressing the underlying individual and environmental factors, as well as the quality of supportive relationships (e.g., family and friends), in understanding and supporting individuals during transitions. We now address interventions to assist individuals through transitions, and where possible, will apply the situation of Dwayne in the discussion.

Awareness of the Impact of Transitional Experiences

It is important that nurses and other professionals recognize the impact of transitions upon individuals. Even if transitions are expected, some individuals will struggle with facing into and getting through the changes. Particularly if past transitional experiences were difficult, present or future experiences may also be challenging. As part of understanding transitions, self-awareness among professionals cannot be overstated. Professionals who understand their own responses to transitions will be better able to be empathetic; they will understand the connection between transitions and personal identity, and that transitions can lead to uncertainty and even fear as individuals wonder "who they are" during these times. They will be able to understand the powerful emotions that emerge, and even the sometimes inappropriate expressions of anger, such as swearing at a healthcare professional or failing to show up for an appointment. These types of behaviors can be understood as expected and, indeed, "human" responses to the disorienting effects of transition.

Assessment of Past Transitional Experiences

In order to understand how individuals experience transitions, nurses and other professionals may assess how individuals have processed and progressed through previous transitions. If individuals have perceived past transitions to be frightening, current or future transitions may be viewed as fear-provoking. Hence, Dwayne's counselor may ask about previous transitions that he experienced, including how he progressed through his school years. She may ask Dwayne about what worked for him when he faced difficulties and what strategies were not effective. The counselor, however, should be mindful of how emotional reactions

to past transitions faced by Dwayne may impact how he is making sense of this transition to university life.

Understanding that Transitional Experiences May Influence a Sense of Identity

Some transitional experiences can impact identity. At times, the impact can be positive; for instance, the change from single status to married can be positive and affirming for individuals. However, some transitions can unsettle how persons perceive or define themselves. This may be the case when individuals move from one profession to another. The change may be unsettling, as how they have defined themselves has now changed (e.g., lawyer to homemaker). This can also occur in retirement, when adults move from specific careers that gave them status and a feeling of importance, as well as largely defined who they were as individuals, have now ended. The impact of transitions upon persons' sense of identity can be even greater if they struggle with who they are as individuals. As in the situation with Dwayne (case example), the wrestling with the transition of becoming a university student is exacerbated by his questions around who he is as an individual; his questions about who he is as an individual have been negatively impacted by his questions and emotional pain regarding being adopted (Kerr-Edwards, 2011).

The astute professional working with someone like Dwayne will ask him how he defines himself, what he is particularly proud of as an individual, and what are his strengths and areas for growth. The professional can then sensitively inquire about if the current transition is affecting how he sees himself as a person and ascertain if there are past and current issues of personal identity that are being aggravated by the situation. If warranted, the nurse or professional can refer an individual like Dwayne to a support group, such as for those struggling with having been adopted (Kerr-Edwards, 2011).

Assessment of Mental State

Transitional experiences, if very difficult, may influence individuals' mental health. Irrespective of age, children, adolescents, adults, and older adults may respond with depressed mood and increased anxiety. Thus, nurses and professionals should routinely assess the mental health impact of transitions upon their clients. When presented with evidence of self-harm, nurses and other professionals should assess individuals, such as Dwayne, for suicidal ideation. The knowledgeable professional will understand that sometimes acts like cutting are intended for suicide, but for others, such acts may be the means to relieve stress, to purge oneself of bad feelings, or to physically punish the self for perceived badness (Hill & Dallos, 2011; Rissanen, Kylma, & Laukkanen, 2011). When mental health is a concern, individuals should be referred to a physician or psychiatrist for assessment.

Assessment of Coping Strategies and Support Systems

In order to intervene with individuals experiencing transitions, nurses and other professionals will assess coping strategies. Coping strategies include how individuals mentally process or appraise situations. For instance, individuals who look upon transitions as frightening and insurmountable may unwittingly, through rumination on negative thoughts, paralyze themselves with fear. The work of the nurse or other professional involves helping individuals examine how they face transitions and changing their thinking into more productive and positive patterns.

Other coping strategies involve finding social support through family or friends, clubs or groups; for some individuals, religious involvement is an important resource during periods of transition. Depending upon the type of transition, individuals may seek new support systems, such as support groups. Nurses and other professionals should assess the support systems (Wright & Leahey, 2013) of those experiencing difficulties in managing transitions — both informal (family and friends) and formal (professional) — and encourage them not to separate themselves from their support. In particular, some age groups may have fewer social supports, such as older adults (Gillath, Johnson, Selcuk, & Teel, 2011), and some individuals, under stress, may have the tendency to isolate themselves.

Dwayne's counselor is aware that he has used cutting as a coping strategy to relieve stress (Hill & Dallos, 2011). Understanding, however, that while cutting may relieve stress for Dwayne, it can also create new stress when others question why he is covered in scars, the counselor will work with him to uncover old coping methods that have worked in the past (but are not being utilized in the present) and to discover new strategies to cope. His counselor will also consider who he has for support and will encourage him to connect with his parents and other support systems regularly during this time.

Knowledge of and Participation in Development of Community Services and Programs

It is helpful for professionals to be aware of services and programs that have developed to assist individuals experiencing transitions. For example, a number of promising practice models in education feature programs to include students in school meetings, as well as school-supervised work experiences, and functionally oriented curricula (Carnaby, Lewis, Martin, Naylor, & Stewart, 2003). Further, in the United Kingdom, transition guidelines have been developed to assist students going to university (Cook, Rushton, McCormick, & Southall, 2005). Additionally, models have been developed to facilitate the age-appropriate participation of youth with developmental disabilities in post-secondary classes (Dolyniuk et al., 2002).

For adults, there are a number of strategies/services to assist through transitions. For instance, many churches offer premarital counseling for couples who are getting married. Within these counseling sessions, couples are encouraged to talk about issues such as finances (and debt), expectations, and conflict resolution. These are topics that they might not address on their own, but in a session they are provided the opportunity to discuss these important and potentially "hot" topics. Further, for adults in their fifties and sixties, there are pre-retirement courses aimed at assisting them in examining financial implications of retirement, as well as considering the need to plan ahead (Hewitt, Howie, & Feldman, 2010).

There are now online support systems that help individuals, such as older adults. Some agencies provide means for online support for older adults who are housebound. Older adults can either access help for their health transitions (resulting in being homebound) through phone support, or can offer support to others through phone or "virtual" support (Cattan, Kime, & Bagnall, 2011; Mukherjee, 2010). Professionals who recognize the importance of programs that help individuals during transitions can refer their clients to relevant programs, or if unavailable, can be involved in the creation of such programs within their region.

SUMMARY

Human transition entails change and adaptation: developmentally, (for example teenager to young adult), personally, within relationships, and situations. The literature provides a clear picture of the experiences, challenges, and desired outcomes for individuals of all ages and their families. Some literature also identifies experiences and perspectives of service providers and community members who are part of the transition process. To date, many of the studies and review articles focus on experiences of transitioning or transferring from one service system to another, for example, from pediatric to adult services. A shift in focus is evident in recent literature that focuses more on a holistic, life course perspective. Understanding the personal and environmental conditions that facilitate or hinder movement through a transition is critical to describing the experience of transition.

Critical Thinking Activities

- What does the word *transition* mean to you? How does your view of transition compare with what you have learned in this chapter?
- Transition is a central concept to understanding human behavior. Based upon your reading to date, assess your own understanding of transitions. Write down your experiences and feelings as you identify a specific experience of transition.
- Interview a professional colleague (e.g., faculty member, university classmate) and ask about a specific experience of transition. Compare his experience with your own.

REFERENCES

Arnett, J. J. (2004). *Emerging adulthood: The winding road from the late teens through the twenties*. New York: Oxford University.

Bachman, J. G., Schulenberg, J., Johnston, L.D., Bryant, A. L., Merline, A. C., & O'Malley, P. M. (2002). *The decline of substance use in young adulthood: Changes in social activities, roles, and beliefs*. Mahwah, NJ: Lawrence Erlbaum Assoc.

Baldo, A. J., & Baldo, T. D. (2003). A dual-career couple's experience with adoption: The dramatic impact of moving from couple to instant parenthood. *The Family Journal, 11*(4), 400–403. doi: 10.1177/1066480703255388

Baltodano, H. M., Mathur, S. R., & Rutherford, R. B. (2005). Transition of incarcerated youth with disabilities across systems and into adulthood. *Exceptionality, 13*(2), 103–124. doi: 10.1207/s15327035ex1302_4

Beach, C., Cheung, D. S., Apker, J., Horwitz, L. I., Howell, E. E., O'Leary, K. J., Patterson, E. S., et al. (2012). Improving interunit transitions of care between emergency physicians and hospital medicine physicians: A conceptual approach. *Academic Emergency Medicine, 19*(10), 1188–1195. doi: 10.111/j.1553-2712.2012.01448.x

Bell, L. (2007). Adolescents with renal disease in an adult world: Meeting the challenge of transition of care. *Nephrology Dialysis Transplantation, 22*(4), 988–991. doi:10.1093/ndt/gfl770

Berge, J. M., Patterson, J. M., Goetz, D., & Milla, C. (2007). Gender differences in young adults' perceptions of living with cystic fibrosis during the transition to adulthood: A qualitative investigation. *Families, Systems, and Health 25*(2), 190–203. doi: 10.1037/1091-7527.25.2.190

Binks, J. A., Barden, W. S., Burke, T. A., & Young, N. L. (2007). What do we really know about the transition to adult-centered health care? A focus on cerebral palsy and spina bifida. *Archives of Physical Medicine and Rehabilitation, 88*(8), 1064–1073. doi: 10.1016/j.apmr.2007.04.018

Blacher, J. (2001). Transition to adulthood: Mental retardation, families, and culture. *American Journal of Mental Retardation,106*(2), 173–188. doi: 10.1352/0895-8017

Blair, S. E. (2000). The centrality of occupational life transitions. *British Journal of Occupational Therapy, 63*(5), 231–237.

Boult, C., Reider, L., Frey, K., Leff, B., Boyd, C. M., Wolff, J. L., Wegener, S., et al. (2008). Early effects of "guided care" on the quality of health care for multimorbid older persons: A cluster- randomized control trial. *Journal of Gerontology: Series A, Biological and Medical Sciences, 63*(3), 321–327.

Bowe, F. G. (2003). Transition for deaf and hard-of-hearing students: A blueprint for change. *Journal of Deaf Studies and Deaf Education, 8*(4), 485–493. doi: 10.1093/deafed/eng024

Bridges, W. (1980). *Transitions: Making sense of life's changes*. Reading, MA: Addison-Wesley.

Bridges, W. (2004). *Transitions: Making sense of life's changes (Rev. ed.)*. Cambridge, MA: Da Capo Press.

Brown, G. W., & Harris, T. O. (1979). *Social origins of depression: A study of psychiatric disorders in women.* London: Tavistock.

Brown, P., & Hesketh, A. (2004). *The mismanagement of talent: Employability and jobs in the knowledge economy.* Oxford: Oxford University.

Bucx, F., & van Wel, F. (2008). Parental bond and life course transitions from adolescence to young adulthood. *Adolescence, 43*(169), 71–88.

Bussing, A., Bissels, T., Fuchs, V., & Perrar, K. M. (1999). A dynamic model of work satisfaction: Qualitative approaches. *Human Relations, 52*(8), 999–1028.

Calasanti, T. M. (1996). Gender and life satisfaction in retirement: An assessment of the male model. *Journal of Gerontology: Social Sciences, 51B*(1), S18–S29. doi: 10.1093/geronb/51B.1.S18

Callahan, C. M., Arling, G., Tu, W., Rosenman, M. B., Counsell, S. R., Stump, T. E., & Hendrie, H. C. (2012). Transitions in care for older adults with and without dementia. *Journal of the American Geriatrics Society, 60*(5), 813–820. doi: 10.1111/j.1532-5415.2012.03905.x

Cameron, C. L., Birnie, K., Dharma-Wardene, M. W., Raivio, E., & Marriott, B. (2007). Hospital-to-community transitions: A bridge program for adolescent mental health patients. *Journal of Psychosocial Nursing & Mental Health, 45*(10), 24–30.

Carnaby, S., Lewis, P., Martin, D., Naylor, J., & Stewart, D. (2003). Participation in transition review meetings: A case study of young people with learning disabilities leaving a special school. *British Journal of Special Education, 30*(4), 187–193. doi: 10.1111/j.0952-3383.2003.00309.x

Carroll, L. (1967). *Alice in Wonderland.* London, UK: Dobson.

Cattan, M., Kime, N., & Bagnall, A.M. (2011). The use of telephone befriending in low level support for socially isolated older people—An evaluation. *Health and Social Care in the Community, 19*(2), 198–206. doi: 10.1111/j.1365-2524.2010.00967.x

Caton, S., & Kagan, C. (2007). Comparing transition expectations of young people with moderate learning disabilities with other vulnerable youth and with their non-disabled counterparts. *Disability and Society, 22*(5), 473–488. doi: 10.1080/09687590701427586

Choi, M., Adams, K. B., & Mezuk, B. (2012). Examining the aging process through the stress-coping framework: Application to driving cessation in later life. *Aging & Mental Health, 16*(1), 75–83. doi:10.1080/13607863.2011.583633

Cleary, M., Walter, G., & Jackson, D. (2011). "Not always smooth sailing": Mental health issues associated with the transition from high school to college. *Issues in Mental Health Nursing, 32*(4), 250–254. doi: 10.3109/01612840.2010.548906

Coleman, E. A., & Williams, M. V. (2007). Executing high quality care transitions: A call to do the right thing. *Journal of Hospital Medicine, 2*, 287–290. doi: 10.1002/jhm.276

Cook, A., Rushton, B. S., McCormick, S. M., & Southall, D. W. (2005). *Guidelines for the management of study transition. The STAR (Student Transition and Retention) Project.* [Internet] Accessed February 20, 2013, from: www.ulster.ac.uk/star/resources/star_guidelines.pdf

Cornwell, P., Fleming, J., Fisher, A., Kendall, M., Ownsworth, T., & Turner, B. (2009). Supporting the needs of young adults with acquired brain injury during transition from hospital to home: The Queensland service provider perspective. *Brain Impairment, 10*(3), 325–340.

Dare, J.S. (2011). Transitions in midlife women's lives: Contemporary experiences. *Health Care for Women International, 32*(2), 111–133. doi: 10.1080/07399332.2010.500753

Davies, S., & Nolan, M. (2004). Making the move: Relatives' experiences of transition to a care home. *Health and Social Care in the community, 12*(6), 517–526. doi10.11 1/j.1365-2524.2004.00535

de Montigny, F., Lacharité, C., & Devault, A. (2012). Transition to fatherhood: Modeling the experience of fathers of breastfed infants. *Advances in Nursing Science, 35*(3), E11–E22. doi: 10.1097/ANS.0b013e3182626167

Desai, R., Williams, C. E., Greene, S. B., Pierson, S., & Hansen, R. A. (2011). Medication errors during patient transitions into nursing homes: Characteristics and association with patient harm. *The American Journal of Geriatric Pharmacotherapy, 9*(6), 413–422.

Dolyniuk, C. A., Kamens, M. W., Corman, H., DiNardo, P. O., Totaro, R. M., & Rockoff, J. C. (2002). Students with developmental disabilities go to college: Description of a collaborative transition project on a regular college campus. *Focus on Autism and Other Developmental Disabilities, 17*(4), 236–241.

Fonda, S. J., Wallace, R. B., & Herzog, A. R. (2001). Changes in driving patterns and worsening depressive symptoms among older adults. *Journal of Gerontology: Social Sciences, 56*(6), 343–351. doi: 10.1093/geronb/56.6.S343

Freed, G. L., & Hudson, H. J. (2006). Transitioning children with chronic diseases to adult care: Current knowledge, practices, and directions. *Journal of Pediatrics, 148*(6), 824–827. doi: 10.1016/j.jpeds.2006.02.010

Gillath, O., Johnson, D. K., Selcuk, E., & Teel, C. (2011). Comparing old and young adults as they cope with life transitions: The links between social network management skills and attachment styles to depression. *Clinical Gerontologist, 34*(3), 251–265. doi: 10.1080/07317115.2011.554345

Goodman, J.H. (2005). Becoming an involved father of an infant. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 34*(2), 190–200. doi: 10.1177/0884217505274581

Greeson, J. K., Usher, L., & Grinstein-Weiss, M. (2010). One adult is crazy about you: Can natural mentoring relationships increase assets among young adults with and without foster care experience? *Children and Youth Services Review, 32*(4), 565–577. doi: 10.1016/j.childyouth.2009.12.003

Grimmer, K., & Moss, J. (2004). The development, validity and application of a new instrument to assess the quality of discharge planning activities from the community perspective. *International Journal of Allied Health Sciences & Practice, 2*(4), retrieved from http://ijahsp.nova.edu/articles/vl2num4/grimmer-carer%20issues.pdf

Hewitt, A., Howie, L., & Feldman, S. (2010). Retirement: What will you do? A narrative inquiry of occupation-based planning for retirement: Implications for practice. *Australian Occupational Therapy Journal, 57*(1), 8–16. doi: 10.1111/j.1440-1630.2009.00820.x

Hill, K., & Dallos, R. (2011). Young people's stories of self-harm. A narrative study. *Clinical Child Psychology and Psychiatry, 17*(3), 459–475. doi: 10.1177/1359104511423364

Holmes, T. H., & Rahe, R. H. (1967). The social readjustment rating scale. *Journal of Psychosomatic Research, 11*(2), 213–218.

Hopwood, C. J., Donnellan, M. B., Blonigen, D. M., Krueger, R. F., McGue, M., Iacono, W. G., & Burt, S. A. (2011). Genetic and environmental influences on personality trait stability and growth during adulthood: A three way longitudinal study. *Journal of Personality and Social Psychology, 100*(3), 545–556. doi: 10.1037/a0022409

Hussain, Y. (2003). Transitions into adulthood: Disability, ethnicity and gender among British South Asians. *Disability Studies Quarterly, 23*(2), 100–112.

Hutchison, E. (2008). *Dimensions of human behavior: The changing life course.* Thousand Oaks, CA: Sage.

Izzo, M. V., & Lamb, P. (2003). Developing self-determination through career development activities: Implications for vocational rehabilitation counselors. *Journal of Vocational Rehabilitation 19*(2), 71–78.

Kaufman, M. (2006). Role of adolescent development in the transition process. *Progress in Transplantation, 16*(4), 286–290.

Kaufman, M., & Pinzon, J. (2007). Transition to adult care for youth with special health care needs. *Paediatrics & Child Health, 12*(9), 785–788.

Keller, T. E., Cusick, G. R., & Courtney, M. E. (2007). Approaching the transition to adulthood: Distinctive profiles of adolescents aging out of the child welfare system. *Social Service Review, 81*(3), 453–484.

Kerr-Edwards, S. (2011). Group work with adopted adolescents. *Adoption & Fostering, 35*(3), 50–60.

Kim, J., & Moen, P. (2002). Retirement trends, gender, & psychological well-being: A life-course, ecological model. *Journal of Gerontology: Psychological Sciences, 57B*(3), P212–P222.

Kingsnorth, S., Healy, H., & Macarthur, C. (2007). Preparing for adulthood: A systematic review of life skill programs for youth with physical disabilities. *Journal of Adolescent Health, 41*(4), 323–332. doi: 10.1016/j.jadohealth.2007.06.007

Kralik, D., Visentin, K., & van Loon, A. (2006). Transitions: A literature review. *Journal of Advanced Nursing, 55*(3), 320–329. doi: 10.1111/j.1365-2648.2006.03899.x

Lawrence, E., Rothman, A. D., Cobb, R. J., Rothman, M. T., & Bradbury, T. N. (2008). Marital satisfaction across the transition to parenthood. *Journal of Family Psychology, 22*(1), 41–50. doi: 10.1037/0893-3200.22.1.41

Learning Disability Association of Canada. (2007). *Putting a Canadian face on learning disabilities.* Accessed March 02, 2013, from www.pacfold.ca/what_is/index.shtml

Lee, K. S., & Ono, H. (2012). Marriage, cohabitation, and happiness: A cross-national analysis of 27 countries. *Journal of Marriage and Family, 74*(5), 953–972. doi: 10.1111/j.1741-3737.2012.01001.x

Lim, H., & Mackey, S. (2012). The menopause transition experiences of Chinese Singaporean women: An exploratory qualitative study. *Journal of Nursing Research, 20*(2), 81–89. doi: 10.1097/jnr.0b013e318254eb25

Maddalena, V., Kearney, A. J., & Adams, L. (2012). Quality of work life of novice nurses: A qualitative exploration. *Journal for Nurses in Staff Development, 28*(4),74–79. doi: 10.1097/NND.0b013e31824b41a1

Manderson, B., McMurray, J., Piraino, E., & Stolee, P. (2012). Navigation roles support chronically ill older adults through healthcare transitions: A systematic review of the literature. *Health and Social Care, 20*(2), 113–127. doi: 10.1111/j.1365-2524.2011.01032.x

Meleis, A. I., Sawyer, L. M., Im, E. O., Messias, D. K., & Schumacher, K. (2000). Experiencing transitions: An emerging middle-range theory. *Advances in Nursing Science, 23*(1), 12–28.

Mortensen, O., Torsheim, T., Melkevik, O., & Thuen, F. (2012). Adding a baby to the equation: Married and cohabiting women's relationship satisfaction in the transition to parenthood. *Family Process, 51*(1), 122–139. doi: 10.1111/j.1545-5300.2012.01384.x

Mukherjee, D. (2010). An exploratory study of older adults' engagement with virtual volunteerism. *Journal of Technology in Human Services, 28*(3), 188–196. doi: 10.1080/15228835.2010.508368

Nalder, E., Fleming, J., Foster, M., Cornwell, P., Shields, C., & Khan, A. (2012). Identifying factors associated with perceived success in the transition from hospital to home after brain injury. *Journal Head Trauma Rehab, 27*(2), 143–153. doi: 10.1097/HTR.0b013e3182168fb1

Naylor, M., & Keating, S.A. (2008). Transitional care: Moving patients from one care setting to another. *American Journal of Nursing, 108*(9 Suppl), 58–63. doi: 10.1097/01.NAJ.0000336420.34946.3a

Newbold, E., Schneidermann, M., & Horton, C. (2012). The Bridge Clinic. *American Journal of Nursing, 112*(7), 56–59. doi: 10.1097/01.NAJ.0000415966.23169.7e

O'Regan, M. (2010). Graduate transition to employment: Career motivation, identify, and employability. University of Reading, Accessed February 20, 2013, from http://www.reading.ac.uk/web/FILES/ccms/Graduate_transitions_to_employment.pdf

Osterling, K. L., & Hines, A. M. (2006). Mentoring adolescent foster youth: Promoting resilience during developmental transitions. *Clinical and Family Social Work, 11* (3), 242–253.

Oxford dictionary. (-). Accessed November 12, 2012, from http://oxforddictionaries.com/definition/english/transition.

Plank, A., Mazzoni, V., & Cavada, L. (2012). Becoming a caregiver: New family carers' experience from hospital to home. *Journal of Clinical Nursing, 21*(13-14), 2072–2982. doi: 10.1111/j.1365-2702.2011.04025.x

Potocnik, K., Tordera, N., & Perio, J. M. (2013). Truly satisfied with your retirement or just resigned? Pathways toward different patterns of retirement satisfaction. *Journal of Applied Gerontology, 32*(2), 164–187. doi:10.1177/0733464811405988

Powers, K., Hogansen, J., Geenen, S., Powers, L. E., & Gil-Kashiwabara, E. (2008). Gender matters in transition to adulthood: A survey study of adolescents with disabilities and their families. *Psychology in the Schools, 45*(4), 349–364. doi: 10.1002/pits.20297

Radovick, S., & DiVall, S. (2007). Approach to the growth hormone-deficient child during transition to adulthood. *Journal of Clinical Endocrinology and Metabolism, 92*(4), 1195–1200. doi: 10.1210/jc.2007-0167

Rasmussen, B., Ward, G., Jenkins, A., King, S. J., & Dunning, T. (2011). Young adults' management of type 1 diabetes during life transitions. *Journal of Clinical Nursing, 20*(13-14), 1981–1992. doi: 10.1111/j.1365-2702.2010.03657.x

Reiss, J. G., Gibson, R. W., & Walker, L. R. (2005). Health care transition: Youth, family, and provider perspectives. *Pediatrics, 115*(1), 112–121. doi: 10.1542/peds.2004-1321

Rissanen, M. L., Kylma, J., & Laukkanen, E. (2011). A systematic literature review: Self-mutilation among adolescents as a phenomenon and help for it—what kind of knowledge is lacking? *Issues in Mental Health Nursing, 32*(9), 575–583. doi: 10.3109/01612840.2011.578785

Ronka, A., Oravala, S., & Pulkkinen, L. (2003). Turning points in adult lives: The effects of gender and the amount of choice. *Journal of Adult Development, 10*(3), 203–215.

Scannapieco, M., Connell-Carrick, K., & Painter, K. (2007). In their own words: Challenges facing youth aging out of foster care. *Child & Adolescent Social Work Journal, 24*(9), 423–435. doi: 10.1007/s10560-007-0093-x

Seltzer, M. M., & Li, L. W. (1996).The transitions of caregiving: Subjective and objective definitions. *The Gerontologist, 36*(5), 614–626. doi: 10.1093/geront/36.5.614

Shyu,Y. L., Chen, M., Chen, S., Wang, H., & Shao, J. (2008). A family caregiver-oriented discharge planning program for older stroke patients and their family caregivers. *Journal of Clinical Nursing, 17*(18), 2497–2508. doi: 10.1111/j.1365-2702.2008.02450.x

Smith, K. P., & Christakis, N. A. (2008). Social networks and health. *Annual Review of Sociology, 34*, 405–429. doi: 10.1146/annurev.soc.34.040507.134601

Stack, S., & Eshleman, J. R. (1998). Marital status and happiness: A 17 nation study. *Journal of Marriage and the Family, 60*(2), 527–536.

Suldo, S. M. Shaunessy, E., Thalji, A., Michalowski, J., & Shaffer, E. (2009). Sources of stress for students in high school college preparatory and general education programs: Group differences and associations with adjustment. *Adolescence, 44* (176), 925–948.

Vander Stoep, A., Beresford, S. A. A., Weiss, N. S., McKnight, B., Cauce, A. M., & Cohen, P. (2000). Community based study of the transition to adulthood for adolescents with psychiatric disorder. *American Journal of Epidemiology, 152*(4), 352–362. doi: 10.1093/aje/152.4.352

Van Naarden Braun, K., Yeargin-Allsopp, M., & Lollar, D. (2006). A multi-dimensional approach to the transition of children with developmental disabilities into young adulthood: The acquisition of adult social roles. *Disability and Rehabilitation, 28*(15), 915–928. doi:10.1080/09638280500304919

van Wesel, F., Boeije, H., Alisic, E., & Drost, S. (2012). I'll be working my way back: A qualitative synthesis on the trauma experience of children. *Psychological Trauma: Theory, Research, Practice and Policy, 4*(5), 516–526. doi: 10.1037/a0025766

Vijayan, T., Benin, A. L., Wagner, K., Romano, S., & Andiman, W.A. (2009). We never thought this would happen: Transitioning care of adolescents with perinatally acquired HIV infection from pediatrics to internal medicine. *AIDS Care, 21*(10), 1222–1229. doi:10.1080/09540120902730054

Wang, M. (2007). Profiling retirees in the retirement transition and adjustment process: Examining the longitudinal change patterns of retirees' psychological well-being. *Journal of Applied Psychology, 92*(2), 455–474. doi: 10.1037/0021-9010.92.2.455

Wong, M. E. (2004). Higher education or vocational training? Some contributing factors to post-school choices of visually impaired students in Britain. Part 1, Great Britain. *British Journal of Visual Impairments 22*(1), 37–42. doi: 10.1177/026461960402200107

Wright, L. M., & Leahey, M. (2013). *Nurses and families: A guide to family assessment and intervention* (6th ed.). Philadelphia: F.A. Davis.

Chapter 2

TRANSITIONS AND OLDER ADULTS: AN OVERVIEW

> *Old age. We dread becoming old almost as much as we dread not living long enough to reach old age.*
> *(Walsh, 1989, American family therapist and writer)*

Reflective Questions

- What aspects of aging make transitions more complex and difficult to manage than in younger adulthood?
- What demographic trends in Canada, the Unites States, and other developed countries complicate how older adults manage transitions?
- What are some challenges that nurses and other professionals face in assisting older adults through transitions?

The pervasive dread of old age within developed countries was poignantly expressed by Walsh (1989). With raw honesty, she articulated the sentiments of numerous individuals in Canada, the United States, and other countries. Many individuals within developed countries do not eagerly anticipate getting old. In fact, through means such as plastic surgery and permanent makeup, some try gamely to resist reflecting their advancing years. Why is old age so feared? What is it about the changes and challenges experienced in older age that frightens many adults? We suggest that some of these changes and challenges involve transitions. While some of these transitions may be readily embraced, for example retirement, a number of them present obstacles to enjoyable and independent living.

Within the first chapter, we addressed the concept of transitions and how transitions may be experienced across the lifespan. Within this second chapter, we consider the types of transitions that older adults face and why are these transitions so daunting. We examine demographic changes in Canada and other developed countries that may impact how older adults experience passages. We also highlight the challenges that nurses and other professionals may face when working with older adults and their family members who are experiencing these life transitions. While we cover illnesses that older adults face, our focus is purposefully on how older adults and their family members face these illnesses *as transitions*, and

how these illnesses may precipitate other transitions; our focus is not to offer an in-depth examination of pathophysiology, pharmacology, or medical treatment.

Intentionally, this chapter is an overview for the subsequent chapters, wherein specific transitions, such as the transition to hospital and then a continuing care facility, such as a nursing home, will be explored in greater depth. In ensuing chapters we will address the complexities of how experiences of transitions in the past color and impact how older adults face current transitions (life course perspective), the circular nature of the influence of transitions upon older adults and older adults' responses to the transitions, and the existential impact of later life transitions upon older adults. Within this chapter we lay a foundation by simplistically pulling out and explicating contextual factors and transitions one by one.

WHY THIS IS AN IMPORTANT TOPIC

Understanding the transitions faced by older adults and the reasons why these transitions can be so difficult is important, in part, due to contextual factors. These contextual factors shape how older adults experience transitions related to age and age-related conditions and include demographic changes such as the explosive growth of our older adult population, the low birth rate, and the substantial geographical mobility in Canadian and American societies and other developed nations, as well as the heterogeneity of the older adult age grouping. In particular, these demographic changes converge to greatly change how older adults experience aging, compared to older adults of earlier generations.

Numbers of Older Adults

Canada's population as a whole continues to age. Statistics Canada (2012) reported that the median age of the Canadian population was 40 years of age. Twenty years prior—1992—the median age was almost 6.5 years younger, approximately 33.5 years of age. By 2036, the median age of Canadians is projected to be between 42 and 45 years of age (Statistics Canada, 2010a). In terms of the older adult population, what does this mean? As of 2012, older adults represented approximately 14.9 percent of the entire population of Canada. This proportion was 11.6 percent in 1992 (Statistics Canada, 2012). The proportion of older adults within Canadian society will continue to increase dramatically; it is projected that by 2036, older adults will comprise somewhere between 23 and 25 percent of the entire population of Canada. Similarly, within the United States, older adults comprised 13 percent of the population in 2009. However, the percentage of older Americans is projected to jump to 20 percent by 2050 (Jacobsen, Kent, Lee, & Mather, 2011). Perhaps even more significant is that the numbers of very old Canadians and Americans—those 80 years of age and older—are expected to escalate significantly between 2040 to 2050 (Jacobsen et al., 2011;

Statistics Canada, 2010a). As the very old generally experience far more physical and cognitive health problems and often require greater amounts of healthcare, this stark increase in the very old demographic will place added importance in supporting the transitions necessary at that stage of life.

Birth Rates

Within the past half century, Canada, as well as other developed countries, has experienced a drastic plunge in birth rates. In 1960, Canadian women gave birth to an average of four children. By 1997, the birth rate dropped to approximately 1.5 children (George, Loh, Verma, & Shin, 2001). Currently, the birth rate in Canada is estimated to be 1.59 children per woman, and in the United States of America, 2.06 children per woman (CIA — The World Factbook, 2012). This means that in Canada, our birth rate is not sufficient to simply replace ourselves.[1] As adult children, particularly adult women, provide the bulk of informal support to their aging parents, this drop in available adult children to help aging parents as they experience transitions is significant. Additionally, the geographical mobility of adults in developed countries further complicates the ability of family members to support older adults through transitions.

Geographical Mobility

Generations ago, it was not unusual for adult children to live in close proximity to their parents. This meant that adult children could attend, even daily, to the concerns and health needs of aging parents. Their close proximity meant that they could be physically present to provide care and to monitor changes in their parents' well-being. However, as many adult children now move away from their parents for education and employment, the ability to provide hands-on care or attention is hampered (Jutras, 1988). This is not to deny that many adult children valiantly attempt to provide some measure of watchfulness and assistance from a distance, but the opportunities to recognize subtle or not so subtle changes in parents is compromised by geographical distance. And, to further compound the issue of monitoring, older adults may hesitate to share their worries regarding health or other transitions, for fear of worrying adult children who are unable to physically address their concerns in the immediate.

---

[1] A related concept to birth rate is termed *replacement rate*. This construct factors in the mortality rates of children within a country, as well as accounts for women who choose not to, or are unable to, have children. In developed nations, the generally accepted replacement rate is 2.1 children per woman, so that a society will replace itself, resulting in "zero population growth." In developing nations, where mortality rates of infants/children are higher, the replacement rates are greater (Rosenberg, 2009).

Employment Rate of Women

As mentioned previously, adult women often provide the vast amount of care to aging parents. Their availability to provide care is now often impacted by employment. Prior to the 1970s, many women were homemakers. For example, in 1976, only 39.1 percent of women with children were employed outside the home (Statistics Canada, 2010b). This meant that a large number of women could care for their children, but also have some flexibility in providing care to aging parents, especially when their children were in school. However, by 2009, 72.9 percent of women with children under the age of 16 were employed (Statistics Canada, 2010b). The considerable increase in women's employment status has reduced the discretionary time available in women's schedules to provide care for their parents. Despite the reduction in flexible time, however, adult women still provide the majority of caregiving for older parents, which is reflected in terms such as the "sandwich generation" (coined by Dorothy Miller in 1981) and "women in the middle" (Dautzenberg, Diederiks, Philipsen, & Stevens, 1998). The toll this takes upon women in this category is being increasingly recognized; their health and well-being is affected by the demands of being in the sandwich generation. Reciprocally, this impacts the care they can provide to one or more aging family members (Kind, 2010).

The Heterogeneity of This Age Grouping

The term *heterogeneity* refers to "the quality of being diverse and not comparable in kind" (Free Online Dictionary, 2012). Older adults, as an age grouping, are the most heterogeneous grouping of all age populations. This means that the degree of differences in older adults is greater than any other age grouping, for example, children or adults. How can this be? First, the classification of old age is somewhat arbitrary and, within developed countries, is often tied to when individuals can access government pensions (Hirst, 1990). Currently, then, older age commences around age 65 in some developed countries. With individuals living so much longer, and the "old-old" (those 85 years of age and older) being the fastest growing group of older adults within Canada (Statistics Canada, 2008), adults may be considered "old" for 20 years or longer. The sheer length of time older adults are considered "old" allows for great diversity in how individuals function and where they live.

Second, there are sub-populations of older adults who are older much earlier than the 65 years of age demarcation, such as those with developmental disabilities (Hirst, Lane, & Seneviratne, 2013), those with HIV/AIDS (Lane, Hirst, & Reed, 2013), older incarcerated individuals (Beckett, Peternelj-Taylor, & Johnson, 2003), and aboriginals within Canada (Grose & Pravikoff, 2012)[2] or Australia (Caple & Schub, 2012).

---

[2] Aboriginal people in Canada have a higher frequency of cardiovascular diseases, diabetes, and HIV/AIDS than the general Canadian population. Their life span is significantly shorter than the national average; on average they die 5 to 17 years earlier than non-Aboriginals (Grose & Pravikoff, 2012).

For these older adults, either disease processes or, in the case of HIV/AIDS, disease processes coupled with the long-term effects of HIV medications, have resulted in these individuals being much older physically, at a much younger age (Lane et al., 2013). These individuals are often considered older adults in their 50s and may require assistance with stable housing, such as group homes, housing support, or eventually, nursing homes. The difficulty in transitioning to other accommodations for this sub-population is that they often do not "fit" with the other residents within these settings. For instance, older adults with HIV/AIDS may find themselves homeless, but accessing a homeless shelter is not a suitable option due to potential exposure to infections (Furlotte, Schwartz, Koornstra, & Naster, 2012). Similarly, accessing nursing home placement is not ideal for individuals with HIV/AIDS or for those with developmental disabilities, as these older adults are significantly younger than most of the residents within these settings.

Third, there is often a sharp discrepancy in the level of health amongst those who are in their late 60s as compared to those who are in the mid 80s or older. As an example, the Canadian incidence of Alzheimer's disease or related dementias is approximately 8 percent at 65 years of age and older. However, by 85 years of age and older, the incidence jumps to 35 percent or higher (Canadian Study of Health and Aging Working Group, 1994). A 68-year-old man, in good physical shape and with intact cognitive abilities, is in a much different stage in his life than an 85-year-old woman with moderate stage Alzheimer's disease who is transitioning to a continuing care facility , such as a nursing home. The 68-year-old man will most likely be living in his home, will require little to no support with activities of daily living, may still be working part-time or volunteering, and will manage his life independently. However, the 85-year-old woman with moderate-stage dementia will need assistance with activities of daily living, such as bathing, dressing, and eating, will not be able to manage her finances and may not recognize family members (Alzheimer Society of Ontario, 2012). The difference between these two individuals is enormous, and by extension, there is a stark difference in the demands placed upon the family members of these older adults.

WHAT ARE THE TRANSITIONS FACED BY OLDER ADULTS?

There are multiple transitions that occur within older age. Some of these transitions are related to societal expectations, such as retirement, and others relate to physiological changes in older adults or their spouses, such as illness or death. Transitioning to an assisted living facility or a nursing home may be precipitated by illness in the older adult, the death of a spouse, or significant cognitive impairment (Buhr, Kuchibhatla, & Clipp, 2006). Transitioning to other living situations may trigger existential issues and cause older adults to consider the meaning of their lives and what it means to die.

Retirement

Retirement—the cessation of part-time or full-time paid employment—marks a major life transition for many aging adults. Although viewed as a "normal," or even "desirable," this transition is far more complex than may appear. There are a number of factors that impact how older adults experience retirement. For instance, is retirement voluntary or forced? Some evidence suggests that older adults cope better with retirement if it is voluntary and anticipated (Hardy & Quadagno, 1995; Reitzes & Mutran, 2006); in these situations, these adults specifically *choose* to leave work. The ability to choose preserves, to some degree, the sense of identity and control in life. Second, are there financial concerns about retirement? Some older adults express significant concern about how they will cope with the reduced income that comes from retirement (Nuttman-Shwartz, 2004). While these older adults may have enough money to pay their bills, will they be able to afford the activities that they find meaningful? If newly retired individuals cannot afford to engage in activities that they once did, how will they manage the boredom of being at home all day and the stress of being in the constant company of their spouses (Nuttman-Shwartz, 2004)?

Third, are there health issues that trigger the retirement, either of a working older adult, or his or her spouse (Hardy & Quadagno, 1995)? While an older man may feel some sense of relief to retire when struggling with a chronic illness, he may also feel that his choice of retirement was taken away, not by a company, but rather by illness and life. In these situations, the perceived lack of control over an illness may result in him feeling demoralized upon retirement. A similar process may occur when leaving work to care for an ailing spouse. When an older woman leaves a job that she loves to care for her ill husband, she may resent being pulled away from the perks of her work: structure in her life, social contact, purpose, and a sense of pride and accomplishment in earning money. If her husband was hospitalized for a serious illness and now is being discharged home, she may feel unprepared and even frightened to be the person solely responsible for her husband's care (Plank, Mazzoni, & Cavada, 2012). Retirement may affect not only how she views herself, it may impact how she views her spouse.

Regardless of the reasons for this transition, retirement can have a profound effect upon individuals' sense of personhood and identity, upon social contacts, and upon daily structure and finances. Older adults may wonder what purpose their life will have after retirement, and this question may cause them to reflect back and wonder if their life had meaning prior to this point in time (Gaede, 2010). Although some older adults welcome retirement and truly flourish during this time, others struggle. Decades ago, some adults held the belief that once retirement came, death followed shortly thereafter. Also, as practitioners working with older adults, we know of situations where retirement has precipitated a suicide attempt in the older adult. The loss of identity and daily structure was too much to bear. Within the upcoming chapters, we will continue to address some concerns

related to retirement, including the need for financial planning, as well as for aging adults to give some consideration to issues of purpose and meaning in life.

Illness

Older adults often experience life-changing illnesses. These illnesses can cause profound transitions. Health crises, such as myocardial infarctions (heart attacks), may be life-threatening or can cause significant changes in physical functioning of older adults. Older adults who suffer ischemic strokes without receiving timely thrombolytic therapy experience significant changes in functional abilities (Smeltzer & Bare, 2004). For example, the older man may become hemiplegic and have great difficulty in dressing himself and bathing; he may be no longer able to manage independently within his home. Arthritis, as the most commonly reported chronic illness by Canadian older adults (Turcotte & Schellenberg, 2007), may hinder an older woman from maintaining her home and yard; climbing stairs may no longer be possible. If her spouse is having difficulty providing care for her due to the extent of her disabilities and structural issues within their home—such as steep staircases—this couple may need to move to a seniors' complex or an assisted living facility. While some older adults look forward to moving to an assisted living facility where their meals are prepared, many grieve the loss of their home. Their home represents more than a physical locality; it incorporates the deeper and richer meanings of comfort, security and community (Gillsjo & Schwartz-Barcott, 2011). The grief, as well as powerful and conflicting emotions experienced (e.g., ambivalence), may be even greater when the move is to a nursing home, rather than an assisted living facility (Davies, 2005; Gill & Morgan, 2011; Kao, Travis, & Acton, 2004). The grief and emotional response associated with the loss of an independent dwelling will be addressed further in Chapter 4.

Widowhood: The Death of a Spouse

The death of a spouse is one of the most stressful and heart-wrenching transitions experienced by an adult (Holmes & Rahe, 1967). Sometimes it is assumed that the death of a younger spouse is more difficult than the death of an older spouse; the underlying premise in this assumption is that the couple should have had many more years together and therefore the death of a younger spouse is more tragic. However, we suggest that advancing age does not necessarily make the death of a spouse easier. Often older couples have developed an interdependence whereby they assume different tasks and roles in their relationship; there is a wonderful sense of needing and being needed. The identity of each is intricately, and sometimes inextricably, entwined with the other; the "two have become one" (Genesis 2:24). Hence, the grief associated with the loss of a spouse can be profound. An older man who has lost his wife has not only lost his spouse of 55 years, but may also have lost a close friend, a confidante, and a cook and housecleaner

(Gibson, 2012); he may feel like he has lost a part of himself, or himself completely. He may wonder why he should continue to exist when his spouse of many years has passed (Damianakis & Marziali, 2012). Social isolation may further complicate his transition to widowhood; he is no longer part of a "couple" and hence may lose social groups to which he and his spouse belonged.[3] Not only does loss have an impact on the quality of life, it may also impact health. For instance, the social isolation and loneliness that come from the loss of a spouse can lead to poorer health outcomes (Working Together for Seniors, 2007).

Transitional Moves to Other Locations

Older adults may experience multiple moves within a very short time, and these moves may not be welcomed or planned. The moves signify a leaving of home. As will be discussed in Chapter 4, the "home" of an aging adult means much more than four walls; the concept of home is imbued with meaning and security (Gillsjo & Schwartz-Barcott, 2011). An older adult may move from her home to the hospital and reside on one or more hospital units during her hospital stay. It may be determined that due to confusion, she is not capable of living safely alone in her home, and she may be transferred to an assisted living facility or a nursing home (depending upon the assessment in hospital). Even when in a facility, she may still experience moves to another facility or back to the hospital. These moves may cause significant emotional responses in older adults; they may experience grief in their moves, as well as anger, confusion, and a sense of being lost (Kao et al., 2004; Newson, 2008).

Death of the Older Adult: The Final Transition

Not only may older adults face the death of a spouse, but by virtue of their age, they face their own impending death. For much of an adult's life, the aging process is either avoided through cosmetic procedures or poked fun at: "You're not 50; you're 41 with nine years experience!" exclaims one "Happy Fiftieth Birthday" card. But over time, the reality of old age and its challenges, become unavoidable: "Old age is no place for sissies," Bette Davis poignantly stated (BrainyQuote).

The losses associated with the aging process can be preparatory in facing one's own passing. But the final transition, heretofore not experienced, can demand all the "tools in the toolbox" of the older adult whose resources may already be taxed. The mindset of North American culture, which is often described as "death denying" (Rando, 1984, pp. 5–8), may also hinder the older adult's preparation in dying; family members may avoid the topic of death, thinking they are being

[3] This complication to an older person's grief is particularly piercing for widowers, who may have solely relied upon their wives for meaningful relationship (Hart, 2001).

helpful. Unfortunately, it is a regular occurrence in palliative care to have family members ask staff not to tell the patient that she is dying: "We don't want Mom to give up hope," is often the rationale. Meanwhile, the older adult in the hospice bed will say confidentially to staff, "I know I'm dying, but my kids don't want to talk about it." How ironic and sad!

Old age and impending death can have profound impact upon a person existentially. *Who am I? What has this all been for? What comes next?* These questions are commonly asked. Belief systems at this point in life can be helpful or hindering in facing into death; in some cases, there is opportunity to do spiritual/existential work in preparation for the final transition. The internal resources the older adult has used in life for meaning and coping can play a large role in how he faces into mortality; the healthier the spiritual, psychological, and emotional resources, the smoother the process is likely to be. However, an exception to this may be in situations where the older adult is experiencing a dementia and the cognitive processes are hindered; but even then, some of the existential structures of the past can be accessed and utilized by family members and healthcare professionals to help bring comfort. Within Chapter 5 we will discuss the existential issues of dying in much greater depth.

Also, an older adult's external resources—support systems—play a vital role in facing into death. Support systems within the family, as well as outside the family, such as friends and community contacts, can be significant. They can provide support, as well as infuse the dying person's journey with meaning.

We touched upon the changing older adult population in North America (and other developed countries) earlier in this chapter. As more adults live into very old age, the need for professional caregiving for the dying will become all the more vital. Hospitals, nursing homes, palliative home care, and hospices all play, and will continue to play, essential roles in providing care for the older adults. Seniors living in larger urban centers are more likely to have access to specialized end-of-life care; unfortunately, those residing in rural areas may have less access to these services. Within Chapter 6 we will delve into the profound issues of death and dying for the older adult.

THE COMPLEXITIES OF TRANSITIONS IN OLDER ADULTHOOD

Within this book, we aim not only to describe the transitions faced by older adults, but also to demonstrate how these transitions can be far more complex than those experienced at earlier years. These complexities impact not only older adults, but their family members. Additionally, nurses and other professionals may need to tailor assessments and interventions to acknowledge and address these complexities. The following example illustrates in a brief manner why transitions can be so arduous for the older adult and her family members.

Case Example

Tina is a 75-year-old woman who is currently staying on a geriatric unit. She was brought to hospital against her will when police received a call from the manager of the apartment building where she had been residing. When the manager entered Tina's apartment, he noticed a foul smell. There were pots and pans scattered throughout the apartment that were used as makeshift toilets. Papers were strewn all over the floor and the only food in the apartment was rotten. Tina looked disheveled with greasy hair; her clothing looked and smelled dirty. The manager informed police that while Tina's apartment was never clean, when her husband was alive, he made sure that there was some semblance of sanitation and that Tina's hygiene was tended to. Sadly, however, Tina's husband passed away six months prior. As police determined that she was a hoarder and unable to safely care for herself, they brought her to hospital under the provincial mental health act.

Initially, Tina spent several days in the emergency department of a hospital in a large urban center in western Canada. She was then transferred to a medical unit, but made life miserable for the nurses and staff. She swore at the nurses and threw her medications and food trays at staff. The staff complained that they were not able to care for Tina, so she was then transferred to a geriatric unit.

Since being on the geriatric unit, Tina has been diagnosed with probable frontal lobe dementia and possibly some vascular dementia related to a previous small stroke. She continues to hoard papers, magazines, and food in her room. In fact, she hides food under her hospital mattress and in her clothing cupboard with soiled laundry. Her son and daughter, both in their early 50s, are extremely ambivalent about becoming involved in the care of their mother. While they care about an older woman who clearly needs help, the fear and even terror of the years spent being emotionally and physically abused has been re-evoked by being in her presence now. Although their father could act as an intermediary between the children and Tina, his death has meant that the "go-between" between them and their mother is gone.

The psychiatrist and staff are in a quandary. Tina clearly cannot care for herself and yet she seems too young and physically well for a nursing home. Her adult children, however, are adamant that they cannot take Tina home to live with them. The psychiatrist explains to Tina's children that although a nursing home is not the best fit for Tina, this is where she will eventually be placed. However, the psychiatrist and staff know that it will take some time before they find a nursing home that will accept Tina.

Although Tina is a composite of older adults we have worked with, her situation illustrates some of the transitional issues faced by older adults and their family members. First, older adults often experience multiple transitions at once or within a relatively short period of time. In Tina's situation, the death of her husband may have exacerbated her hoarding tendency, and certainly, the death revealed her inability to care for herself. This then led to being taken to hospital against her will. Within the hospital, she experienced the transition of moving from the emergency room to a medical unit and then to a geriatric unit. The multiple moves within the hospital have, unfortunately, exacerbated her confusion (Detwiler, 2003) and anger.

Second, some of the physical and cognitive changes associated with illnesses in older age—such as myocardial infarctions or dementia—represent transitions in and of themselves, but they also may trigger a new transition, such as retirement (Turcotte & Schellenberg, 2007) or placement into a continuing care facility, such as a nursing home (Alzheimer Society of Ontario, 2012). While the issue that triggered the call to police related to pungent odors wafting through the apartment hallways, Tina's inability to take care of hygiene needs and cook for herself resulted in the transition to hospital, and ultimately, to a nursing home.

Third, older adults are more likely to experience widowhood than younger adults (Government of Canada, Newsletter of the National Advisory Council on Aging, 1998). In Tina's situation, her husband was a stable influence in her life. He made sure that she received proper nutrition and that she maintained some measure of hygiene. When he passed away, Tina not only lost her husband, but lost her partner who, through his efforts, allowed her to live in an independent dwelling. Six months after the transition of the death of her spouse, Tina is now residing in a hospital awaiting placement in a nursing home. Hence, her move to a nursing home was precipitated by the death of her husband. Like Tina, some seniors in Canada and other developed countries are able to remain in their homes, as long as their spouses are able to compensate for their deficits by cooking, doing housework, assisting in hygiene and providing continuous monitoring. When the spouses pass away, the functional weaknesses in individuals such as Tina are revealed and/or exacerbated, forcing transitions that are not necessarily welcomed by these older adults. The death of a spouse becomes much more than the death of a spouse; it often becomes a series of life-changing transitions.

Fourth, transitions faced by older adults may require the decision making involvement of adult children, such as the move to a nursing home or hospice. The decision of adult children to place their parent can be extremely difficult and traumatic to make (Chang & Schneider, 2010; Noonan, Tennstedt, & Rebelsky, 1999; Silverberg, 2011). In some circumstances, such as with Tina, adult children may have great difficulty making decisions on behalf of their older parent, because

that parent was abusive when the children were younger. As in the situation of Tina, dealing with her hospitalization and impending placement re-evoked painful childhood memories for the children. The current events are, in essence, retraumatizing the adult children as they relive the memories of their childhood. Even if the relationship was not tainted by prior abuse or neglect, the decision on behalf of the children to place an older parent may negatively impact the child–parent relationship, at least temporarily (Gill & Morgan, 2011).

Fifth, when younger, some older adults may have developed and cultivated coping mechanisms, such as strenuous exercise, to decrease stress and enhance feelings of control and well-being. By the time some of these older adults reach their sixth and seventh decades, they may need to greatly curtail or adjust their level of exercise due to chronic pain and osteoarthritis (Statistics Canada, 2010c). For some older adults, the inability to utilize exercise as a coping mechanism can be a significant loss. While we do not know if Tina exercised or what coping methods she used, her husband provided some stability in her life, which may have enhanced her coping.

Finally, unhealthy coping methods in earlier years, such as the abuse of alcohol or other substances, may have more deleterious effects with advancing age. For instance, older adults may be less able to metabolize benzodiazepines than in previous decades, and now may experience confusion or gait imbalances (Lilley, Harrington, Snyder, & Swart, 2011), which can lead to falls and fractured hips. Although we do not know whether Tina abused substances, or even whether she would admit to this if asked, this may not be a substantial problem for her, as she does not appear to have experienced withdrawal symptoms.

UNDERLYING ASSUMPTIONS IN WORKING WITH OLDER ADULTS

As we begin to consider how nurses and other professionals can work with older adults to assist them with life changing transitions, we would like to address assumptions which underpin our discussion in the subsequent chapters. The underlying premises include:

- **Older adults are amazingly resilient, despite the multiple challenges they face.** To work effectively with older adults and their family members, nurses and other professionals should adopt a strengths-oriented stance. This may involve a conscious choice on the part of nurses and other professionals to view older adults as resilient, rather than as weak and full of deficits and problems. As noted by Hwang and Cowger (1998), many practitioners believe they operate out of a strengths-oriented approach, but may actually fail to do so.

- **Transitions in older adulthood may be more difficult to face than those in younger adulthood.** The multiplicity of health changes and illnesses that occur in advancing age, as well as magnitude and permanence of changes (e.g., retirement, death of a spouse, death of friends) can converge to make transitions in older life extremely challenging. Not only may the older adult and family members feel befuddled on how to make sense of the multitude of changes and what to address first, but healthcare professionals may also be at a loss on how to unravel the complexities of a situation.
- **Experiences with transitions in earlier life may influence how older adults manage current transitions**. This assumption is congruent with a life course perspective in which past situations and circumstances (both in terms of personal circumstances, as well as the historical context) impact how older adults face present situations. If aging adults experienced transitions in earlier life as negative or devastating, they may approach current changes with dread. Conversely, if transitions such as immigration, education, and marriage were experienced as challenging, but rewarding and even exciting, older adults may face present day changes with greater optimism. Interestingly, older adults may not consciously tie their current dread of a transition to previous negative transitional experiences. They understand that they feel fear and anxiety over the changes today, but they do not recognize that this fear is in part driven by traumatic transitional experiences in the past.
- **Illnesses, particularly those that impact physical or cognitive functioning, are transitions in and of themselves, and often lead to further transitions.** Although challenging, illnesses in adulthood often do not lead to significant changes in living locations or to changes in being able to care for oneself. In older adulthood, illnesses may lead to moves from home to hospital, to assisted living facilities or nursing homes, or to hospices. In some cases, the move to nursing homes or hospices represents a physical fracture in the relationship with spouses, as these older adults no longer share a bed or physical location with their spouses. Even if spouses remain in the same physical locale, illnesses may change the dynamic of the relationship, whereby the spousal relationship becomes a caregiver–care receiver relationship, rather than an interdependent marital partnership.
- **There can be a circular relationship between transitions and the responses of older adults** (Wright & Leahey, 2013)**.** The influence of the transition(s) may lead older adults to think, feel, and behave in certain ways, which can complicate or ameliorate the impact of the transition upon the older adult. When older adults perceive transitions to be devastating, they may become depressed and anxious and unable to exercise positive actions on behalf of themselves. This may then exacerbate the impact of the transition. For instance, an 80-year-old man who is unable to cope with the death of his wife may become severely depressed and stop eating or caring for himself. This may

cause his children to worry about his safety and question his ability to live alone. The children may then make plans for an assessment for nursing home placement, which further reinforces to the older man that life is not worth living. Thus, the circular relationship (Wright & Leahey, 2013) between this man's responses to the initial transition of widowhood precipitates further negative emotions, thinking, and actions (or inactions), and eventually leads to his children's initiation of an assessment for placement.

- **Transitions in older adults may influence their very sense of personhood and can lead to existential issues.** While arguably, the ability to weather and successfully move through transitions at any age impact a sense of personhood, this is particularly the case for older adults, *due to the magnitude and sometimes permanence of transitions.* Transitions in older age often involve significant changes in functional abilities, and possibly, in areas that are quite personal and that, in the past, were associated with maturity and independence. For example, when toddlers master bowel and bladder control, this may be seen as a sign of maturity and mastery. In advancing years, the loss of bowel and bladder control may be viewed as a return to a more infantile and dependent state and viewed with humiliation and horror. Transitions related to changes in housing are not associated with moving to "bigger and better" like younger adults, but rather for some aging adults, are associated with a downward progression to dependence and death. "This is the last stop," said one older adult in response to the nursing home he was entering.
- **Transitions in older adults place enormous challenges upon family members.** As will be discussed throughout this book, the transitions faced by older adults result in major stressors for spouses and adult children. Not only do family members often step in to fill in the deficits in daily functioning—personal care, cooking, driving to doctors' appointments, and other such tasks—but present day demands can re-evoke painful issues of the past. These painful issues may have occurred between parents and children, or they may have transpired between the siblings. Adult siblings, who for years communicated very little, now have to come together in some fashion for the care of aging adults. This can be positive and result in some measure of restoration of relationships, but can also reinitiate feuds between siblings. We suggest one more point about the stressors experienced by adult children; that is, adult children may become frightened by the changes and challenges experienced by their parents. This is often the case when adult children are attending to a parent with dementia. The level of memory loss, behavioral changes, and total dependency may scare them. They understandably ask, "Will this be me in 20 years?" Adult children may also wonder about the meaning and purpose of life, if all their years of hard work amount to the fate of one or more parents: experiencing dementia, nursing home placement, and death. They may question "the point" of their efforts now, if there is no experience of fulfillment, meaning and joy at the end of their labors.

- **Nurses and other professionals need to assess and intervene**. Professionals need to be especially astute about how the interactions of multiple transitions affect the abilities of older adults and their family members to cope. Sadly, nurses and other professionals may view work with older adults as unappealing, requiring fewer clinical skills and not intellectually challenging (Happell & Brooker, 2001; Stewart, Giles, Paterson, & Butler, 2005; Swanlund & Kujath, 2012). Unwittingly, professionals have often assimilated negative views on aging, even prior to entering work in the health care or human service sectors. We suggest that working with older adults experiencing transitions requires highly sophisticated assessment and intervention skills, not just with the seniors, but also with their family members. It also requires a sensitivity towards, and willingness to discuss, issues that are larger than life, and indeed, transcend the present understandings of reality. (This will be addressed further in Chapter 5).

These underlying assumptions will be interwoven through the fabric of discussion in upcoming chapters.

CHALLENGES FOR NURSES AND OTHER PROFESSIONALS

With these underlying assumptions made explicit, there are a number of challenges that nurses and other professionals may encounter when assessing and intervening with older adults experiencing transitions. These challenges relate to the lack of educational preparation in Canada and some other developed countries to work knowledgeably with older adults, the circumstances of the older adult, the inclusion of the family in working with the older adult, the personal/professional circumstances of professionals, as well as systems issues faced by those intervening on behalf of the older adult.

Lack of Undergraduate and Graduate Gerontological Content

Many undergraduate and graduate nursing and social work programs have a limited amount of gerontological content within their programs (Baumbusch & Andrusyszyn, 2002; Grocki & Fox, 2004; McCleary, McGilton, Boscart, & Oudshoorn, 2009; Roberts & Blieszner, 2007). Pathophysiology, mental health, and pharmacology are taught within the adult context, but not necessarily the *older adult context.* The underlying assumption is that disease processes and life stressors affect older adults the same way as younger adults. Unfortunately, this is not true. For instance, many healthcare professionals are not aware that older adults may have significant infections, but not register as febrile (feverish) (Smeltzer & Bare, 2004).

Further, many professionals are not aware of how older adults with depression can present differently than their younger counterparts (Canadian Mental Health Association — Ontario, n.d.).

Approximately three decades ago, a call went forth in nursing literature for the need to educate nurses in gerontology in order to meet the changing demographics—the boom of the older adult population. What has been the response to this call?

Despite the recognition that knowledge about older adults is absolutely crucial to provide good care to our aging population, interest in and commitment to this specialty is relatively small in comparison to the need for knowledge. First, there appears to be confusion surrounding how best to teach gerontological concepts within nursing and social work programs. There are differences in position as to whether it is best to teach gerontological content within an integrated approach (where content is assimilated into existing courses), or to offer stand-alone courses (Hirst, Lane, & Stares, 2012). While students may like an integrated approach, the challenge is to monitor *how much* gerontological content is being taught and *how* it is being taught. Some researchers call for a mixed approach where there are stand-alone courses and integrated content (Gebhardt, Sims, & Bates, 2009). However, the trend seems to be toward integrated curriculums. In their 2008 survey of undergraduate and graduate nursing and social work programs in Canada, Hirst and colleagues (2012) found that 79 percent of programs reported that gerontological content was assimilated into the curriculum.

Second, despite the attempts of nursing and social work programs to bolster gerontological content within their programs (Hirst et al., 2012), there are very few faculty members that report gerontology as their specialty and relatively few students indicate a commitment toward working with older adults. In the above cited survey, only 2.4 percent of master's prepared faculty and 6 percent of doctorally prepared faculty had a gerontological focus. Correspondingly, only 6 percent of students chose a gerontological setting for their final practicum experience (Hirst et al., 2012). How do these Canadian results compare with other countries? There are similar results from the United States. In 1996 only 3 percent of Master's of Social Work students identified older adults as their population of focus (Scharlach, Damron-Rodriguez, Robinson, & Feldman, 2000). In a pilot study of American nursing students, Swanlund and Kujath (2012) found that gerontology tied with psychiatry for seventh place out of a possible 10 places to work. Placements such as pediatrics, obstetrics, intensive care, the operating room, and oncology took precedence over working with older adults. Similarly, in an Australian study, very few students entering nursing chose gerontology as a preferred area to work in the future. Rather, most students chose obstetrics, pediatrics, and critical care (Happell, 1999).

There are extrapolations that can be made from the lack of expertise among faculty and the lack of interest in gerontological work among students in developed countries. With few faculty members truly excited to work with older adults,

how can programs ensure that content about older adults will be taught in an accurate and effective manner? Also, how will students become interested in this specialty? In our teaching experience, students often choose an area of specialty when they are taught and mentored by faculty who are knowledgeable and enthusiastic about an area of expertise. Once in the work environment, will these new graduates be able to find mentors that are committed to working with older adults? If these students return to graduate school, how will they find appropriate faculty supervisors if there are a limited number of professors specializing in the care of older adults?

Circumstances of Older Adults

Some aging adults experience life circumstances that complicate how they experience transitions, and thus, add to the complexity of the work of nurses and other professionals. Some of these life circumstances include the multiplicity of transitions that can occur concurrently or in rapid succession, the compromised mental status of some older adults, inexperience with new systems, the impact of transitions upon older adults' perceptions of personhood and the sense of hopelessness in some older adults.

Multiple Transitions

For older adults, one transition often involves multiple transitions. As mentioned earlier, a serious illness may result in involuntary retirement or in a move to a facility, such as an assisted living facility, a lodge, or a nursing home. In these situations, the first transition, that of experiencing a serious and life-changing illness, directly impacts other life circumstances, such as work or living location. Not only does the older adult need to contend with changes in his physical or cognitive status, but he also now has to cope with a change in his social contacts. If this older adult is no longer employed, not only does he lose the structure of going to work on a regular basis, he may lose collegial relationships; the context for his relationships—the work environment—is no longer available to him. Even if this man continues contact with these work colleagues, he can no longer share in the camaraderie of present day work strategizing or gossip.

Additionally, depending upon how he defines himself as a person, he may wonder who he is in relation to others and how he can now define himself. In this situation, the nurse or other professional working with this man needs to consider not just the physical illness, such as cardiac problems, but also how he is holistically impacted by retirement. Is this older adult depressed, not just because of the health problems, but because he does not know how to make use of his days in a meaningful and productive manner and is feeling isolated from others? If this is the case, the assessment of the nurses and other professionals will need to be more comprehensive, with interventions focused not solely on his illness. Professionals may also need to consider the impact of his health upon his marriage and social life.

Not only does the professional need to consider if there are other transitions than the most obvious change, but also, the professional needs to explore if there are more transitions occurring—like a domino effect—because of the first one, or if other unrelated transitions are occurring concurrently. The professional then needs to untangle from this complex ball of yarn the transition (s) that is/are causing the greatest adjustment difficulties for the older adult, isolating the following threads: What are the adjustment challenges, how can they be addressed in the immediate, and what issues can be targeted in the long run? This may take some time as the professional may view the situation differently from the older adult.

Mental Status

Another circumstance that may impact how older adults manage transitions involves mental status. If older adults experience cognitive decline related to a dementia, their ability to utilize coping strategies to process transitions will be diminished (Haase, 2010). Hence, an individual who could mentally strategize how to navigate through a difficult transition in years past, or who could restructure his thoughts (as part of cognitive restructuring) (Austin & Boyd, 2010) to reconceptualize strenuous circumstances, will no longer be able to tap into these mechanisms. In order to assist cognitively impaired older adults, nurses, and other professionals have to expand their assessments and interventions to include family members of these individuals, as well as the environments in which they live. A key goal of professionals will be to ensure the safety of older adults who cannot singly negotiate the transition to, for example, a nursing home, and support them, as well as family members, in the transition, thereby decreasing stress upon older adults with dementia, as well as family members (Haase, 2010).

Inexperience with Societal Norms of Relating

There is a small sub-population of older adults that have been incarcerated for many years. In their older years (50s and 60s), they may face a transition into the community to live in group homes or nursing homes (Snyder, van Wormer, Chadha, & Jaggers, 2009). These older adults may be very fearful and uncertain about the move into the community (Beckett et al., 2003). In part, they may have protected themselves within the prisons by withdrawing or becoming as inconspicuous as possible; now they may feel uncertain as to how to relate to others within mainstream society. There are other aspects that can complicate the transition for these older adults. Receiving facilities, such as nursing homes, may be very reluctant to accept someone who has been imprisoned for many years (Beckett et al., 2003). Also, family members who could offer support in the transition to a group home or nursing home may no longer be accessible; family members may have abandoned the relationship with the incarcerated member years ago (Snyder

et al., 2009). Finally, older adults who have been incarcerated for years often have significant health problems at a much earlier age than individuals in the general population. Thus, they may have mental health issues, such as depression, as well as substantial physical health issues, that may hinder their ability to form relationships with others and adjust in the new setting.

Assessing the Impact of Transitions Upon Sense of Personhood

In older age, transitions can significantly impact how older adults view themselves—their sense of personhood. Personhood can be defined as "the state or condition of being a person" (Free Online Dictionary, 2012). This definition, however, does not reflect the intangible aspects of personhood, such as identity, self-expression and decision making (Hirst, Lane, & Reed, 2013). Older adults who can no longer bathe on their own or dress themselves may feel a deep sense of humiliation. They may feel that they have become burdens and have little to offer to their families or society. An important aspect of working with these individuals is to encourage them to do whatever they can do for themselves, rather than quickly taking over the acts of dressing or bathing. Also, nurses and other professionals need to look for areas of strength in these older adults and verbally acknowledge these strengths to older adults.

As another example, moving to a nursing home can be traumatic for older adults, as who they were in the past may not be recognized by staff; instead, staff may view them as decrepit and dependent. Staff members need to make a conscious effort to understand who their residents were in the past, and who they are today (Greenfield, 1984). This knowledge can help staff to tailor activities to the interests and abilities of individual residents. Also, independent homes or apartments are often viewed by older adults as a reflection of their personhood—their walls, shelves, and cabinets display pictures and items that reflect who they are and what they enjoy. Staff may need to encourage older adults and family members to bring cherished items from home that reflect the personhood of the older adults and that help them feel more "at home" within their new residence (Cook, 2010).

Hopelessness: How Do You Instill Hope?

In my work in geriatric mental health (AML), one of the most difficult aspects of the work involved the instillation of hope, or perhaps the *reinstallation* of hope (Bergin & Walsh, 2005). Hope is absolutely critical, not only to quality of life, but to life itself. Individuals who experience great degrees of hopelessness are at greater risk for suicide (Uncapher, Gallagher-Thompson, Osgood, & Bongar, 1998). Even if individuals do not commit suicide, a loss of hope can be associated with illness and death. For example, within concentration camps in World War II, individuals who lost hope were prone to suffer illness and die more quickly than those who held steadfastly to hope (Fink, 2000, p. 391).

When older adults have lost so much due to declining functional abilities, death, and illness, how do nurses or other professionals help them rediscover meaning, hope and purpose in their lives? This is especially problematic when individuals' sources of hope are found in the "here and now," and are not partially rooted in an afterlife or in spiritual beliefs. It can also be difficult when the hopeless older adult is cognitively impaired and cannot engage in cognitive therapy to re-engage with life (Cutcliffe & Grant, 2001), or finds himself in difficult circumstances, such as the incarcerated older adult (Duggleby, 2005).

For nurses and health professionals, the struggle with hopelessness in older adults can impact their own sense of personhood. Despair can result. These professionals may wrestle greatly with how to bring purpose to their patients' lives, or help them reconnect with purpose. They may try to avoid speaking of issues of meaning. In healthcare settings where there is an interprofessional staff, these duties can be delegated. Chaplain and social work referrals are common. For the home care nurse, she often wears more than one hat in her role; how can she bring hope to elderly patients who are struggling?

Assessment Needs to Include Family Members, as Well as Older Adults

While a family approach to working with older adults in transitions is imperative when there is cognitive impairment, as a basic tenet for professional practice, family members should be included, irrespective of the older adult's status. Family inclusion in assessment and intervention will allow the nurse or other professional to understand the older adult within the context of her family (Wright & Leahey, 2013) and will also open up other possibilities for intervention—that is, with family members. While some professionals avoid family contact because of the amount of time it takes to intervene with relatives, intervening with family members may consume more time in the immediate, but by circumventing problems in the long run, end up saving countless hours on the part of nurses and other members of the health care team (Wright & Leahey, 2013).

Although including the family can bolster the support that relatives offer to older adults who are experiencing transitions, it can also unveil longstanding family issues (such as physical abuse or substance abuse) that impact how relatives are responding to and coping with the older adult's transition. This difficult circumstance was previously illustrated in the example about Tina. Issues from the past may also result in a stalemate between individuals within the family, whereby family members cannot come to an agreement on a plan of action for their elderly member and are vehemently opposed to working with each other. Professionals may become frustrated and even angry, as a family decision making stalemate can result in a lengthier hospital stay for the older adult, and in effect, block a hospital bed from another older adult who needs to be admitted. These situations will be explored at greater length in Chapter 7.

The Challenges of Working on an Interprofessional Team

In a number of settings where professionals work with older adults, they function as part of an interprofessional team. This team may consist of a physician or psychiatrist, nurses, one or more social workers, an occupational and recreational therapist, a psychologist, and a chaplain. The benefit of such a team is that professionals assess different aspects of functioning in their older clients (Dyer et al., 2003). For instance, a physician or psychiatrist, as well as nurses, may assess the mental and physical functioning of an older adult. Social workers may assess the family situation, as well as explore discharge options. Further, there is often overlap in what the professionals assess. This provides for a rich texture of clinical opinions and options in terms of how the team can help their elderly client.

However, the differing opinions may result in heated arguments about how the care of the client should be approached. In these situations, not only may professionals have differing life experiences that cause them to arrive at varied conclusions, but their professional discourses may influence their judgments. For instance, a prominent disciplinary discourse in nursing is that of safety; safety of the patient should be promoted at all costs (Lane, 2007). However, social work, as a profession, strongly promotes self-determination. In our experience, differences in disciplinary discourse can result in nurses and social workers, as well as other professionals, taking opposing sides in the decision to place an older adult in a nursing home. Nurses may argue for safety, while social workers may argue for self-determination, and therefore, a less restrictive environment for the client (Lane, 2007). Neither profession is wrong; they simply advocate for their older adults differently, depending upon the underlying tenets of their profession. Thus, members of interprofessional teams need to present their arguments to each other with maturity and respect, solid communication skills (Dyer et al., 2003; Junger, Pestinger, Elsner, Krumm, & Radbruch, 2007), and an understanding of each others' professional discourses (Lane, Waegemakers Schiff, Suter, & Marlett, 2010).

The Clashing of Professional and Personal Experiences

Nurses and other professionals working with older adults bring into their work not just their professional experiences, but also their personal experiences. This can be very positive. Previous experiences with older adults, such as grandparents, may enhance the opinions of professionals toward older adults (Wesley, 2005). In our experience, some professionals working in gerontology specifically chose to work with older adults because of fondness towards and respect for older family members. However, there can also be a downside. When professionals

have experienced personally traumatic experiences and a professional situation encountered in some way mirrors those previous experiences, professionals can feel traumatized. For instance, caring for an older woman who is an alcoholic may trigger frightening memories of being raised by an alcoholic mother. In our experience, we have seen professionals weep over work situations that have triggered personal memories. Also, professional experiences may trigger emotional responses from previous professional experiences, such as working with aggressive older adults, which may re-evoke feelings of fear and even terror in stepping into situations which bear similarities to the previously fearful situation (Scott, Ryan, James, & Mitchell, 2011). Nurses and other professionals working with older adults need to be mindful of how work experiences affect them professionally and personally.

Another issue related to the clash between personal and professional experiences involves compassion fatigue. Compassion fatigue refers to physical and psychological fatigue caused by extreme professional demands that sap the resources and reserves of professionals. It can result in professionals experiencing lowered levels of concern for patients or clients, exhaustion, lowered job satisfaction and increased absenteeism (Leon, Altholz, & Dziegielewski, 1999). Within acute care settings, compassion fatigue is normally associated with nurses and other professionals working in the emergency department (Hooper, Craig, Janvrin, Wetsel, & Reimels, 2010), critical care (e.g., Jenkins & Warren, 2012) or oncology (Aycock & Boyle, 2009); however, those working with older adults may also experience this.

There are a number of reasons why professionals may experience compassion fatigue in working with older adults. First, in working with older individuals, professionals may come face to face with their own fears about aging and death. These fears may especially be triggered if the professional is currently helping aging parents or family members. Second, depending upon the situation (hospital versus community, city versus rural), services for older adults may be relatively sparse. Third, as discussed earlier, older adults often have multiple illnesses and issues and dealing with the complexity of the situations may be physically and mentally exhausting for professionals (Leon et al., 1999).

Not only can helping aging parents trigger personal fears and issues regarding aging and death in nurses and other professionals, the *actual physical work of caring for aging parents* can contribute to the physical and psychological exhaustion already experienced at work (Ward-Griffin, St-Amant, & Brown, 2011). Ward-Griffin and colleagues (2011) conducted a qualitative analysis of two previous studies of nurse–daughter caregivers.[4] In analyzing the data of 20 Canadian

[4] In this specific study, all the nurses were female, hence the nurse–daughter categorization. It is noteworthy, however, that just as the majority of nurses are female, so are the majority of caregivers!

registered nurses who were also caring for aging relatives, they found that these women were at risk for compassion fatigue. Because of the context of being both daughters and nurses, there was a blurring of personal and professional boundaries. Further, the limited personal and professional resources of the nurses, combined with increasing expectations by healthcare providers on them to provide care to their aging family members, resulted in great burden upon these nurses (Ward-Griffin et al., 2011).

There is perhaps one more reason why nurses and other professionals may experience compassion fatigue in working with older adults. Eric Gentry, an American psychotherapist suggested,

> People who are attracted to caregiving often enter the field already compassion fatigued. They come from a tradition where they are taught to care for the needs of others before caring for themselves. (ISNA Bulletin, 2012, p. 5)

We agree wholeheartedly. Often individuals entering caring professions have already filled caring and caregiving roles within their families, churches and communities. While their previous experiences can be beneficial, in that they bring insight and compassion, they can also be problematic. Some of these individuals may already be tired from years of providing care to ailing family members. When they begin working as nurses, social workers, psychologists, etc., they may find themselves intensely fatigued and not realize why (as some degree of compassion fatigue is their "norm"); they now have caregiving roles within their families and communities, as well as their professions. Occasionally, professions involving caregiving will attract individuals who experience great mental distress and who only feel acceptable when they give of themselves extensively and to detrimental degrees. When these individuals face compassion fatigue or great challenges in their work situations, they may undergo a major existential and mental health crisis.

Systems Issues

There are "systems issues" that can complicate the work of professionals on behalf of older adults. By using the term *systems issues*, we refer to the structure or processes within healthcare systems that make the work of professionals challenging. One such structural issue relates to the relatively few readily available options[5] for older adults if they are not able to function independently within their homes.

---

[5] There are certainly more options available than nursing homes and assisted living facilities. However, other options, such as low-cost seniors' complexes or lodges may have long wait lists. Thus, for elderly individuals who are on a hospital unit awaiting placement, the major placement options include assisted living (or designated assisted living), as well as nursing homes. This will be discussed in further detail in Chapter 4.

Often, particularly if the older adult is currently in hospital and placement needs to occur quickly, the choices available boil down to nursing homes or assisted living facilities. Assisted living facilities are often upscale and can be expensive, and some older adults do not have the financial resources to afford this option. Further, if older adults are experiencing mental illness that impacts how they dress and relate to others, staff in assisted living facilities may be reluctant to allow them entrance. And yet, these same individuals, if healthy physically, may not meet the necessary requirements for nursing home entrance (Lane, 2011; Lane, McCoy, & Ewashen, 2010). Thus, just like in the case of Tina, professionals are in a quandary to find a suitable placement option. Their older clients do not fit comfortably in any of the facilities that are available.

Another systems issue relates to the extreme acuity of patients in acute care environments and heavy workloads for nurses and other professionals (Vander Zyl, 2002). High patient acuity coupled with weighty workloads results in professionals having less time than they otherwise would for older individuals who may need extra time for bathing, dressing, eating, and talking. The older adult who might need more time to reflect, answer questions, and make connections between past life events and current situations may not be given the time that he needs, not because of indifference on the part of the professional, but due to the extreme demands on the professional's time. The professional who enters a caring profession to respond to the suffering of individuals may become disillusioned at not being able to provide the care that she feels is required. This may lead to compassion fatigue (as mentioned above) and can actually become a spiritual and existential crisis for the professional. The nurse or professional is no longer able to find meaning and purpose in work (Vander Zyl, 2002) and may wonder what she should do next for employment (finances), as well as for deriving meaning in her life.

SUMMARY

Within this chapter we presented an overview of the transitional challenges faced by older adults, as well as the demographic changes in Canadian and developed countries that complicate how older adults experience these challenges. We offered the assumptions upon which we predicate our discussion about transitions in older adults. Finally, we briefly touched upon challenges that nurses and other professionals may face in working with older adults experiencing transitions.

While "old age is no place for sissies" (Bette Davis), neither is working with older adults! We suggest, however, that the impact upon these elderly patients, and the meaning for professionals working with them, can be profound. Within the next chapter, we address illnesses as transitions in older adults.

Critical Thinking Exercise

You are a nurse working on a medical unit in a large urban hospital. Your patient, Mark, is a 70-year-old man with insulin dependent diabetes. Mark's daughter called emergency medical services two days ago when she popped by her father's house to visit. She found Mark confused and disheveled. Mark was not able to tell his daughter when he had last eaten and whether he had injected his insulin. After spending some time in the emergency department, Mark was moved to a medical unit with a provisional diagnoses of diabetes mellitus and insulin shock. Although Mark has improved on the medical unit, his physician is wondering if Mark may have some beginning signs of vascular dementia. In conversation with the physician and the nurse, Mark's daughter cries. She admits to finding it difficult to look after Mark, her husband and children, as well as to fulfill her duties at work. She expresses guilt and anger in not being able to share the care with her two other siblings, as they claim they are "too busy" to regularly help out.

- As the nurse caring for Mark, what are your priorities for him while in hospital?
- What factors in Mark's home life may have contributed to his health crisis? What factors will you assess to help the geriatric team in their decision regarding whether Mark returns to his home?
- In your work with Mark's daughter, what are your priorities? What factors in her life might be contributing to her feelings of guilt and frustration? How can you help Mark's daughter deal with her challenges in balancing her father's needs and those of her own family?

REFERENCES

Alzheimer Society of Ontario. (2012). Caring for someone—long term care. Accessed October 14, 2012 from www.alzheimer.ca/en/on/Living-with-dementia/Caring

Austin, W., & Boyd, M. A. (2010). *Psychiatric & mental health nursing for Canadian practice* (2nd ed.). Philadelphia: Lippincott Williams & Wilkins.

Aycock, N., & Boyle, D. (2009). Interventions to manage compassion fatigue in oncology nursing. *Clinical Journal of Oncology Nursing, 13*(2), 183–191. doi: 10.1188/09.CJON.183–191

Baumbusch, J. L., & Andrusyszyn, M. (2002). Gerontological content in Canadian baccalaureate nursing programs: Cause for concern? *Canadian Journal of Nursing Research, 34*(1), 119–129.

Beckett, J., Peternelj-Taylor, C., & Johnson, R. L. (2003). Growing old in the correctional system. *Journal of Psychosocial Nursing & Mental Health Services, 41*(9), 12–18.

Bergin, L., & Walsh, S. (2005). The role of hope in psychotherapy with older adults. *Aging & Mental Health, 9*(1), 7–15. doi: 10.1080/13607860412331323809

BrainyQuote.com. Accessed on November 12, 2012, from www.brainyquote.com/quotes/quotes/b/bettedavis126805.html

Buhr, G. T., Kuchibhatla, M., & Clipp, E. C. (2006). Caregivers' reasons for nursing home placement: Clues for improving discussions with families prior to the transition. *The Gerontologist, 46*(1), 52–61.

Canadian Mental Health Association—Ontario. (n.d.). Seniors and depression. Accessed March 06, 2013, from www.ontario.cmha/seniors.asp?cID=5800

Canadian Study of Health and Aging Working Group. (1994). Canadian study of health and aging: Study methods and prevalence of dementia. *Canadian Medical Association Journal, 150*(6), 899–913.

Caple, C., & Schub, T. (2012). Aborginal population, Australia: Providing culturally competent care. *CINAHL, January 06,* 1–4.

Chang, Y.P., & Schneider, J. K. (2010). Decision-making process of nursing home placement among Chinese family caregivers. *Perspectives in Psychiatric Care, 46*(2), 108–118. doi: 10.1111/j.1744-6163.2010.00246.x

CIA—The World Factbook. (2012). Total fertility rate—country comparison. Accessed October 10, 2012, from www.cia.gov/library/publications/the-world-factbook/fields/2127.html

Cook, G. (2010). Ensuring older residents retain their unique identity. *Nursing & Residential Care, 12*(6), 290–293.

Cutcliffe, J. R., & Grant, G. (2001). What are the principles and processes of inspiring hope in cognitively impaired older adults within a continuing care environment? *Journal of Psychiatric and Mental Health Nursing, 8*(7), 427–436. doi: 10.1046/j.1365-2850.2001.00399.x

Damianakis, T., & Marziali, E. (2012). Older adults' response to the loss of a spouse: The function of spirituality in understanding the grieving process. *Aging & Mental Health, 16*(1), 57–66. http://dx.doi.org/10.1080/13607863.2011.609531

Dautzenberg, M. G., Diederiks, J. P., Philipsen, H., & Stevens, F. C. (1998). Women of a middle generation and parent care. *International Journal of Aging and Human Development, 47*(4), 241–262.

Davies, S. (2005). Meleis' theory of nursing transitions and relatives' experiences of nursing home entry. *Journal of Advanced Nursing, 52*(6), 658–671. doi: 10.1111/j.1365-2648.2005.03637.x

Detwiler, C. (2003). The client with a cognitive disorder. In W. K. Mohr (Ed.), *Johnson's psychiatric-mental health nursing* (5th ed.; pp. 607–640). Philadelphia: Lippinicott Williams & Wilkins.

Duggleby, W. (2005). Fostering hope in incarcerated older adult. *Journal of Psychosocial Nursing & Mental Health Services, 43*(9), 15–20.

Dyer, C. B., Hyer, K., Feldt, K. S., Lindemann, D. A., Busby-Whitehead, J., Greenberg, S., Kennedy, R. D., et al. (2003). Frail older patient care by interdisciplinary teams: A primer for generalists. *Gerontology & Geriatrics Education, 24*(2), 51–62. doi: 10.1300/J021v24n02_05

Fink, G. (2000). *Encyclopedia of stress.* San Diego, CA: Academic.

Free Online Dictionary. (2012). Accessed October 08, 2012, from www.thefreedictionary.com

Furlotte, C., Schwartz, K., Koornstra, J. J., & Naster, R. (2012). "Got a room for me?" Housing experiences of older adults living with HIV/AIDS in Ottawa. *Canadian Journal on Aging, 31*(1), 37–48. doi: 10.1353.cja.2012.0003

Gaede, B. A. (2010). What will I do next? Discerning God's callings for retirement. *Journal of Religion, Spirituality & Aging, 22*(1-2), 27–40. doi: 10.1080/15528030903313847

Gebhardt, M. C., Sims, T. T., & Bates, T. A. (2009). Enhancing geriatric content in a baccalaureate nursing program. *Nursing Education Perspectives, 30*(4), 245–248.

George, M. V., Loh, S., Verma, R. B., & Shin, Y. E. (2001). *Population projections for Canada, provinces and territories, 2000–2026.* Ottawa: Statistics Canada.

Gibson, J. (2012). How cognitive behaviour therapy can alleviate older people's grief. *Mental Health Practice, 15*(6), 12–17.

Gill, E. A., & Morgan, M. (2011). Home sweet home: Conceptualizing and coping with the challenges of aging and moving to a care facility. *Health Communication, 26*(4), 332–342. doi: 10.1080/10410236.2010.551579

Gillsjo, C., & Schwartz-Barcott, D. (2011). A concept analysis of home and its meaning in the lives of three older adults. *International Journal of Older People Nursing, 6*(1), 4–12. doi: 10.1111/j.1748-3743.2010.00207.x

Government of Canada, Newsletter of the National Advisory Council on Aging. (1998). Bereavement: A life passage. *Expression, 12,* 1–8.

Greenfield, W. L. (1984). Disruption and reintegration: Dealing with familial response to nursing home placement. *Journal of Gerontological Social Work, 8*(1/2), 15–21.

Grocki, J. H., & Fox, G. E. (2004). Gerontology coursework in undergraduate nursing programs in the United States: A regional study. *Journal of Gerontological Nursing, 30*(3), 46–51.

Grose, S., & Pravikoff, D. (2012). Aboriginal people living in Canada: Providing culturally competent care. *CINAHL Nursing Guide, June 22,* 1–7.

Haase, M. (2010). Delirium, dementias, and other related disorders. In W. Austin and M.A. Boyd (Eds.), *Psychiatric & mental health nursing for Canadian practice* (2nd ed.; pp. 750–789). Philadelphia: Lippincott Williams & Wilkins.

Happell, B., & Brooker, J. (2001). Who will look after my grandmother? Attitudes of student nurses towards the care of older adults. *Journal of Gerontological Nursing, 27*(12), 12–17.

Happell, B. (1999). When I grow up I want to be a . . . ? Where undergraduate student nurses want to work after graduation. *Journal of Advanced Nursing, 29*(2), 499–505. doi: 10.1046/j.1365-2648.1999.00913.x

Hardy, M. A., & Quadagno, J. (1995). Satisfaction with early retirement: Making choices in the auto industry. *Journal of Gerontology: Social Sciences, 50B*(4), S217–228. doi: 10.1093/geronb/50B.4.2217

Hart, A.D. (2001). *Unmasking male depression.* Nashville, TN: Thomas Nelson.

Hirst, S.P. (1990). Psychogeriatrics: What's in a name? *Perspectives, 14*(3), 10–12.

Hirst, S. P., Lane, A. M., & Reed, M. B. (2013). Personhood in nursing homes: Results of an ethnographic study. *Indian Journal of Gerontology, 27*(1), 38–54.

Hirst, S. P., Lane, A. M., & Seneviratne, C. C. (2013). Growing old with a developmental disability. *Indian Journal of Gerontology, 27*(1), 69–87.

Hirst, S. P., Lane, A. M., & Stares, B. (2012). Gerontological content in Canadian nursing and social work programs. *Canadian Geriatrics Journal, 15,* 8–15. doi: http://dx.doi.org/10. 5770/cgj.15.21

Holmes, T. H., & Rahe, R. H. (1967). The social readjustment rating scale. *Journal of Psychosomatic Research, 11,* 213–218.

Hooper, C., Craig, J., Janvrin, D. R., Wetsel, M. A., & Reimels, E. (2010). Compassion satisfaction, burnout, and compassion fatigue among emergency nurses compared with nurses in other selected inpatient specialties. *Journal of Emergency Nursing, 36*(5), 420–427. doi: 10.1016/j.jen.2009.11.027

Hwang, S. C., & Cowger, C. D. (1998). Utilizing strengths in assessment. *Families in Society, 79*(1), 25–31. doi: 10.1606/1044-3894.1797

Indiana State Nurses Association (ISNA). (2012). "I've fallen and I can't get up": Compassion fatigue in nurses and non-professional caregivers. *ISNA Bulletin, 38*(3), 5–12.

Jacobsen, L. A., Kent, M., Lee, M., & Mather, M. (2011). America's aging population. *Population Bulletin, 66*(no.1). Washington, DC: Population Reference Bureau.

Jenkins, B., & Warren, N. (2012). Concept analysis: Compassion fatigue and effects upon critical care nurses. *Critical Care Nursing Quarterly, 35*(4), 388–395. doi: 10.1097/CNQ.0b13e318268fe09

Junger, S., Pestinger, M., Elsner, F., Krumm, N., & Radbruch, L. (2007). Criteria for successful multiprofessional cooperation in palliative care teams. *Palliative Medicine, 21*(4), 347–354. doi: 10.1177/0269216307078505

Jutras, S. (1988). Formal and informal caregivers: Towards a partnership in prevention. *Health Promotion,* (Fall), 9–12.

Kao, H. F., Travis, S. S., & Acton, G. J. (2004). Relocation to a long-term care facility: Working with patients and families before, during and after. *Journal of Psychosocial Nursing & Mental Health, 42*(3), 10–16.

Kind, V. (2010). *The caregiver's path to compassionate decision making: Making choices for those who can't.* Austin, TX: Greenleaf.

Lane, A.M. (2007). *The social organization of geriatric mental health.* Unpublished doctoral thesis. University of Calgary.

Lane, A.M. (2011). Placement of older adults from hospital mental health units into nursing homes: Exploration of the process, systems issues and implications. *Journal of Gerontological Nursing, 37*(2), 49–55.

Lane, A. M., Hirst, S. P., & Reed, M. B. (2013). Housing options for North American older adults with HIV/AIDS. *Indian Journal of Gerontology, 27*(1), 55–68.

Lane, A. M., McCoy, L., & Ewashen, C. (2010). The textual organization of placement into long term care: Issues for older adults with mental illness. *Nursing Inquiry, 17* (1), 3–14. doi: 10.1111/j.1440-1800.2009.00470.x

Lane, A. M., Waegemakers Schiff, J., Suter, E., & Marlett, N. (2010). A critical look at participation of persons with mental health problems in training mental health professionals within university education. *CURRENTS, 9*(2), 1–18.

Leon, A. M., Altholz, J. A., & Dziegielewski, S. F. (1999). Compassion fatigue: Considerations for work with the elderly. *Journal of Gerontological Social Work, 32*(1), 32–62.

Lilley, L., Harrington, S., Snyder, J.S., & Swart, B. (2011). *Pharmacology for Canadian health care practice* (2nd ed.). Toronto, ON: Elsevier Canada.

McCleary, L., McGilton, K., Boscart, V., & Oudshoorn, A. (2009). Improving gerontology content in baccalaureate nursing education through knowledge transfer to nurse educators. *Canadian Journal of Nursing Leadership, 22*(3), 33–46.

Newson, P. (2008). Relocation to a care home, part one: Exploring reactions. *Nursing & Residential Care, 10*(7), 321–324.

Noonan, A. E., Tennstedt, S. L., & Rebelsky, F. G. (1999). Getting to the point: Offspring caregivers and the nursing home decision. *Journal of Gerontological Social Work, 31*(3–4), 5–27. doi: 10.1300/J083v31n03_02

Nuttman-Shwartz, O. (2004). Like a high wave: Adjustment to retirement. *The Gerontologist, 44*(2), 229–236. doi: 10.1093/geront/44.2.229

Plank, A., Mazzoni, V., & Cavada, L. (2012). Becoming a caregiver: New family carers' experience during the transition from hospital to home. *Journal of Clinical Nursing, 21* (13/14), 2072–2082. doi: 10.1111/j.1365-2702.2011.04025.x

Rando, T. (1984). *Grief, death and dying: Clinical interventions for caregivers.* Champaign, IL: Research Press.

Reitzes, D. C., & Mutran, E. J. (2006). Lingering identities in retirement. *The Sociological Quarterly, 47*(2), 333–359.

Roberts, J., & Blieszner, R. (2007). Infusion of gerontology content: An ethical imperative. *The Journal of Baccalaureate Social Work, 12*(2), 129–140.

Rosenberg, M. (2009). Accessed on November 11, 2012, from http://geography.about.com/od/populationgeography/a/fertilityrate.htm

Scharlach, A., Damron-Rodriguez, J., Robinson, B., & Feldman, R. (2000). Educating social workers for an aging society: A vision for the 21st century. *Journal of Social Work Education, 36*(3), 521–538.

Scott, A., Ryan, A., James, I. A., & Mitchell, E.A. (2011). Psychological trauma and fear for personal safety as a result of behaviors that challenge in dementia: The experiences of healthcare workers. *Dementia, 10*(2), 257–269. doi: 10.1177/1471301211407807

Silverberg, E. (2011). Applying the 3-A grief intervention approach to nursing home placement. *Canadian Nursing Homes, 22,* 22–25.

Smeltzer, S. C., & Bare, B. G. (2004). *Textbook of medical-surgical nursing.* Philadelphia: Lippincott Williams & Wilkins.

Snyder, C., van Wormer, K., Chadha, J., & Jaggers, J. W. (2009). Older adult inmates: The challenge for social work. *Social Work, 54*(2), 117–124.

Statistics Canada. (2008). Census snapshot of Canada — Population (age and sex). Statistics Canada — Catalogue No. 11-008.

Statistics Canada. (2010a). Population projections: Canada, the provinces and territories. Accessed October 05, 2012, from www.statcan.gc.ca/daily-quotidien/100526/dq100526b-eng.htm

Statistics Canada. (2010b). Women in Canada: Paid work. Accessed October 05, 2012 www.statcan.gc.ca/daily-quotidien/101209/dq101209a-eng.htm

Statistics Canada. (2010c). Pain or discomfort that prevents activities. Statistics Canada — 82-229-X.

Statistics Canada. (2012). Canada's population estimates: Age and sex, July 1, 2012. Accessed October 05, 2012, from www.statcan.gc.ca/daily-quotidien/120927/dq12097-eng.pdf

Stewart, J. J. Giles, L., Paterson, J. E., & Butler, S. J. (2005). Knowledge and attitudes towards older people: New Zealand students entering health professional degrees. *Physical & Occupational Therapy in Geriatrics, 23*(4), 25–36. doi: 10.1300/J148v23n04_02

Swanlund, S., & Kujath, A. (2012). Attitudes of baccalaureate nursing students towards older adults: A pilot study. *Nursing Education Perspectives, 33*(3), 181–183.

Turcotte, M., & Schellenberg, G. (2007). *A portrait of seniors in Canada*. Statistics Canada. Catalogue no. 89-519.

Uncapher, H., Gallagher-Thompson, D., Osgood, N.J., & Bongar, B. (1998). Hopelessness and suicidal ideation in older adults. *The Gerontologist, 38*(1), 62–70. doi: 10.1093/geront/38.1.62

Vander Zyl, S. (2002). Compassion fatigue and spirituality. *Nursing Matters, 13*(12), 4, 14.

Walsh, F. (1989). The family in later life. In B. Carter and M. McGoldrick (Eds.), *The changing family life cycle: A framework for family therapy* (pp. 311–332). Toronto, ON: Allyn & Bacon.

Ward-Griffin, C., St-Amant, O., & Brown, J. (2011). Compassion fatigue within double duty caregiving: Nurse-daughters caring for elderly parents. *Online Journal of Issues in Nursing, 16*(1), 1–21. doi: 10.3912/OJIN.Vol16No01Man04

Wesley, S. C. (2005). Enticing students to careers in gerontology. *Gerontology & Geriatrics Education, 25*(3), 13–29. http://dx.doi.org/10.1300/J021v25n03_02

Working Together for Seniors. (November 2007). Working Together for Seniors – Federal/Provincial/Territorial Ministers Responsible for Seniors. Accessed October 14, 2012, from www.seniors.alberta.ca/Seniors/docs/WorkingTogetherForSeniors.pdf.

Wright, L. M., & Leahey, M. (2013). *Nurses and families: A guide to family assessment and intervention* (6th ed.). Philadelphia: F.A. Davis.

Chapter 3

HEALTH TRANSITIONS IN OLDER ADULTS

For age is opportunity no less
Than youth itself, though another dress
And as the evening twilight fades away
The sky is filled with stars, invisible by day.
(Henry Wadsworth Longfellow, American poet and professor)

Reflective Questions

- What are some of the physical, mental, and cognitive changes that older adults may experience?
- How do transitions in health affect the functional abilities, social abilities, and social contact with others?
- How should nurses and other professionals assess and intervene with older adults experiencing health transitions?

The quote of American poet and professor Henry Wadsworth Longfellow expressed an important truth about advancing age. Although changes occur from earlier years, these changes can be meaningful and full of opportunity. However, older adults may face more transitional challenges in trying to keep life purposeful and rich. While many adults enter the older life stage in good health, significant numbers of older adults will experience some health problems as they enter their 70s and 80s. Depending upon the nature of the health issues, as well as the degree of disabilities that come from these challenges, older adults may face other transitions related to the health concerns, such as moves from personal homes into assisted living facilities or nursing homes. The compounding nature of the transitions can result in profound stress for older adults and demands significant resilience and adaptability on their part. If older adults do not possess this hardiness or adaptability due to extreme health conditions, such as dementia, then added responsibility is placed upon family members and nurses and other professionals to support them in their health transitions.

Within this chapter we discuss some of the health challenges faced by older adults, such as physical illnesses, chronic illness and pain, addictions, mental illness, and dementias. We propose that life transitions, such as the loss of a spouse, can lead to illness in older adults, such as depression. However, we also suggest that illnesses, *in and of themselves*, are transitions for older adults; their ability to manage day-to-day functioning can decrease significantly and may even lead to another transition—a move to a hospital, assisted living, or a nursing home. Additionally, we address how nurses and other professionals may assess and intervene with older adults experiencing significant issues in health.

PHYSICAL ILLNESS: CHRONIC

Chronic illness or conditions refer to "long-term diseases that develop slowly over time, often progressing in severity, and can often be controlled, but rarely cured" (Ministry of Health and Long-Term Care, 2007). Common chronic illnesses in older adults include some forms of heart disease, cancer, diabetes, and arthritis. Other common illnesses such as strokes (cerebrovascular accidents) are acute in that they occur suddenly, but after the initial event, the changes incurred generally become constant or chronic. The impact of chronic illness in Canada, as well as worldwide, is astronomical. Chronic illnesses are a significant cause of death and disability throughout the world; the World Health Organization projected that by 2005, 89 percent of all deaths in Canada would be related to chronic illnesses (WHO, n.d.).

The presence of a chronic illness can restrict the activities that older adults take part in. Chronic illnesses may also lead to involuntary retirement in older adults; that is, some older adults need to retire because of health issues, rather than by choice. If the senior enjoyed work, cherished the camaraderie with colleagues, and appreciated the purpose and structure work gave, retirement can be a major loss (Smith, 2012). Not only can the cessation of work represent a loss for the older adult, finding an alternate purposeful and enjoyable replacement may be difficult due to the limitations caused by the chronic illness. Lack of purpose in life results in an existential crisis (Frankl, 2006). The older adult may question, "What good is my life anymore?"

When chronic illness causes some sort of physical disability, for example, difficulties negotiating stairs due to cardiac problems or arthritis, then a move may be necessary. Older adults may move to a retirement community, a seniors' complex, or an assisted living facility. While some older adults find that they enjoy the newfound companionship that comes with living in an assisted living facility or a seniors' complex, others grieve the loss of their home (Pickersgill, 2001). They grieve because home represents much more than physical structure or a place to sleep. For some older adults, a lifetime of memories is tied up within the walls of the home; the home is where they raised their families, cooked and entertained,

cared for ailing parents, and dreamed of the future. Beyond a lifetime of memories, their homes have represented security (Greenfield, 1984) and may also symbolize freedom and independence. Moving out of the home may be viewed as the first step down a slippery slope toward total dependence and mortality (Gill & Morgan, 2011). And, as will be discussed in Chapter 4, the concept of "home" takes on a somewhat ethereal quality.

The previous section offered some common problems associated with chronic illness. In the following section, we will provide some statistics and specifically address what it is like for older adults to live with heart disease, strokes, diabetes, and arthritis.

Heart Disease and Strokes

Although the prevalence of cardiovascular diseases (which includes diseases of the heart and strokes) has declined by about 50 percent in the last 20 years (Heart and Stroke Foundation of Canada, 2012), they still are common in older adulthood. For instance, in 2008, cardiovascular diseases accounted for 29 percent of all deaths in Canada, of which 54 percent were attributed to ischemic heart disease, 20 percent to strokes (cerebrovascular accidents), and 23 percent to heart attacks (myocardial infarction) (Heart and Stroke Foundation of Canada, 2012).

Living with the impact of cardiovascular diseases in older adulthood can be difficult. Heart disease impacts all areas of life for older adults (Rhodes & Bowles, 2002). Older adults experience less energy, shortness of breath, and severe fatigue. With these symptoms, aging individuals need to scale down their physical activities and social contacts. Finances may become an issue if the cardiovascular disease results in forced retirement (Rhodes & Bowles, 2002; Zambroski, 2003). The emotional sequelae from heart disease include intense grief, feelings of great loss (including loss of control in life), guilt, fear, as well as depression (Zambroski, 2003). Some older adults report feeling imprisoned by their illness (Ekman, Ehnfors, & Norberg, 2000).

Stroke

When older adults are left with functional deficits following a stroke, the sudden catastrophic event leads to life with significant changes. Older adults with deficits following a stroke often experience exhaustion, changes in physical abilities, such as difficulties in utilizing an affected hand for personal care or household duties, difficulties with mobility (walking and driving), changes in cognitive function, aphasia (problems with verbal communication), and changes in vision (Ekstam, Tham, & Borell, 2011; McKenna, Liddle, Brown, Lee, & Gustafsson, 2009; Northcott & Hilari, 2011). These changes can have a profound effect upon older adults' social lives, lead to a loss of friends, resulting in loneliness, which in turn, can precipitate depression. In their article entitled "Why do

people lose their friends after a stroke?" Northcott and Hilari (2011) examined why strokes can damage friendships. The research participants spoke of their challenges following the stroke event, including the experiences listed above. However, they also reported that their friends offered unhelpful responses, such as ridicule, telling them how they should feel, or patronization. Individuals also conveyed that they "closed in on themselves." With the difficulties in communicating, exhaustion, and transportation challenges, as well as embarrassment at being seen as unwell, getting together with friends was no longer enticing. Because of how they felt about themselves, as well as the responses of others, they simply withdrew (Northcott & Hilari, 2011).

Diabetes

Some older adults living with diabetes have managed their illness for years. Living with diabetes includes dietary management, administration of insulin or oral hypoglycemics, blood glucose monitoring, and other tasks. However, there are some changes that come with aging, as well as co-morbidities that may impact how older adults manage their illness. First, older adults may have visual problems that can influence medication administration. Changes in the daily exercise or physical activities can result in lower food intake, which can then result in hypoglycemia (low blood glucose). Developing cognitive impairment in some older adults can affect how they manage blood glucose monitoring, diet, and medication administration (George & Thomas, 2010).

Aging with diabetes demands changes in how an older adult lives his or her life. Initially, individuals may feel some anger, sadness, and fear (Canadian Diabetes Association, 2012). Older adults may also experience a change in self-identity (Hood, Huber, Gustaffson, Scambler, & Asimakopoulou, 2009). Some older individuals with diabetes experience depression. Depression, in conjunction with diabetes, may decrease the commitment of older adults to follow through with the daily self-care regimens (Jack, Airhihenbuwa, Namageyo-Funa, Owens, & Vinicor, 2004).

Further, living with diabetes may trigger existential issues in older adults. George and Thomas (2010) interviewed 10 older adults living in rural America about their experiences with insulin-dependent diabetes. The research participants had been diagnosed with diabetes seven to 39 years previously. All had complications from the diabetes and each participant had one or more chronic illnesses in addition to the diabetes. The researchers concluded that the rural participants lived with fear of hypoglycemic reactions and subsequent death, a disconnect between what healthcare providers told them to do and how they actually managed their diabetes, a somber recognition that the only escape from diabetes involves death, as well as a stoicism to continue on. As the researchers noted, living with advanced diabetes caused older adults to ask existential questions (George & Thomas, 2010).

Arthritis

Although there are a number of forms of arthritis, the most common forms of arthritis are rheumatoid arthritis and osteoarthritis (The Arthritis Society, 2012). Osteoarthritis is one of the most common causes of disability in older adults (Baird, Yehle, & Schmeiser, 2007). Arthritis, particularly rheumatoid arthritis, results in physical disabilities (including problems with mobility and physical activities), chronic pain (which can be severe in nature), decreased energy, and depression (Melanson & Downe-Wamboldt, 1995). Particularly troublesome is the lack of control and independence that some older adults experience because of rheumatoid arthritis, as well as fear for the future due to the progressive nature of the disease (Melanson & Downe-Wamboldt, 1995). Depending upon the severity of the physical limitations, some older adults need to transition to assisted living facilities, seniors' complexes, or nursing homes because of their inability to manage in their homes.

CHRONIC OR PERSISTENT PAIN

According to the International Association for the Study of Pain (IASP) (1994), persistent pain refers to the "continuous or recurrent pain that persists past the normal time of healing, most commonly about three months' duration." Chronic pain is often caused by chronic illnesses, such as arthritis (osteo or rheumatoid), neuropathic pain (related to nerve damage from diabetes), heart disease, and cancer (Help the Aged, 2008; Ramage-Morin, 2008). Estimates of the prevalence rates of chronic pain in older adults living in developed countries varies. For instance, within Canada it is estimated that 27 percent of older adults living independently and 38 percent of those living within nursing homes have chronic pain (Ramage-Morin, 2008). Similarly, one Australian study reported that 27 percent of older males and 31 percent of older women experience chronic pain (Blyth, March, Brnabic, & Jorm, 2001). However, prevalence rates from the United States are higher. The National Institute of Health (NIH) Medline Plus (2011) reported that about 50 percent of older Americans living independently experience chronic pain, and the percentage climbs to 75 to 85 percent of those living in nursing homes.

Considerable consequences ensue from the presence of chronic pain in the lives of older adults. Living with persistent pain leads to problems sleeping, fatigue, and a reduction in what older adults can accomplish in terms of household work and activities (Jakobsson, Hallberg, & Westergren, 2004; Roberto & Reynolds, 2002). Besides the impact upon physical health and functional abilities, however, chronic pain may lead to debilitating mental health issues. For example, the inability to perform necessary daily tasks and experience enjoyable activities may cause a change in how older adults view themselves—their sense of self and

mastery (Roberto & Reynolds, 2002). Older adults have described the experience of decreased mobility related to pain as not only frustrating, but tremendously *humiliating* (Help the Aged, 2008). Decreased self-esteem and declining functional abilities can result in loneliness, because older adults may sequester themselves, hiding themselves within their homes (Smith, 2012). Loneliness, in and of itself, can be a risk factor for depression in older adults (Canadian Coalition for Seniors' Mental Health, 2009). However, when loneliness is coupled with persistent and longstanding pain, it is not uncommon for older adults to become very depressed. A complex, entangled web of chronic pain, depression and loneliness and social isolation may result. Unfortunately, for some older adults, suicide is the end result of this web of despair (Juurlink, Herrmann, Szalai, Kopp, & Redelmeier, 2004). Others may choose substances such as alcohol to medicate the physical and emotional pain (Gambert & Albrecht, 2005).

Despite the incredible limitations that chronic pain may cause, older adults may delay seeking help for their persistent pain (Roberto & Reynolds, 2002). They may believe that pain is "normal" in advancing years, or that their pain will not be taken seriously by healthcare professionals (Schofield, 2006). They may also feel that family and friends will not understand. Roberto and Reynolds (2002) conducted focus groups and individual interviews with older women to explore how they managed their chronic pain. These women admitted that they wanted their pain to be acknowledged, but also believed that very few people truly understood. This resulted in an emotionally painful and lonely predicament for some of these women: To share their physical pain and have it minimized would trigger emotional pain; however, to keep quiet and not share their pain meant that they were existentially alone with it.

Chronic illness coupled with pain can result in suicide in older adults. In one Canadian study (Juurlink et al., 2004), researchers examined coroners' records of the suicides of older adults in Ontario from 1992–2000. They determined that of the 1354 older adults who committed suicide during this time period, a number of these individuals suffered from congestive heart failure, chronic obstructive pulmonary disease (COPD), anxiety disorders, depression (as well as other mental illnesses), and moderate or severe pain. The researchers noted that where individuals had multiple illnesses, the risk of suicide was higher. Sadly, almost 50 percent of these older adults had seen a physician in the week prior to committing suicide (Juurlink et al., 2004).

MENTAL ILLNESS

Mental illness in older adults has been present since the recording of history. However, historically, these aging adults were under the charge of their families (Smoyak, 1992) or were neglected (Thompson, 1994). In the past, minimal help was available for aging mentally ill individuals. It has only been over the past

several decades that services have been developed to actively treat older adults with mental illness.

Mental illness in older age can have a heartrending effect upon individuals and their family members. While older adults experience the same types of mental illnesses as younger adults, including depression, adjustment disorders, anxiety, schizophrenia, and bipolar disorder, they may additionally develop Alzheimer's disease or other dementias.[1] Because the focus of this book is on transitions in older adults, and not specifically mental illness, we will focus on just depression, anxiety, dementias, and addictions.

Depression

Contrary to past societal beliefs, depression in older adults is not normal (Canadian Coalition for Seniors' Mental Health, 2009). Depression may develop from the stress of dealing with a life-changing and gut-wrenching transition, such as the loss of a spouse; it can occur in those who have a previous experience with depression in the past, have illnesses that impact brain functioning (such as strokes or dementias), in response to chronic illness and pain, as well as from medications or alcohol abuse (Canadian Coalition for Seniors' Mental Health, 2009). Much more than feeling "out of sorts" or "being moody," depression involves significant sadness, fatigue, anhedonia (a loss of pleasure in activities once considered enjoyable), concentration difficulties, guilt and suicidal thoughts (American Psychiatric Association, 2000).[2]

A significant number of older adults experience symptoms of depression (although they may not necessarily meet the criteria for Major Depressive Disorder within the *Diagnostic and Statistical Manual of Mental Disorders*). In Canada, it is estimated that up to 20 percent of older adults living in the community experience symptoms of depression. This percentage doubles to 40 percent for seniors living within continuing care facilities, such as nursing homes (Canadian Coalition for Seniors' Mental Health, 2009). For aging individuals, living with depression can make life miserable, and for some, even intolerable.

How painful and unbearable life can be for some depressed older adults is reflected in suicide rates of this age grouping. Men 80 years of age and older have the highest suicide rate in Canada (Health Canada, 2002). Further, the rates of suicide among older adults may actually be notably higher than reported. This is

---

[1] We recognize that a small number of adults develop Alzheimer's disease or related dementias in their 40s or 50s; however, the vast number of individuals affected are considered older adults (Alzheimer's Association, 2013).

[2] Throughout this book, we refer to classifications of illnesses within the *Diagnostic and Statistical Manual of Mental Disorders IV edition – Text Revision* (DSM IV-TR) (American Psychiatric Association, 2000). However, we are aware that the fifth edition of the DSM is expected to be available sometime between spring and fall (2013).

because judging the intentionality of the actions of individuals can be difficult. Particularly if the suicide is nonviolent, the death may be wrongly attributed to illness (Juurlink et al., 2004). Also, within Canada, when coroners perform autopsies, they may initially label the cause of death as "undetermined." However, after an autopsy is completed and the cause of death is confirmed as suicide, the change may not be registered in the mortality database (Health Canada, 2002).

Suicide is not the only way in which older adults with depression may eventually die. The impact of depression upon older adults can shorten lives. One study (Reynolds, Haley, & Kozlenko, 2008) examined the effects of depression upon the active life expectancy of older Americans (70 years of age and older) who were living in the community. The researchers found that depressive symptoms decreased the life expectancy of young-old adults (70 years of age) by 6.5 years in men and 4.3 years in women, and by 3.2 years in old-old men (85 years old) and 2.2 years in old-old women.

Anxiety

Like depression, anxiety can be extremely enervating in advancing years. Anxiety and depression may occur concurrently. Anxiety may have been a pre-existing condition that affected the older individual in earlier years. Or, anxiety can be relatively new and be related to health conditions such as cardiac disease (Grenier et al., 2012) or diabetes (Poulsen & Pachana, 2012). Further, anxiety can be a precursor to, or an initial symptom of, cognitive impairment (Potvin, Forget, Grenier, Preville, & Hudon, 2011). Despite the debilitating impact of anxiety in older adults, in one Canadian study, only 20.8 percent of older Canadian adults with an anxiety disorder (and no concurrent mood disorder) accessed mental health services. The researchers concluded that older adults suffering from anxiety are less likely to seek mental health services than older adults who are depressed (Scott, Mackenzie, Chipperfield, & Sareen, 2010).

Anxiety in older adults may be directed toward a fear of falling. In these situations, it is not just a past history of falls or the use of a walking aid that predicts fear of falling (Sharaf & Ibrahim, 2008); rather, it is the presence of anxiety (or depression) that predicts the fear of falling (Painter et al., 2012; Sharaf & Ibrahim, 2008). To reiterate, it is not the fear of falling that causes anxious worry in older adults, but instead, pre-existing anxiety leads to a fear of falling (Painter et al., 2012). While it is understandable that older adults want to prevent falling—falling can lead to death or premature admission into nursing homes—the anxiety is strong enough that it leads to individuals curtailing their activities (Painter et al., 2012). When older adults significantly restrict their outside interests, venturing out of their homes infrequently, loneliness may result. And, as noted earlier, loneliness may lead to depression (Canadian Coalition for Seniors' Mental Health, 2009). The daily experience of anxiety in older adults may then put into motion a vicious cycle: Anxiety leads to restriction of outside interests and pursuits, which

may lead to social isolation and loneliness, which then can lead to depression and further exacerbation of anxiety.

Alzheimer's Disease and Related Dementias

Alzheimer's disease and related dementias have a profound impact upon older adults, their spouses, and their family members. Alzheimer's disease refers to a progressive degenerative disease that results in memory loss (especially short-term memory loss), inability to make decisions, impaired ability to perform activities of daily living, changes in mood and behavioral problems, and communication problems that may lead to aphasia (loss of speech) (Alzheimer Society of Canada, 2012). Alzheimer's disease is believed to be caused by neurofibrillary tangles and neuritic plaques (Detwiler, 2003). While Alzheimer's disease is the most common form of dementia, there are a number of other forms of dementia, including vascular dementia, frontal lobe dementia, Creutzfeldt-Jakob disease, and Lewy body dementia (Trigoboff, 2009).

The losses associated with dementias, such as Alzheimer's disease, are so profound and impact the very personhood of those affected, that some have labeled the experience of Alzheimer's disease as "the loss of self" (Cohen & Eisdorfer, 2001). The person with Alzheimer's disease will eventually not be able to recognize family members or even him- or herself (in the mirror). By the middle stages of the illness, family members usually place the senior into a nursing home, as the care demands become too much. Death usually occurs somewhere between seven and 10 years after the onset of the illness, however, some individuals live much longer (Alzheimer Society of Canada, 2012).

The stress upon family caregivers is enormous and cannot be overstated. In fact, it is not all that uncommon for a spousal caregiver of someone with Alzheimer's disease to die because of the stresses of caregiving. In one study (Schulz & Beach, 1999), 392 spousal caregivers were compared to 427 non-caregivers. All of the older adults were between the ages of 66 to 92 years of age. The results revealed that spousal caregivers had a 63 percent increased mortality rate over the non-caregivers. Schulz and Beach (1999) concluded that caregivers who experience emotional and mental stress related to caregiving have a greater likelihood of dying than non-caregivers. In situations such as illustrated by this study, Alzheimer's disease ends up taking two individuals: the older adult with the disease and the spousal caregiver. In our experience, caregiving may not only lead to increased mortality rates for spouses, but at times, spousal caregivers may actually pass away *before* the partner with Alzheimer's disease. And, in rare situations, an adult child may pass away before the parent with dementia. I (AML) remember sitting at the unit desk (on a geriatric mental health unit) one morning reviewing a patient's chart when a caring psychiatrist entered the unit. She seemed upset. She told me that a particular person had died. I looked up, somewhat distracted, and said something like, "Well, she was very old." I was referring to the fact that our past

patient was 95 years of age, if not by now, 96 years of age. The psychiatrist looked at me, paused, and said, "No, her daughter died." I was stunned. I asked what had happened. This psychiatrist explained the circumstances of this adult daughter's death and her health challenges. I felt badly for the adult daughter, as well as for the psychiatrist, because the psychiatrist had worked hard to convince the daughter to scale back her efforts at caregiving and to consider nursing home placement, rather than solely providing help within her home. For various reasons, including cultural beliefs, the daughter could not accept help in caregiving and ultimately, the stress involved in being the only person providing care may have shortened her life.

Grief is so intricately tied to seeing a family member (with dementia) not only progressively lose the ability to care for herself, but also to see the personality characteristics that uniquely defined her as a person disintegrate (Rolland, 1993). However, grief is complex and unresolved, in that the person with Alzheimer's disease has not passed away, but the person the caregiver knew is gone. Pauline Boss (1999) termed this situation "ambiguous loss." Initially, she coined this term to refer to American soldiers who were missing in action. Although they were presumed dead, family members could not see a dead body. Hence, they were physically dead, but psychologically present to family members. She then applied this expression to individuals experiencing dementias, but flipped the meaning. Because individuals with Alzheimer's disease or related dementias are not dead, they are physically present. However, as their personalities have changed and they forget who others are, they are psychologically dead (Boss, 1999). This results in complicated grieving for family members, because they grieve the loss of the older adult with Alzheimer's disease, but the individual has not yet died. "I lost my mom a long time ago," is a common sentiment of an adult child coping with her parent's dementia.

The notion of anticipatory grieving is somewhat different, but also related to the concept of ambiguous loss. Anticipating the death of a spouse with a progressive illness, such as Alzheimer's disease, can be as painful as the actual physical death of the individual (Rolland, 1993). While awaiting an eventual death, spouses and family members grieve each downward drop in functioning. They often feel as if they are losing their older adults "one piece at a time." Because the course of Alzheimer's disease is often somewhere between seven to 10 years (Alzheimer Society of Canada, 2012), but can be longer, family members live in a state of grief for long periods of time (Rolland, 1993). This is both emotionally and physically exhausting. In our experience, by the time older adults with Alzheimer's disease pass away, spouses and family members often admit that much of their grieving is done. This is not an indication that a spouse or family members did not love the older adult, but rather, that they carried their grief for long periods of time and now were ready to place this grief down. More will be discussed on the grief associated with ambiguous loss in Chapter 6.

MEDICATION USAGE AND ADDICTIONS

Medication usage, in and of itself, is not be a sign of addiction in older adults. However, there are physical changes that occur in older adults, in addition to the numbers of medications older adults consume, that can become problematic and increase the chances of having to transition to hospital and possibly a nursing home. It is estimated that over 60 percent of Canadians 65 years of age and older take five or more kinds of prescription medications yearly. Further, 20 percent of older adults ingest 10 or more kinds of prescribed medications per year (Canada Safety Council, 2012).

Concurrently, older adults consume over-the-counter medications, often to a great extent. In one study, older adults reported using double the amount of over-the-counter medications to prescription medicines (Conn, 1992). Considering that many older adults take at least five prescription medications yearly, the degree of over-the-counter drug usage is staggering. Older adults may use cold medications, decongestants, antihistamines, analgesics, and laxatives (Rolita & Freedman, 2008). Although these medications are sold over the counter, they are not benign; this applies to all people, but especially to older adults. For instance, older adults taking antihistamines may experience confusion, delirium, and hallucinations (Rolita & Freedman, 2008).

There are well-founded reasons to be concerned about the usage of medications and over-the-counter pharmaceuticals in older adults. As individuals age, their abilities to metabolize and excrete medications are reduced to due physiological changes: decreased size of liver and reduced blood flow to the liver, increased body fat, decreased muscle mass, and impaired kidney function (Rolita & Freedman, 2008). This means that medications remain in the body longer and adverse reactions may occur. The identified characteristics of an older adult who is particularly at risk from complications of medications are as follows: being 85 years of age or older, having some degree of renal impairment, taking more than 12 dosages of medication per day, being on nine or more medications and having low body weight (Bushardt & Jones, 2005). This subgroup within the older adult population is significant.

Adverse reactions may lead to hospitalizations due to delirium (an acute confusional state caused by medications, infections, or other health issues) (Trigoboff, 2009). Delirium may be life threatening and includes symptoms such as confusion, disorientation, delusions and hallucinations, and agitation. Additionally, the length of hospital stay of older adults with delirium is twice that of those who are not experiencing a delirium. Tragically, 25 percent of older adults die of delirium within the first month of being hospitalized (Trigoboff, 2009). While older adults living in the community may experience a delirium, those residing in nursing homes are at particular risk. This risk is in part due to the fact that by the time older adults enter nursing homes, they are often more frail, cognitively impaired, unable to effectively manage continence, and thus,

more prone to infections (please see the above risk factors for delirium). For older adults residing in a nursing home, the presence of delirium necessitates hospitalization, as it is a medical emergency (Trigoboff, 2009). Unfortunately, the transition from the nursing home to the hospitalization can further exacerbate confusion.

There is another significant adverse effect of some medications in older adults. Some medications affect balance and gait and can result in falls in seniors (Huang et al., 2012). Falls may cause fractured hips and may lead to disability or death (Huang et al., 2012). Even if older adults survive the fall and possible surgery, disabilities related to the fall may result in loss of independent living and possible transition to an assisted living facility or nursing home. MBR, in community chaplaincy, escorted one senior to a surgeon's appointment following the breakage of both ankles. Representing the nephew who provided care, but was not able to be present, I posed his question: "Is it time for Aunt Lou to go into care?" Responding to the question, the surgeon indicated, "This type of injury usually precipitates a change in residence."

The preceding discussion about medications, including the physiological changes in older adults that make them particularly susceptible to complications from medications and potential adverse effects, is presented with the underlying assumption that medications are taken as prescribed and that there are no intents to misuse or be psychologically reliant on substances. However, substance abuse can be a problem for some older adults and, combined with the numbers of over-the-counter and prescription medications ingested, can be dangerous or even deadly.

Substance abuse is included in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM IV — TR) (American Psychiatric Association, 2000). However, unraveling the reasons behind substance abuse is complicated. Substance abuse by older adults may be an attempt to self-medicate depression, anxiety, sleep problems, physical pain, and boredom (Amoako, Richardson-Campbell & Kennedy-Malone, 2003; Boyle & Davis, 2006), or substance abuse may have caused depression and other health problems (Government of Canada, 2006). Like the proverbial cart and the horse, sometimes it is difficult to know which has come first.

There is another possible explanation, however. Aging individuals may abuse substances to deal with existential issues. In an interesting study, Wiklund (2008) explored the experiences of individuals living with addictions with a focus upon existential issues. She interviewed nine individuals between the ages of 35–46. Although the research participants were not seniors, the findings may be considered relevant to the situations of some aging adults. Some of Wiklund's (2008) participants described experiencing life as meaningless and as a battle between life and death. However, when they took drugs, they felt alive, even if this type of existence was not really who they were as individuals. Could it be that some retired, chronically ill older adults are confused about their identity within a world where youth and productivity are revered, and find that alcohol or drugs not only quells

loneliness and emotional pain, but on some level, makes them feel alive? However comprehensible the reasons for using/abusing substances in advancing years, the results can be deleterious and even dangerous.

The most commonly abused substance among older Canadian seniors is alcohol. In the Canadian Addiction Survey (Health Canada, 2005), almost 15 percent of older Canadians drank four or more times per week. While older adults are generally considered less likely to be heavy drinkers (five drinks or more at one time at least once a month over a 12-month period), some older adults do consume amounts of alcohol considered to be problematic. For instance, in 2003, 12 percent of Canadian older men and 3 percent of Canadian older women were rated as heavy drinkers (Turcotte & Schellenberg, 2006). While these rates are not extremely high, some suggest that that rates of abuse of alcohol and substances may increase in the coming years, as "baby boomers"—who have abused alcohol and other drugs—age (Boyle & Davis, 2006). Also, it has been suggested that older adults particularly at risk for alcohol abuse include those who experienced involuntary retirement and have had problems with alcohol abuse in the past (Kuerbis & Sacco, 2012). It should also be noted that alcohol abuse is higher in older adults with mental health issues (Gambert & Albrecht, 2005).

The use of substances such as alcohol, in conjunction with other prescription medications, can have dangerous effects. For instance, alcohol has a depressant effect on the central nervous system (CNS). In combination with other medications, such as benzodiazepines, which also have a CNS depressant effect, can magnify or potentiate the depressant effect. This can lead to respiratory depression and death (Wesson, Smith, Ling, & Seymour, 2005; Wilson, Shannon, & Stang, 2004). Older adults who may have combined prescribed medications, over-the-counter medicines, and alcohol younger in life may not be aware of the dangers of mixing substances in their advancing years. And, if they are bored or depressed due to the activity restrictions from chronic pain or chronic illness, or feeling empty due to forced retirement, they may be prone to use alcohol or other substances to numb their feelings. While retirement or chronic illness does not cause a person to abuse substances, if the inclination to use substances is there and the senior is depressed, lonely, or bored, substances may be used to fill the void (Gambert & Albrecht, 2005).

FRAMEWORKS WITHIN WHICH TO UNDERSTAND ILLNESS

Before presenting a case study and addressing assessment and intervention, we believe it is useful to offer some insights from Rolland's work on chronic illness and the family life cycle (2005), as well as his psychosocial typology of illness (1987, 2005). These insights reveal the degree of challenges and suffering faced by older adults and their family members.

Chronic Illness and the Family Life Cycle

Serious illness experienced by older adults can place enormous challenges and pressures upon family members. Aging adults and their family members need to deal with the present realities of the illness, as well as the future eventualities, *all at the same time*. Further, they need to do the practical work of managing the disease (e.g., medical appointments, adapting the living environment), alongside dealing with the emotional work of coping (Rolland, 2005). And when death looms in the not too distant future, family members struggle with wanting intimacy and their need to emotionally let go of the older adult.

According to Rolland (2005), it is important to consider chronic illness over the course of time, as well as to be cognizant of the demands that phases place upon the individual and family members. He divided chronic illnesses into three phases: crisis, chronic, and terminal phases. The crisis phase includes the time just before diagnosis and immediately after diagnosis. During the crisis phase, the individual (older adult) and family members need to adjust to the diagnosis and grieve for the loss of life as they once knew it. They must cope with the illness and create meaning out of the situation. They also have to become flexible regarding future plans and adjust their hopes and dreams (Rolland, 2005).

The chronic phase involves the time between the initial diagnosis and when the illness becomes terminal. This phase may be constant, in that there is little change after the initial event. It can also be progressive, meaning that there is a downward progression in the illness or the chronic phase may be episodic (periods of stability mixed with episodes of exacerbation). In this phase, family members have to get used to living with the illness as it is; this means that they need to psychologically adapt to how the illness manifests, as well as change their organizational structure to accommodate the illness. In situations such as dementia, the chronic phase can be lengthy, despite the downward progression of the illness. Family members can become exhausted. In coping during the chronic phase, family members need to hold onto as much autonomy as they can while still providing help for their ailing member (Rolland, 1987, 2005).

During the terminal phase of chronic illness, death is inevitable and imminent. Family members have to move from controlling the illness (or aspects of the illness) to letting go. This phase involves both the tasks of caring, as well as dealing with emotions related to the impending death. Family members may be dealing with unfinished business and determining how to say good-bye to the older adult (Rolland, 1987, 2005).

Psychosocial Typology of Illness

Rolland's psychosocial typology of illness (1987, 2005) assists professionals in understanding the unique challenges that come with managing varying illness trajectories that come with some of the diseases previously discussed in this chapter.

This typology classifies illnesses according to onset, course, outcome, incapacitation, and uncertainty (Rolland, 1987). In this typology, Rolland differentiated between the demands and challenges experienced with an acute onset illness as compared to those with a chronic illness. Because we previously mentioned his framework for understanding chronic illness, there is some overlap between the concepts just discussed and those that will be discussed next. However, the challenges in dealing with chronic illness will be addressed in greater depth below.

Depending upon the onset, course, and outcome, individuals and families will face specific challenges that will impact how they respond psychologically. For instance, Rolland (1987) included two categories under onset: acute and gradual. An acute onset can include such events as strokes or myocardial infarctions (heart attacks); gradual onset can include such illnesses as Parkinson's disease or multiple sclerosis. In illnesses that present with an acute onset, family members need to mobilize crisis management skills and support in a short period of time. Although dealing with a chronic illness demands just as many psychosocial resources in individuals and family members, the gradual onset of such illnesses offers time within which to adjust to the changes in health (Rolland, 1987).

Rolland (1987) conceptualized the illness course as generally taking three types: progressive, constant, and relapsing/episodic. Alzheimer's disease (and many related dementias) fall under the progressive course. When an individual has Alzheimer's disease, the disease course is usually continuous in terms of experiencing symptoms, but the symptoms worsen over time. Family members experience little relief from the constant caregiving demands; they risk becoming physically and mentally exhausted as they need to take on new demands as the disease progresses. The progressive category is in contrast to the constant-course category, where after an initial event, the disease course stabilizes, such as with spinal cord injury. The relapsing or episodic course that can occur with illnesses such as asthma involves vacillations between periods of stability and acute flare-ups. While family members receive a break from caregiving during periods of stability, they psychologically live with the uncertainty of when an acute crisis may occur. The demands of this living with impending danger, even within the periods of stability, can be emotionally strenuous for families (Rolland, 1987).

The outcome aspect of illness involves the likelihood that an illness will result in death and the extent to which it can abbreviate someone's life (Rolland, 1987). When family members first receive the diagnosis, what is the likelihood that the illness will result in death? This is a significant question as the expectation of death sets in motion anticipatory grieving in family members, and family members and the ill older adult are caught in the tension of wanting intimacy and trying to pull away from each other. The extreme emotions experienced in trying to deal with an impending death can lead to difficulties in getting the practical day-to-day tasks done. Further, if family members are already conceptualizing their older adult as buried and gone, they may exclude him from important family responsibilities (Rolland, 1994).

Incapacitation

Incapacitation refers to the degree of disability caused by the illness, and may involve impairment in cognition (e.g., from Alzheimer's disease), in senses (e.g., blindness), and in movement (e.g., rheumatoid arthritis or multiple sclerosis) (Rolland, 1994). The onset of the incapacitation (e.g., spinal cord injury) will determine when the greatest amount of adaptability needs to occur. As an example, incapacitation from a sudden spinal cord injury from a motorcycle accident is severe at onset and requires strong adaptability from the affected individual and family members from the outset of the injury. Other illnesses with a more progressive course toward incapacitation allow for individual and family adaptation to changes at a slower pace (Rolland, 1994).

Rolland (1994) noted one more important form of disability—that arising from social stigma. Whether an illness results in stigma due to facial or bodily disfigurement, such as severe burns, or stigma due to its association with a marginalized group, such as those living with AIDS and individuals who are homosexual or intravenous drug users, stigma can be experienced as a huge handicap for those affected (Rolland, 1994). Even though AIDS does not carry the immediate death sentence that it once did, individuals aging with HIV/AIDS now worry about where they will live when they can no longer care for themselves (as we will discuss in later chapters).

ASSESSMENT AND INTERVENTION

Assessing and intervening with older adults experiencing transitions involves sophisticated and highly nuanced skills. The process involves digging deeper than the surface level of assessment and intervention. Assessment and intervention are related and are difficult to separate; for instance, by asking questions in assessment, the nurse or other professional is actually also intervening (Wright & Leahey, 2013). The following case study reveals the complexities of unraveling the complications stemming from transitions in an older adult's life.

Case Example

John is 75-year-old man who was admitted to a mental health unit in a hospital in central Canada. John was diagnosed with depression and suicidal ideation. There have been several events that are related to his depression. First, John retired seven years ago. He loved his work and did not want to retire, but felt that he needed to look after his wife who was deteriorating with Alzheimer's disease. Second, John's wife Susan died six months ago. From the time he retired until the death of his wife, he spent most of his time caring for her. Initially, John's wife lived within their home. He stoically tried to keep her in the home, but after several years caregiving, he needed

to place her in a nursing home. Not only was Susan voiding in the living room, she no longer recognized John. She also would leave the home when John was asleep and wander. Once, Susan was found wandering on a busy street, only scantily clad in the dead of winter. John was frantic with worry. His physician was concerned; John's blood pressure was high, and John now needed medications to calm his frazzled nerves and to sleep. When Susan entered a nursing home, John's caregiving did not stop. He would come daily to feed his wife. Even though he was not concerned about the care given at the facility, he felt that he could spend more time coaxing her to eat. In the years of caregiving for Susan, John lost most of his friends and social contacts. Initially, friends tried to keep in contact John, but at times he would turn down their invitations because he was too tired. Also, John sensed that his friends really did not understand. They told him that he should "get on with his life," but John did not feel this was possible. He felt compelled to help Susan even when she did not recognize him or acknowledge his help.

The past six months after the death of Susan were a blur. John felt intense loneliness and lack of purpose. He did not know how to rekindle his prior friendships. John spent his days medicating his grief, loneliness, and boredom with alcohol. While the numbness was not particularly pleasant, John felt it was much better than feeling his pain. As a result of his pain and his attempts to deal with it, John began to become very depressed and even suicidal.

When on the mental health unit, the nurses and social worker began to work with John to examine the triggers of his depression. They agreed with John that the years of caregiving for Susan resulted in deep physical exhaustion that contributed to his depression. They also noted that John lost his sense of identity when he gave up his work and only seemed to recapture a sense of identity and purpose in life when he devoted himself wholeheartedly to Susan. After about one week on the unit, John began to develop trust in the staff, and made connections between his past experiences and his current depression. John told nursing and social work staff about impact of the death of his mother when he was in his early fifties. John was temporarily working halfway across the country when his father phoned him to tell him that that his mother was ill. John's father asked him to return, but he chose not to when his father stated that the illness did not appear to be too serious. John admitted that the unresolved grief and guilt of this situation haunted him throughout his adult years. Also, John admitted that about a year after the death of his mother, he had a brief affair. Although he confessed this to Susan and they worked to rebuild their marriage and trust, John could never quite forgive himself. And, of great concern to him, his relationship with his son and daughter was strained, in part due to their knowledge of the affair, and in part due to misunderstandings caused by the stress of caregiving for Susan.

John's situation illustrated some of the concepts described within this chapter. Retirement, the loss of a spouse, social isolation, and loneliness can lead to profound loss, depression, and suicidal ideation in an older adult. Self-medicating

with alcohol can exacerbate depression. Further, from a life course perspective, events from the past can have an acute impact on how older adults experience current transitions, even if they are not aware of the connections between the past and present. And, as will be explained shortly, some older adults have a significant need for forgiveness, from themselves, from others, and/or from God (Enright, 1996).

Assessment

Assessment of transitions such as the death of a spouse, as well as depression related to that transition, necessitates a multifaceted approach. This approach entails examining the past, insofar as it relates to the present, as well as examining the present and possible future scenarios.

In working with John, nursing staff and the social worker examined past and current triggers of the depression and suicidal ideation. Through the questions asked of John, the professionals were able to ascertain that relatively current stressors included the exhaustion of caregiving and the death of his wife. In posing questions about his past experiences with grief, they found out that John had unresolved issues of grief and guilt related to his mother's death many years prior, as well related to the affair he had shortly after the death of his mother. By gently asking John whether these experiences contributed to his current experiences of grief, John was able to make the connection between past grief ("ghosts of the past") and his current grief. In essence, nurses and professionals were connecting the unresolved issues of John's past encounters with transitions to his present stressful experiences (Krause, 2007). This insight facilitated John's understanding of why he was unable to accept the advice of friends and family in getting additional help to care for Susan. It might have also assisted John to connect past transitions with ones he faces in the future.

With knowledge of the risk of suicide among older adults (Canadian Coalition for Seniors' Mental Health, 2009), professionals continually assessed John's level of depression and suicidal risk. This not only provided the staff a gauge with which to determine his progress, but also may have helped John understand the importance of self-monitoring when he returned home. Staff were also aware that examining past issues can be traumatic in and of itself, so they were cognizant to check in regularly with him to assess John's level of depression and suicidal ideation.

Understanding the importance of examining the reciprocal nature of the influence of the illness upon John and his ability to influence illness (Wright & Leahey, 2013; Wright, Watson, & Bell, 1996), nursing staff asked John to describe how depression has impinged upon his life. As a followup question, they asked him if there were things he did that influenced the impact of depression upon his life. For instance, on days where he had appointments or had to help a neighbor, did his feelings of depression lessen? Professional staff on the mental health unit purposefully posed this question. They were aware that what John believes about the illness, including his ability to exert influence on the impact of the illness on his life, would impact how he thinks and responds to depression (Wright, Watson, & Bell, 1996).

While some nursing staff on the unit became frustrated by John's complaints of physical pain, others were particularly astute in listening for covert messages in John's conversation. For example, when John complained about a headache or back pain, they wondered if he was saying, "My head hurts, but I also hurt inside." Some of the nurses were aware that older adults may have more difficulty in admitting to mental distress. Growing up in an era where emotional problems were not spoken of and where individuals were expected to "put up and shut up" about internal pain, many older adults incorporated a deep-seated belief that mental illness is shameful. Even though the stigma attached to mental illness has lessened somewhat in the twenty-first century, at the core of their being, many aging adults are unwilling to admit mental distress (Connor, Copeland, Grote, Koeske, Rosen, et al., 2010). A number of the nurses on John's ward were not aware, however, that physical distress and pain can be linked to depression as the same neurotransmitters involved in mood (serotonin and norepinepherine) are also believed to be involved in pain (Bailey, 2003).

Nurses and other professionals also explored John's support system (Wright & Leahey, 2013). Specifically, who did he have for support, both professional and family/friend/neighbor support? Who could he access for help on a regular basis and what kind of help would that entail? The staff also explored John's beliefs about accepting help: *Does accepting help from others indicate weakness or an inability to cope?* Further, what were his coping methods and which methods were effective and which were not? Staff explored previous coping methods—besides drinking alcohol—to see if he utilized healthy coping mechanisms in the past and could return to some of these. They also probed about John's past experiences with illness to understand how he might respond to depression in the future.

As John's depression started to lift and his suicidal ideation dissipated, staff assessed John's level of awareness regarding depression. Not only did this entail asking about his knowledge about the illness and medications, but also how he would be able to monitor himself in the future. Specifically, staff asked John how he would know when he was starting to become depressed again? What would he be feeling, doing, and thinking? They also asked who he would turn to if he noticed he was thinking, feeling, and behaving in ways that indicated his depression was back and worsening.

A key part of assessment also involved asking John about what gives him hope and meaning in life (Duggleby et al., 2011). This tied into the existential issues that some older adults face. Nurses asked John about what has given him hope in the past and what now gives him hope. The psychologist even asked John if positive meaning has come from the illness and death of Susan (Kim, Kjervik, Belyea, & Choi, 2011). They assessed what he can do activity wise that will foster hope and a sense of purpose and meaning. They asked if John has engaged in volunteer work in the past and if this would give him structure and meaning in his life.

An important aspect of finding hope and meaning, as well as self-acceptance (Ingersoll-Dayton & Krause, 2005) also entails self-forgiveness. John was finding

it difficult to forgive himself for not being present with his mother at her death and for having an affair about a year after the death of his mother. Unfortunately, as is often the case, professionals on the unit felt uncomfortable dealing with the spiritual issues and tried to avoid talking about forgiveness (Ramsay, 2008). What staff did not realize is that for some older adults, particularly those who espouse religious faith, emotional health and spiritual health are inextricably tied (Ramsay, 2008). Nursing staff, as well as John, were also unaware of the potential connection between John's unexpressed feelings of guilt and grief over missing the passing of his mother and the extramarital affair one year later. They did not realize that in the process of "shutting down" the grief and guilt felt over not being present for his mother's passing, John also emotionally shut down to others, such as his wife. This created a context within which he considered and engaged in a brief affair, when previously, this kind of behavior was unthinkable to him (McGoldrick, 1993).

Interventions

As mentioned earlier, the very process of assessing through questioning is an intervention (Wright & Leahey, 2013). Questions are a powerful means to encourage older adults, such as John, to reflect on their lives (Wright & Leahey, 2013), make connections between the past and present, and develop insight (McGoldrick, 1993). Insight allows older adults to make different choices about how they face future transitions and losses.

When John started to feel better and have increased concentration, staff took the opportunity to provide teaching on depression, medications, and the potential of relapse. To increase the likelihood that John could respond differently to future transitions, John needed to understand what depression is, how it can be treated, and how he can decrease the chances of ending up in hospital for depression in the future.

Although nursing and medical staff did not feel comfortable addressing John's spiritual issues, they referred him to the hospital chaplain. This chaplain, who was particularly astute at understanding the importance of self-forgiveness for physical, emotional, and spiritual health, worked with John to help him address this area. She understood that for some older adults, it is easier to grasp the concept of God's forgiveness, or forgiveness of others, than self-forgiveness. Also, she grasped the notion that self-forgiveness involves reconciling differences between real and ideal self-schemas (views of how older adults perceive themselves) (Ingersoll-Dayton & Krause, 2005). In her assessment of John's belief systems, the chaplain determined that John does not hold to a specific faith. Her practice was based upon the foundation that the needs of the client determine the intervention (Speck, 1998), and so she did not suggest that John seek solace from biblical scriptures or seek God's forgiveness and help with self-forgiveness. Rather, she walked John through a process that examined his ability to connect his past regrets within the context of unresolved grief about his mother's death. Because John was not able to cognitively change his evaluation standards of himself, she focused on helping

John to acknowledge this mistake and learn from it, as well as make reparations through a discussion with his son (Ingersoll-Dayton & Krause, 2005). She assisted John in recognizing that self-forgiveness does not mean condoning his previous behavior (Ramsay, 2008), but involves moving forward with new insight into the circumstances that resulted in his behavior and an honest acknowledgment of his efforts to live in a respectful manner toward others.

Although life review therapy was not offered by the occupational therapist on John's unit, nursing and social work staff informally engaged John in some life review. Life review is believed to be an effective intervention for older adults with depression (Chippendale & Bear-Lehman, 2012). Specifically, they asked John to review aspects of his life of which he is particularly proud, not just his regrets. The staff members were attempting to help John re-story his life in a balanced way, acknowledging his positive contributions to his wife, family, and the community; the purpose was to help him integrate the pieces of his life into the whole of self. If a life review therapy/narrative therapy intervention had been offered on the unit, the occupational therapist might have worked with John to ask him to write about specific periods of his life or to write about different life themes in the presence of the occupational therapist. The writing could have occurred in individual sessions or within group sessions (Korte, Bohlmeijer, Cappeliez, Smit, & Westerhof, 2012). When writing about negative events, the occupational therapist could have helped participants like John integrate negative experiences into their lives in a meaningful way. He could have posed questions that helped participants construct alternate stories about their negative experiences, such as how they coped through such events, what they learned, and what good came out of the situation. Participants would have been asked to link these written observations to their identity as a person and to future goals. They would also have been asked to write about positive memories; these memories might have been forgotten or subsumed under negative memories (Korte et al., 2012).

Nursing and other professional staff, such as the recreational therapist, engaged John in activities. Not only did this allow the recreational therapist to assess John's level of concentration and to assess how he interacted with others, but also to reintroduce John to the meaning and enjoyment of structured activities. As part of recreational therapy, John may have learned the importance and enjoyment of engaging in activities or hobbies, with the hope that those learnings would be transferred to John's home life.

Related to the importance of structured activities, nursing, social work, and recreational therapy staff suggested that John consider volunteer work. They mentioned to John that the importance of volunteer work goes far beyond providing structure and some social contact in his life. Older adults who are active in volunteer work experience self- reported better physical health (Lum & Lightfoot, 2005) and lower levels of depression (Musick & Wilson, 2003). Volunteer work is also associated with lower mortality rates for some older adults (Musick, Herzog, & House, 1999). Some older adults who volunteer even report benefits for their

family members; namely, family members are less worried about them and also, family members benefit from the knowledge about information and resources that their older members gain (Morrow-Howell, Hong, & Tang, 2009). Further, an important aspect of volunteer work is that it can foster a sense of meaning and purpose in life and continued growth (Choi & Landeros, 2011). Meaning and purpose is integral to personhood. Staff specifically suggested that John consider work that is meaningful to him, perhaps work that is related to social causes or areas of personal or professional strengths. Ideally, this work would also link to his personal values or spiritual beliefs. In this way, his actions for the good of others would be congruent with, and indeed, an expression of, his beliefs and values (Choi & Landeros, 2011). The sense of "putting back"—with his new understanding of his real and ideal self—could also aid him in forgiving himself for incidents in his life that he had previously tried to forget. Volunteer work could be a form of empowerment that counteracts the losses he has experienced, as well as the loss of control he may be feeling in other avenues in life (Tang, Copeland, & Wexler, 2012).

Observing his enjoyment of reading, staff also proposed John consider educational pursuits as part of his need for continued growth (Choi & Landeros, 2011) and self–achievement (Cha, Seo, & Sok, 2012). Older adults may take classes, such as university classes or classes focused on activities such as dancing or exercise (Morrow-Howell, Kinnevy, & Mann, 1999). Although educational pursuits may result in less significant benefits than volunteer opportunities, in one study, older adults still rated class taking as valuable (Morrow-Howell et al., 1999). Presumably, how John chooses to express his sense of personhood—educational versus volunteer pursuits—will be based in part upon what he values and what opportunities are available in his community.

John's psychiatrist suggested that John and his family members have a meeting with his nurse or the social worker on the unit. This was in part to assess family dynamics, including how John's son and daughter relate to him and each other. The professional would also be able to provide teaching about mental illness and supports that could be put into place to help John. However, the purpose of the meeting was also to examine how John and his children wanted their relationship to proceed. John regretted the strained relationship and wanted to explore with his children if they could resume some contact and what this contact would entail.

SUMMARY

Physical and mental health problems in advancing years may be considered a life transition, due to the multiplicity of changes that occur and the fact that the illness transition may cause other transitions, such as retirement or changes in living environments. Nurses and other professionals who assess and intervene with older individuals need to consider not only these transitions, but also how these older clients have weathered previous transitions and the impact of these experiences on current transitions. Further, understanding that illness trajectories differ according to the progressive nature of an illness, or the eventuality of acute

flare-ups within a progressive disease course, will help professionals recognize the enormous burden faced by older adults and their family members.

Critical Thinking Activity

- Consider if you had been a therapist on a community mental health team and had visited John in his home after Susan had died, but prior to his admission to hospital. What might you have observed in John and his surroundings that might suggest he was depressed? How would you have assessed John? Specifically, what questions would you ask him and what steps would you have taken if you determined he was at risk for suicide?
- As you consider the events of John's life from the life course perspective, and also ponder possible connections between the unresolved grief and guilt from his mother's death to the brief extramarital affair, what thoughts come to mind? Does this seem plausible or simply an excuse for past behavior? How will you help older adults who are struggling with past decisions or behaviors with which they cannot come to terms?

REFERENCES

Alzheimer's Association. (2013). Younger/early onset Alzheimer's & dementia. Retrieved March 20, 2013, from www.alz.org/alzheimer's_disease_early_onset.asp

Alzheimer Society of Canada. (2012). *What is Alzheimer's disease*? Retrieved from www.alzheimer.ca/en/About-dementia/Alzheimer-s-disease

American Psychiatric Association (APA). (2000). *The diagnostic and statistical manual of mental disorders—text revision (DSM IV TR).* Washington, DC: Author.

Amoako, E. P., Richardson-Campbell, L., & Kennedy-Malone, L. (2003). Self-medication with over-the-counter drugs among elderly adults. *Journal of Gerontological Nursing, 29*(8), 10–15.

The Arthritis Society. (2012). Facts & figures about arthritis. Retrieved November 08, 2012, from www.arthritis.ca/page.aspx?pid=6239

Bailey, K. (2003). Physical symptoms comorbid with depression and the new antidepressant duloxetine. *Journal of Psychosocial Nursing & Mental Health Services, 41*(12), 13–18.

Baird, C. L., Yehle, K. S., & Schmeiser, D. (2007). Experiences of women with osteoarthritis in assisted living facilities. *Clinical Nurse Specialist, 21*(6), 276–286. doi: 10.1097/01.NUR.0000299616.44098.cb

Blyth, F. M., March, L. M., Brnabic, A. J., Jorm, L. R. (2001). Chronic pain in Australia: A prevalence study. *Pain, 89*(2–3), 127–134.

Boss, P. (1999). *Ambiguous loss: Learning to live with unresolved grief.* Cambridge: Harvard University.

Boyle, A. R., & Davis, H. (2006). Early screening and assessment of alcohol and substance abuse in the elderly: Clinical implications. *Journal of Addictions Nursing, 17*(2), 95–103. doi:10.1080/1088460060066829

Bushardt, R. L., & Jones, K. W. (2005). Nine key questions to address polypharmacy in the elderly. *Journal of the American Academy of Physician Assistants, 18*(5), 32–37.

Canada Safety Council. (2012, October). Drug safety for seniors. Retrieved October 12, 2012, from http://canadasafetycouncil.org/node/1393

Canadian Coalition for Seniors' Mental Health. (2009). Depression in older adults: A guide for seniors and their families. Retrieved October 15, 2012, from www.ccsmh.ca

Canadian Diabetes Association. (2012). Diabetes and you. Retrieved December 10, 2012, from www.diabetes.ca/diabetes-and-you/living/complications.

Cha, N. H., Seo, E. J., & Sok, S. R. (2012). Factors influencing the successful aging of Korean older adults. *Contemporary Nurse, 41*(1), 78–87.

Chippendale, T., & Bear-Lehman, J. (2012). Effect of Life Review Writing on depressive symptoms in older adults: A randomized controlled trial. *American Journal of Occupational Therapy, 66*(4), 438–446. doi:10.5014/ajot.2012.004291

Choi, N., & Landeros, C. (2011). Wisdom from life's challenges: Qualitative interviews with low- and moderate-income older adults who were nominated as being wise. *Journal of Gerontological Social Work, 54*(6), 592–614. doi: 10.1080/01634372.2011.585438

Cohen, D., & Eisdorder, C. (2001). *The loss of self: A family resource for the care of Alzheimer's disease and related dementias* (Rev. ed.). New York: W. W. Norton.

Conn, V. S. (1992). Self-management of over-the-counter medications by older adults. *Public Health Nursing, 9*(1), 29–36. doi: 10.1111/j.1525-1446.1992.tb00069.x

Connor, K. O., Copeland, V. C., Grote, N. K., Koeske, G., Rosen, D., et al. (2010). Mental health treatment seeking among older adults with depression: Impact of stigma and race. *American Journal of Geriatric Psychiatry, 18*(6), 531–543. doi: 10.1097/JGP.0b013e3181cc0366

Detwiler, C. (2003). The client with the cognitive disorder. In W. K. Mohr (Ed.), *Johnson's psychiatric-mental health nursing* (5th ed.;pp. 607–640). Philadelphia: Lippincott Williams & Wilkins.

Duggleby, W., Hicks, D., Nekolaichuk, C., Holtslander, L., Williams, A., Chambers, T., & Eby, J. (2012). Hope, older adults, and chronic illness: A meta-synthesis of qualitative research. *Journal of Advanced Nursing, 68*(6), 1211–1223. doi: 10.1111/j.1365-2648.2011.05919.x

Ekman, I., Ehnfors, M., & Norberg, A. (2000). The meaning of living with severe chronic heart failure as narrated by elderly people. *Scandinavian Journal of Caring Sciences, 14*(2), 130–136.

Ekstam, L., Tham, K., & Borell, L. (2011). Couples' approaches to changes in everyday life during the first year after stroke. *Scandinavian Journal of Occupational Therapy, 18*(1), 49–58. doi: 10.3109/11038120903578791

Enright, R. D. (1996). Counseling within the forgiveness triad: On forgiving, receiving forgiveness, and self-forgiveness. *Counseling & Values, 40*(2), 107ff .

Frankl, V. E. (2006). *Man's search for meaning.* Boston: Beacon Press.

Gambert, S. R., & Albrecht, C. R. (2005). The elderly. In J. H. Lowinson, P. Ruiz, R. B. Millman, and J. G. Langrod (Eds.), *Substance abuse: A comprehensive textbook* (4th ed.; pp. 1038–1048). Philadelphia: Lippincott Williams & Wilkins.

George, S. R., & Thomas, S. P. (2010). Lived experience of diabetes among older, rural people. *Journal of Advanced Nursing, 66*(5), 1092–1100. doi: 10.1111/j.1365-2648.2010.05278x

Gill, E. A., & Morgan, M. (2011). Home sweet home: Conceptualizing and coping with the challenges of aging and the move to a care facility. *Health Communication, 26*(4), 332–342. doi: 10.1080/10410236.2010.551579

Government of Canada. (2006). *The human face of mental health and mental illness in Canada, 2006.* Ottawa, Canada: Minister of Public Works and Government Services.

Greenfield, W. L. (1984). Disruption and reintegration: Dealing with familial response to nursing home placement. *Journal of Gerontological Social Work, 8*(1/2), 15–21.

Grenier, S., Potvin, O., Hudon, C., Boyer, R., Preville, M., Desjardins, L., & Bherer, L. (2012). Twelve-month prevalence and correlates of subthreshold and threshold anxiety in community-dwelling older adults with cardiovascular disease. *Journal of Affective Disorders, 136*(3), 724–732. doi: 10.1016/j.jad.2011.09.052

Health Canada. (2005). *Canadian Addiction Survey: A national survey of Canadians' use of alcohol and other drugs.* Ottawa: Author.

Health Canada. (2002). *A report on mental illness in Canada.* Retrieved February 28, 2012, from www.phac-aspc.gc.ca

Heart and Stroke Foundation of Canada. (2012). Retrieved December 15, 2012, from www.heartandstroke.com.

Help the Aged. (2008). *Pain in older people: Reflections and experiences from the older person's perspective.* London: Author.

Hood, G., Huber, J., Gustaffson, U., Scambler, S., & Asimakopoulou, K. (2009). 'With age comes wisdom almost always too late': Older adults' experiences of T2DM. *European Diabetes Nursing, 6*(1), 23–28. doi: 10.1002/edn.128

Huang, A. R., Mallet, L., Rochefort, C. M., Eguale, T., Buckeridge, D. L., & Tamblyn, R. (2012). Medication-related falls in the elderly. *Drugs & Aging, 29*(5), 359–376.

Ingersoll-Dayton, B., & Krause, N. (2005). Self-forgiveness: A component of mental health in later life. *Research on Aging, 27*(3), 267–289. doi: 10.1177/0164027504274122

International Association for the Study of Pain (IASP). (1994). *Classification of chronic pain: Description of chronic pain syndromes and definitions of pain terms.* Seattle: IASP.

Jack, L., Airhihenbuwa, C., Namageyo-Funa, A., Owens, M., & Vinicor, F. (2004). The psychosocial aspects of diabetes care: Using collaborative care to manage older adults with diabetes. *Geriatrics, 59*(5), 26–32.

Jakobsson, U., Hallberg, I. R., & Westergren, A. (2004). Overall and health related quality of life among the oldest old in pain. *Quality of Life Research, 13*(1), 125–136.

Juurlink, D. N., Herrmann, N., Szalai, J. P., Kopp, A., & Redelmeier, D. A. (2004). Medical illness and the risk of suicide in the elderly. *Archives of Internal Medicine, 164*(11), 1179–1184.

Kim, S. H., Kjervik, D., Belyea, M., & Choi, E. S. (2011). Personal strength and finding meaning in conjugally bereaved older adults: A four-year prospective analysis. *Death Studies, 35*(3), 197–218. doi: 10.1080/07481187.2010.518425

Korte, J., Bohlmeijer, E., Cappeliez, P., Smit, F., & Westerhof, G. (2012). Life review therapy for older adults with moderate depressive symptomatology: A pragmatic

randomized controlled trial. *Psychological Medicine, 42*(6), 1163–1173. doi: 10.1017/S0033291711002042

Krause, N. (2007). Evaluating the stress-buffering function of meaning in life among older people. *Journal of Aging and Health, 19*(5), 792–812. doi: 10.1177/0898264307304390

Kuerbis, A., & Sacco, P. (2012). The impact of retirement on the drinking patterns of older adults. A review. *Addictive Behaviors, 37*(5), 587–595. doi:10.1016/j.addbeh.2012.01.022

Lum, T., & Lightfoot, E. (2005). The effects of volunteering on the physical and mental health of older people. *Research on Aging, 27*(1), 31–55. doi: 10.1177/0164027504271349

McGoldrick, M. (1993). Echoes from the past: Helping families mourn their losses. In F. Walsh and M. McGoldrick (Eds.), *Living beyond loss: Death in the family* (pp. 50-78). New York: W. W. Norton.

McKenna, K., Liddle, J., Brown, A., Lee, K., & Gustafsson, L. (2009). Comparison of time use, role participation and life satisfaction of older people after stroke with a sample without stroke. *Australian Occupational Therapy Journal, 56*(3), 177–188. doi: 10.1111/j.1440-1630.2007.00728.x

Melanson, P. M., & Downe-Wamboldt, B. (1995). The stress of life with rheumatoid arthritis as perceived by older adults. *Activities, Adaptation & Aging, 19*(4), 33–47. http://dx.doi.org/10.1300/J016v19n04_03

Ministry of Health and Long-Term Care. (2007). *Preventing and managing chronic disease: Ontario's framework.* Retrieved November 05, 2012, from www.health.gov.on.ca/english/providers/program/cdpm/pdf/framework_full.pdf

Morrow-Howell, N., Hong, S-I., & Tang, F. (2009). Who benefits from volunteering? Variations in perceived benefits. *The Gerontologist, 49*(1), 91–102. doi: 10.1093/geront/gnp007

Morrow-Howell, N., Kinnevy, S., & Mann, M. (1999). The perceived benefits of participating in volunteer and educational activities. *Journal of Gerontological Social Work, 32*(2), 65–80. http://dx.doi.org/10.1300/J083v32n02_06

Musick, M. A., Herzog, A. R., & House, J. R. (1999). Volunteering and mortality among older adults: Findings from a national sample. *Journal of Gerontology: Social Sciences, 54B*(3), S173–S180. doi: 10.1093/geronb/54B.3.173

Musick, M. A., & Wilson, J. (2003). Volunteering and depression: The role of psychological and social resources in different age groups. *Social Science & Medicine, 56*(2), 259–269.

National Institute of Health Medline Plus. (2011). Seniors and chronic pain. Retrieved October 20, 2012, from www.nlm.nih.gov/medlineplus/magazine/issues/fall11/articles/fall11pg15.html

Northcott, S., & Hilari, K. (2011). Why do people lose their friends after a stroke? *International Journal of Language & Communication Disorders, 46*(5), 524–534. doi: 10.1111/j.1460-6984.2011.00079.x

Painter, J. A., Allison, L., Dhingra, P., Daughtery, J., Cogdill, K., & Trujillo, L. G. (2012). Fear of falling and its relationship with anxiety, depression, and activity engagement among community-dwelling older adults. *The American Journal of Occupational Therapy, 66*(2), 169–176.

Pickersgill, M. (2001). Grieving within a care home. *Nursing & Residential Care, 3*(12), 564–566.

Poulsen, K., & Pachana, N. A. (2012). Depression and anxiety in older and middle-aged adults with diabetes. *Australian Psychologist, 47*(2), 90–97. doi: 10.1111/j.1742-9544.2010.00020.x

Potvin, O., Forget, H., Grenier, S., Preville, M., & Hudon, C. (2011). Anxiety, depression, and 1-year incident cognitive impairment in community-dwelling older adults. *Journal of the American Geriatrics Society, 59*(8), 1421–1428. doi:10.1111/j.1532-5415.2011.03521.x

Ramage-Morin, P. L. (2008). *Chronic pain in Canadian seniors.* Ottawa: Statistics Canada. Catalogue no. 82-003-X.

Ramsay, J. L. (2008). Forgiveness and healing in later life. *Generations, 32* (2), 51–54.

Reynolds, S. L., Haley, W. E., & Kozlenko, N. (2008). The impact of depressive symptoms and chronic diseases on active life expectancy in older Americans. *American Journal of Geriatric Psychiatry, 16*(5), 425–432. doi: 10.1097/JGP.0b013e31816ff32e

Rhodes, D. L., & Bowles, C. L. (2002). Heart failure and its impact on older women's lives. *Journal of Advanced Nursing, 39*(5), 441–449.

Roberto, K. A., & Reynolds, S. G. (2002). Older women's experiences with chronic pain: Daily challenges and self-care practices. *Journal of Women & Aging, 14*(3-4), 5–23. doi: 10.1300/J074v14n03_02

Rolita, L., & Freedman, M. (2008). Over-the-counter medication use in older adults. *Journal of Gerontological Nursing, 34*(4), 8–17.

Rolland, J. S. (1987). Chronic illness and the life cycle: A conceptual framework. *Family Process, 26*(2), 203–221. doi: 10.1111/j.1545-5300.1987.00203.x

Rolland, J. S. (1993). Helping families with anticipatory loss. In F. Walsh and M. McGoldrick (Eds.), *Living beyond loss: Death in the family* (pp. 144–163). New York: W. W. Norton.

Rolland, J. S. (1994). *Families, illness, and disability: An integrative treatment model.* New York: Basic Books.

Rolland, J. S. (2005). Chronic illness and the family life cycle. In B. Carter and M. McGoldrick (Eds.), *The expanded family life cycle: Individual, family, and social perspectives* (3rd ed.; pp. 492–511). New York: Pearson.

Schofield, P. (2006). Pain management in care homes. *Journal of Community Nursing, 20* (6), 30–34.

Schulz, R., & Beach, S. (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *Journal of the American Medical Association, 282*(23), 2215–2219.

Scott, T., Mackenzie, C., Chipperfield, J. G., & Sareen, J. (2010). Mental health service use among Canadian older adults with anxiety disorders and clinically significant anxiety symptoms. *Aging & Mental Health, 14*(7), 790–800. doi: 10.1080/13607861003713273

Sharaf, A. Y., & Ibrahim, H. S. (2008). Physical and psychosocial correlates of fear of falling among older adults in assisted living facilities. *Journal of Gerontological Nursing, 34*(12), 27–35.

Smith, J. M. (2012). Portraits of loneliness: Emerging themes among community-dwelling older adults. *Journal of Psychosocial Nursing & Mental Health, 50*(4), 34–39. doi: 10.3928/02793695-20120306-04

Smoyak, S. A. (1992). Sociopolitical and historical contexts of geropsychiatric nursing. In K. Buckwalter (Ed.), *Geriatric mental health nursing: Current and future challenges* (pp. 1–16). Thorofare, NJ: Slack.

Speck, P. (1998). Spiritual issues in palliative care. In D. Doyle, G. W. C. Hanks and N. MacDonald (Eds.), *Oxford textbook of palliative medicine* (2nd ed.; pp. 805–814). Oxford: Oxford University.

Suicide Awareness Voices of Education (SAVE). (2013). Suicide facts. Retrieved February 16, 2013, from www.save.org/index.cfm?fuseaction=home.viewpage&page

Tang, F., Copeland, V. C., & Wexler, S. (2012). Racial differences in volunteer engagement by older adults: An empowerment perspective. *Social Work Research, 36* (2), 89–100. doi: 10.1093/swr/svs009

Thompson, J. W. (1994). Trends in the development of psychiatric services, 1844–1944. *Hospital and Community Psychiatry, 45*(10), 987–992.

Trigoboff, E. (2009). Cognitive disorders. In C.R. Kneisl and E. Trigoboff (Eds.), *Contemporary psychiatric-mental health nursing* (2nd ed.; pp. 296–322). Upper Saddle River, NJ: Prentice Hall.

Turcotte, M., & Schellenberg, G. (2006). *A portrait of seniors in Canada*. Ottawa: Statistics Canada. Catalogue no. 89-519.

Wesson, D. R., Smith, D. E., Ling, W., & Seymour, R. B. (2005). Sedative-hypnotics. In J. H. Lowinson, P. Ruiz, R. B. Millman, and J. G. Langrod (Eds.), *Substance abuse: A comprehensive textbook* (4th ed.; pp. 302–313). Philadelphia: Lippincott Williams & Wilkins.

Wiklund, L. (2008). Existential aspects of living with addiction—Part 1: Meeting challenges. *Journal of Clinical Nursing, 17*(18), 2426–2434. doi: 10.1111/j.1365-2707.2008.02356.x

Wilson, B. A., Shannon, M. T., & Stang, C. L. (2004). *Nurses' drug guide*. Upper Saddle River, NJ: Pearson/Prentice Hall.

World Health Organization (WHO). (n.d.). *Facing the facts: The impact of chronic disease in Canada*. Retrieved November 10, 2012, from www.who.int/chp/chronic_disease_report/en

Wright, L. M., & Leahey, M. (2013). *Nurses and families: A guide to family assessment and intervention*. Philadelphia: FA Davis.

Wright, L. M., Watson, W. L., & Bell, J. M. (1996). *Beliefs: The heart of healing in families and illness*. New York: Basic Books.

Zambroski, C. (2003). Qualitative analysis of living with heart failure. *Heart & Lung, 32*(1), 32–40. doi: 10.1067/mhl.2003.10

Chapter 4

HOUSING TRANSITIONS

There is nothing permanent except change.
Heraclitus (Greek philosopher)

Reflective Questions

- What residential options are available to older adults and what might influence their selection?
- What factors might influence the transition process for older adults who are changing settings?
- What interventions might be used to support the transition process for older adults and their families?

Redfoot and Gaberlavage (1991) wrote that "Housing . . . provides a secure and meaningful old age or magnifies the disability and isolation that too often accompany advanced years" (p. 35). However, with advancing years, transitions in housing occur. Such moves may include moving from one's own residence to another residence, moving from one institution to another, moving from one room in a facility to another, or moving from one's own residence to an institution. For older adults, their life course journey (e.g., employment positions, marriage, divorce, never married, retirement) influence their housing options in their later years. In addition, there are many factors, both positive and negative, that influence the transition experience for the older adult, and the family, that may sway the decision to relocate. When we talk about the transition from one place of residence to another, we often use the term *relocation.*

In this chapter, we will describe the importance of home, explore some of the housing options that are available to older adults, discuss some of the theory and research that underlies our understanding of transitions (relocation), and identify interventions to promote positive adaptation to a new environment.

It is important to note that while there is a growing body of knowledge on the housing options of older adults, there is much that we do not yet know about the housing needs of older adults. For instance, the vast majority of research in this area is focused on urban populations. Yet, in Canada, 39.35 percent of older adults reside in rural settings (Turcotte & Schellenberg, 2007). As of 2007, seniors in the United States made up 7.5 million of the 50 million people living

in rural areas (www.raconline.org/topics/aging). Older adults in rural areas may have limited options for relocation when needed and may need placement in a continuing care facility, such as a nursing home, in a town or city miles away from home. There are also other sub-populations of older adults that are more vulnerable than the general population of older adults to relocation issues, such as those living with AIDS. Their housing needs are largely unknown. An exception is the work of Furlotte, Schwartz, Koornstra, and Naster (2012). They examined the housing experiences of 11 older adults living with HIV/AIDS and reported that participants' stories yielded three themes: concern regarding being accepted into retirement homes and continuing care facilities, barriers to accessing subsidized housing, and homelessness. Participants experienced confusion and concern about their future housing prospects.

Another vulnerable sub-population of older adults is those aging with a developmental disability. These older adults, in essence, may "fall between the cracks" within the housing sector for aging individuals. If they are placed in residential living, such as a group home, staff may not know how to address health problems, including a dementia that presents in some older adults with Down syndrome. However, if they enter a continuing care facility such as a nursing home, staff may not know how to address communication difficulties that may be due to the developmental disability. Also, older residents in a continuing care facility may not know how to connect with the adult who is admitted with a developmental disability, as this individual will probably be significantly younger (possibly in the 50s or early 60s) than them.

The importance of safe housing cannot be overstated. Housing is the means by which individuals can take care of their health and their families (Lane, Hirst, & Reed, 2013). The significance of housing has been demonstrated in a housing project for severely mentally ill individuals within the United States (Housing First project). Historically, significantly mentally ill individuals only obtained housing when they had shown improvement in symptoms due to compliance with the treatment program (medications, etc.). The rationale for this protocol was the notion that the severely mentally ill could only maintain housing when they were mentally well (Tsemberis, Moran, Shinn, Asmussen, & Shern, 2003). Thus, some mentally ill individuals chose to remain on the streets. However, the Housing First project rejects the assumption that the mentally ill must first comply with a treatment program prior to receiving housing. This program considers housing a basic human right (Tsemberis et al., 2003), and thus, individuals can access housing without adherence to a treatment program.

This program and approach has been demonstrated to be effective. In a longitudinal study, 225 individuals with mental illness were randomly assigned to receive housing based upon mental health treatment and sobriety (control group), and the other half received immediate housing with no conditions regarding treatment (experimental group) (Tsemberis, Gulcur, & Nakae, 2004). Over a two-year period, individuals in the Housing First group accessed housing sooner and

remained securely housed. The participants in the Housing First group stated that they felt more in control of their lives. Interestingly, there were no differences between the control and experimental groups in regards to the use of substances or in symptoms of mental illness (Tsemberis et al., 2004).

From the example of Housing First, it is evident that housing is crucial for individuals to maintain health and stability. We propose that just as housing provides the basis for those with severe mental illness to maintain health and stability, so secure housing should be available for all older adults, regardless of health or financial status (Lane et al., 2013).

THE CONCEPT OF HOME

The Oxford dictionary defines *home* both as a place of origin and as a goal or destination (www.oed.com). Hollander (1991) documented that the Germanic words for home, *heim, ham, heem*, are derived from the Indo-European *kei* meaning lying down and something dear or beloved. The implication of his work is that the *home* is a place to lay down one's head; it is also a place that evokes warm emotions.

Home provides basic shelter and security, and is the place where one belongs. The meaning of *home*, however, extends far deeper than a physical location, or even the autonomy and safety that the physical building affords. The meaning of *home* takes on an ethereal quality. In an interesting study, Gillsjo and Schwartz-Barcott (2011) interviewed three older women about their understanding of *home*, including a description of it, the location of home, and what home means to them. Two of the women were currently living within their own residences in the community and one had just moved into a residential facility. The women spoke of home as a place, as involving cherished relationships, and as including experiences and memories. Two women discussed multiple homes, including their anticipated homes in heaven. The authors suggested the importance of healthcare professionals recognizing that for older individuals, home is more than a building, but rather it is the very center of their lives (Gillsjo & Schwartz-Barcott, 2011).

The meaning of home differs between individuals and may vary between those with and without cognitive impairment. The multifaceted understanding of *home* is recognized by nurses and professionals who work with older adults experiencing dementia. Some individuals with dementia may frequently repeat the sentence "I want to go home." This has raised questions as to the meaning of home for those with dementia. Does this mean the home of their childhood, as dementia usually robs more of the short-term memory than long-term memory? Does this mean that the older adult wants to leave the hospital or the continuing care facility and return to his or her previous place of residence? Or, does this individual just want to feel safe and comfortable? Despite the fact that we may not know what individuals with dementia mean when they frequently ask to go home, it is clear that the

construct of home involves much more than a building; it is imbued with feelings of security and warmth.

Whatever meaning is ascribed to the concept of *home*, for some aging individuals, this meaning includes the presence of pets, including cats and dogs. Pets can provide companionship within the home, a sense of security, emotional support, and a reason to get up in the morning. We know of individuals who have had dogs, lost their pets (through death), and afterwards noticed a strange phenomenon. These individuals reported feeling like there was no reason to come home; nobody (their pet) was waiting for them. They felt empty. Hence, at a certain point, these individuals bought another dog or cat so that the feeling of warmth and being welcomed within the home would return. There are also other benefits to pet ownership. Aging adults who regularly walk their dogs show increased levels of exercise and fitness (Parker-Pope, 2009; Thorpe et al., 2006). They also may experience an increased sense of *home* within their neighborhoods when walking their dogs; individuals will readily stop to pet their dog, talk about the animal, and exchange pleasantries (Cangelosi & Sorrell, 2010). While some contest the benefits of pets upon the psychological health of older adults, a number of therapists acknowledge the therapeutic value of pets upon the mental health of individuals (Imber-Black, 2009; Walsh, 2009). The powerful attachment that older adults have to pets may be illustrated by older adults' unwillingness to leave their homes during wide-scale disasters without their pets (Torgusen & Kosberg, 2007). Within Chapter 8 (Future Directions) we will offer suggestions regarding the presence of dogs and cats within assisted living facilities, as well as nursing homes.

Just as the concept of home is imbued with meaning, so is the notion of *leaving home* loaded with significance. Aminzadeh, Dalziel, Molnar, and Garcia (2009) explored the perspectives of individuals with dementia regarding their meanings and experiences associated with imminent relocation to a care facility. A qualitative design was employed, which involved in-depth interviews with 16 individuals with dementia at their homes within two months prior to relocation. Participants viewed relocation to a facility as a major residential change and life transition requiring significant adaptive efforts. The experience of leaving their current home to move into a new one had profound personal meaning for them. The researchers noted that the participants recognized that relocation symbolized the end of an era and that life, as they once knew it, would be changed. Participants also spoke about how relocation signaled the downward decline of aging and meant that they would reside in a more dependent and structured environment. Of note, some participants also mentioned how they were survivors and could use their coping skills to make the best of the situation. This is significant, as the "home" can be representative of security and self-identity (Aminzadeh et al., 2009). By drawing on the metaphor of "survivor," these aging individuals with dementia were expressing that even though their identity within their home may be left behind, they would still carry some identity as survivors into the new setting. Presumably,

their identity as survivors would carry them through the initial adjustment period in the care facility.

Ideally, a home should provide the highest possible level of independence, function, and comfort. Many older adults prefer to remain in their own homes and *age in place*, rather than relocate, particularly to institutional living. The ability to age in place depends on appropriate support for changing physical and psychosocial needs, so the older adult can stay where he wants to be. In order to support continued aging in place, basic home care services may be provided and/or the individual can purchase services from a private healthcare agency.

Within developed countries, home care services may include assessment, case management, professional nursing, rehabilitation therapy, social work, and personal care. Services are based on assessed unmet need(s) for short-term or long-term care and may include end-of-life care. Home care also provides assessments for applications to continuing care centers (such as nursing homes), designated assisted living sites, and facility-based respite care. Assessment is of special importance since each situation is unique and therefore requires a review of the functional capacity of the older adult and individual health status. Services may be provided on a daily or intermittent basis, according to the needs of the older adult. In the provision of such services, good communication strategies are needed to ensure that all members of the healthcare team, and the client's family, are aware of the older adult's needs and progress towards identified goals. Chappell, Havens, Hollander, Miller, and McWilliam (2004) found that home care is significantly less expensive than a continuing care facility, even when informal caregivers' (e.g., family members) time is valued at either minimum or replacement wage.

GLOBAL PERSPECTIVE

Within a larger societal context, *age-friendly communities* are places that actively value, involve, and support older adults, both active and frail, with infrastructure and services that effectively accommodate their changing needs. Within this context, there is a global initiative to develop age-friendly communities and increase opportunities to age in place. An *age-friendly* community is one that provides opportunities for people to age in place by making resources available for day-to-day living. It means, for example, that grocery stores, pharmacies, transportation services, healthcare facilities, community centers, and religious buildings are within easy reach of and accessible to older adults. The implication is that older adults can continue to live in and make contributions to their community. It also means that services are available when needed, such as home-delivered meals. In other words, the community is one in which older adults may live with dignity and independence.

Through the World Health Organization (WHO), 33 cities, including four in Canada, have implemented and evaluated age-friendly principles. Portland,

Oregon, was the only city in the United States to participate in WHO's original study. Because of the positive response to this project, WHO created a global network of age-friendly communities (WHO, 2007). In Canada, the Age-Friendly Communities Initiative, based on WHO program principles, is led by the Public Health Agency of Canada (PHAC) in collaboration with other federal, provincial, territorial, and non-government partners. At the provincial level, British Columbia, Manitoba, Nova Scotia, and Quebec have Age-Friendly Community programs (PHAC, 2008). Several municipalities beyond these provinces have both formally and informally adopted age-friendly principles by assessing their communities and designing interventions to enhance the ability of older adults to remain in their own homes and familiar environment.

Why are age-friendly communities or cities necessary? It is estimated by the year 2030, two thirds of the population (worldwide) will live in urban areas. Additionally, within cities in higher income countries, it is projected that approximately one-quarter of the population will be 60 years of age or older (McGarry, 2012). The sheer numbers of the older adult population justify the need to make communities more amenable and accessible to older adults. Second, another reason why age-friendly communities are necessary is because the current physical layout and structure of most cities work against the older population, particularly those who are frail or who cannot drive. Many decades ago (up to 100 years ago), residential areas were moved away from commercial areas in order to deal with the congestion of people and unsanitary conditions. This was done by city policies and zoning regulations (Scharlach, 2009). This meant that families grew up in residential communities away from the overcrowding of the inner city, but were geographically removed from many stores and services. For younger families who are healthy and have access to cars, this has and still does work out well. However, within the twenty-first century, there is recognition that older adults are compromised by this type of city structure, particularly for those who cannot drive or for whom the bus system does not work out well (Kennedy, 2010). Third, housing structures were built in the past, and are still currently constructed in the present, for younger individuals; they are not designed for aging individuals (Scharlach, 2009). For instance, many houses have multiple stairs; some stairways may be quite steep. Aging individuals may have difficulty navigating these stairs. With a basic understanding of the principles of age-friendly communities, we will now discuss current housing options for older adults within developed countries.

HOUSING OPTIONS IN LATER LIFE

Some aging adults, by choice or by need, move from one type of residence to another. The term that we used earlier in this chapter was *relocation*. Residential options range along a continuum from remaining in one's home; to retirement communities; to shared housing with family members, friends, or others; to

residential care communities such as assisted living settings; and for those with most needs, to continuing care facilities (such as nursing homes and auxiliary hospitals). There are many different types of housing. The terms used to describe the various types depend upon geographic location. Generally, all housing options can be categorized into one of three main categories: independent living options, supportive housing, and healthcare facilities.

A great deal of work has been done on the housing options for older adults, but far less research has been conducted on what influences the decision making process. In examining the housing choices of older Canadians, Perks and Haan (2010) identified that social support characteristics are the strongest predictors of dwelling type; this means that older adults choose their residence type primarily on the basis of their social needs and wants, rather than on their economic resources or even their health characteristics.

While a number of housing options exist especially for those with sufficient finances, not all older adults have such resources. Strohschein's (2012) study was designed to investigate characteristics of seniors in the Canadian population who were involuntary stayers and to assess the associations with health. *Involuntary stayers* refers to older adults who want to relocate, but are unable to due to finances or other situations. Data from the 1994 Canadian National Population Health Survey, with the sample restricted to those 65 and older ($N = 2551$) was used. Almost one in 10 older adults was identified as an involuntary stayer. Those older with few socioeconomic resources, poor health, greater need for assistance, and low social involvement were more likely to identify as an involuntary stayer. Furthermore, those older adults who were involuntary stayers reported significantly more distress and had greater odds of low self-rated health than their peers. This study brings into visibility older adults who are unable to move from their present location despite their desire to do so. Despite the current emphasis on "aging in place," this study identified that not all aging adults want to remain in their current location.

Independent Living Options

Independent living describes any housing arrangement in which the older adult maintains control over the environment. It may describe the home that an older adult has lived in for most or even all of his life. Or it may be used to describe a housing facility, with the same goal (of maximizing independence) that is exclusively for older adults, generally those aged 55 and over. With respect to the latter distinction, housing options vary widely, from apartment-style living to freestanding homes. Other terms associated with independent living include *retirement communities, retirement homes, senior housing,* and *senior apartments.*

With the aging of the baby boomer generation, architects, engineers, and builders are focusing on home designs that adjust to the changes that may

accompany aging. Their goal is to enable older adults to stay in their homes safely even if they experience illness and functional decline. These new designs are marketed as transgenerational or universal designs and can benefit everyone, not just older adults. Designs and modifications may include fittings in the bathroom, walk-in showers, wider hallways, remote-controlled devices for lights, raised counter tops, and adjustable-height sinks. These kinds of modifications facilitate older adults or individuals with disabilities living independently longer.

Social Housing

Social housing is also often referred to as *subsidized housing* or *public housing*. Subsidized housing encompasses all types of housing in which the government provides some type of subsidy or rent assistance. In most situations, the subsidy ensures that the older adult does not spend more than 30 percent of personal income on rent. Social housing is an important option for older adults who are experiencing poverty or significantly restricted incomes. While social housing fills an important niche in housing options for older adults, depending upon the city, the demand for this option can be high, resulting in older adults being placed on long waitlists to access housing.

Life Lease Arrangements

A *life lease* is an arrangement where the older adult purchases the *right to occupy* a housing unit and to use the common facilities, usually until he or she dies or moves. The major market for life lease arrangements are adults aged 55 and older. This arrangement means that older adults can move into smaller and usually more affordable housing. At any time, the aging individual can decide to transfer this right of occupancy back to another qualifying purchaser either directly or by way of the sponsor organization, depending upon the lease contract arrangements. In this way, older adults earn a return on their investment similar to the return on the sale of their own home. Usually, the lease requires a single upfront payment as well as monthly fees for management and maintenance of the property and yard.

Adult Lifestyle Communities

Adult lifestyle communities are also known as retirement communities or 55-plus communities. Housing is usually condominiums—in a tower, townhouses, or semi-detached homes. The units are designed for the newly retired adult and the community often includes recreation facilities (e.g., golf course, tennis courts, swimming pool). Some of these communities are gated and may have security. Many have age requirements.

While little research has been conducted on age-restricted housing, there are a few exceptions. Schafer (2000) demonstrated that about 7 percent of Americans,

aged 70 years and over, who resided outside of continuing care facilities and other institutions, resided in age-restricted housing. Of these residing in age-restricted housing, fewer than 50 percent had access to nursing care. As expected, the percentage requiring nursing care rose with advancing years. It is interesting to note that Schafer (2000) found income, wealth, education, and even need for assistance did not strongly influence the likelihood of selecting this type of housing option.

Bekhart, Zauszniewski, and Nakhala's (2009) study was undertaken to understand the reasons why older adults move to retirement communities. In their qualitative analysis, the researchers found that there were three categories of triggers to move into retirement communities: *pushing* factors, *pulling* factors, and *overlapping* factors. Pushing factors included an older adult's or spouse's failing health, getting rid of responsibilities, not feeling helped with activities, the previous facility closed, and loneliness. Factors that pulled older adults to move into retirement communities included familiarity, and reputation of the facility, security, and joining friends. The third category reflected overlapping pushing and pulling factors, which constituted their reason for moving.

Supportive Housing

Shared Housing

Shared housing among adult children and their older relatives is a preferred choice for some older adults. The sharing may relieve the economic burdens of maintaining a home after widowhood or retirement on a fixed income. Cultural influences predict the frequency of multigenerational residences. In Canada, about half of multigenerational households are headed by immigrants; the majority of them are of Asian origin. Among Asian and South Asians living in Canada, shared housing is often an expectation (Kaida, Moyser, & Park, 2009). While citing U.S. census data, Keene and Batson (2010) provided an overview of multigenerational families, citing that among these households, the largest group consists of adult householders, their children, and their grandchildren, which comprises about 65 percent of these families (or 2.6 million families). In these multigenerational families, the householder is the grandparent; an adult child with his or her children have moved in with the grandparent. Other family configurations are those in which a parent or parent-in-law lives with the householder and his or her children, which accounts for about one-third of multigenerational households or 1.3 million households. In these multigenerational families, the householder is the adult child with whom the aging parent lives, in addition to dependent children that may still be living within the home.

Relocating from one's own home to the home of an adult child can have many benefits, but without adequate preparation it can also be stressful for both the family and the older adult. Older adults and adult children need to negotiate the new shared living arrangement in terms of roles (who does what?), a balance between

togetherness and privacy, joint or single social gatherings, and even parenting. For instance, the older adult may not want to be "parented" by her children; also, an adult child may not appreciate the aging individual parenting his children (grandchildren of the aging adult). Being able to navigate close proximity between the generations takes flexibility on the part of all involved, as well as a sense of humor!

A variation of shared housing has long existed in what has become known as "granny flats." These may be apartments added to existing homes or the construction of small housing units on family property with privacy, as well as sharing of time and resources. These arrangements allow families to be close enough to be of assistance if needed but to remain separate from their older member. For some families, the private apartment or suite facilitates the need for privacy in the midst of togetherness.

A variety of other shared intergenerational housing options have emerged in the community over the last few decades. Small home residences that offer independent or supportive housing may not have the extensive amenities of a multi-unit complex, but they can provide a home-like atmosphere and personal touches. Increasingly, homeowners are expanding or opening their homes to several "guests." Accommodations may range from an individual suite to a bedroom in a shared residence with the homeowner. Most often these situations provide some level of support to ensure the older adult stays safe, but housing "guests" are mainly there to provide companionship and socializing for the older adult in a family-like setting. An older adult provides some additional finances for the family, as well as the benefits of their presence and wisdom, while the guests provides company, safety, and a home environment for the aging individual.

A variation of this theme is when an older adult opens up the family home for a younger generation—for example, a university or college student. Often this will appeal to older adults who can care for themselves without outside assistance but who live alone and are struggling with isolation, lack of stimulation, and have concerns for personal well-being should they have an accident with no one around. The student may provide help with snow shoveling or the garden in return for a minimal amount of rent. There are many such programs scattered throughout North America, the United Kingdom, Europe, and Australia; for example, there are approximately 100 homesharing programs throughout the United States (Steinisch, 2007). The purpose of the match-up is for the mutual benefit of the older adult and the younger adult. The young adult lives for very little cost in the home of an older adult and provides agreed-upon services, and the older adult not only has services provided for free, but also has the greater safety with the student living in the home. Proponents of these programs suggest that they delay institutionalization (Fox, 2010); the safety of having another individual in the home, as well as the services he or she can provide, delays the need to move to more supervised levels of care. Regardless of whether these arrangements delay institutionalization, they provide a solution for older adults who want to remain in their homes, but are lonely, desire socializing with another, or perhaps want the safety of having another person within their home.

Assisted Living Facilities

As adults age, there is a tendency to simplify living space and lifestyles. Assisted living is a housing option for older adults who want or need help with some of the activities of daily living (e.g., cooking meals, getting up to the bathroom in the middle of the night, keeping house, and traveling to appointments), but also want and can maintain some independence. Perkins, Ball, Whittington, and Hollingsworth's (2012) study involved a synthesis of findings from three qualitative grounded theory studies that addressed aspects of autonomy in assisted living facilities. Their data analysis identified that older adults, living in these facilities, viewed autonomy as an expression of the self that is uniquely defined by each older adult and is based upon personal experiences and environmental and social contexts.

Assisted living is the fastest growing type of housing option for older adults in the United States (Stevenson & Grabowski, 2010). These facilities are designed for older adults who do not need care in a continuing care facility (such as a nursing home or auxiliary hospital), but who need more support than is available in shared housing. This type of facility is known by different names across the continent, including assisted living, retirement homes, seniors' residences, personal care homes (terminology based on jurisdiction), retirement residences, residential care, board and care, congregate care, and sheltered housing.

In general, assisted living is a residential type facility, ranging from converted homes to apartment buildings. Assisted living facilities are often operated by for-profit corporations or by not for-profit organizations. In countries such as Canada and United States, they are not part of the formal healthcare system and costs are not covered through provincial or territorial health insurance. Older adults are tenants who pay fees for accommodation and for any healthcare purchased. Most of these facilities offer two or three meals per day, light weekly housekeeping and laundry services, as well as providing optional social activities. Many facilities have transportation services and Internet access. Some have exercise facilities, movie theaters, pharmacies, and hair dressing services. Some provide apartment-style living with scaled down kitchens, while others provide rooms. In some, an older adult may need to share a room. The housing unit is adjusted to meet the needs of the older individual, for example grab bars in the bathroom, call for help lights, or low kitchen cabinets. Most facilities have a group dining area and common areas for social and recreational activities.

Within assisted living facilities, resident councils are often encouraged for older adults to provide support systems for each other; one example is where a resident council creates a system in which older adults check on one another the first thing each morning. Older adults may sit on the councils and, depending upon the facility, the council may determine some policies for that facility. Resident councils offer older adults a greater sense of control and influence upon their living environment and hence, some aging individuals value and enjoy taking part in this opportunity.

Many older adults and their families prefer assisted living facilities to continuing care centers because they are more homelike and offer more opportunities for control, independence, and privacy. Because some facilities have a healthcare professional on staff, or may contract out to the local community health center for services, older adults can still receive care and yet function somewhat independently. However, many older adults may have long-term healthcare needs associated with chronic illnesses, and with time they may require more care than the facility is able to provide. Bellantonio and colleagues' (2008) randomized trial study was conducted to determine whether an interprofessional team intervention minimized unanticipated transitions out of an assisted living facility for persons with dementia. Such unanticipated transitions included permanent relocation to a nursing facility, emergency department visits, and acute care hospitalization. Findings identified that falls were the primary reason for a transition. While the intervention reduced the risk of unanticipated transitions, the results were not statistically significant. What is relevant is that more men than women experienced an unanticipated transition. Several explanations were provided by the researchers in reference to this last finding. Men entered the facilities with a greater number of comorbidities. Moreover, men are more likely to have Parkinson's disease or Lewy body disease, which are more commonly associated with gait and balance disorders. In addition, men with dementia may have more support to remain at home than women (because women tend to live longer than men and hence provide care for their husbands) and may delay relocation longer than women, thus entering the facility with a higher level of disability.

Healthcare Facilities

Continuing Care Facilities

Continuing care facilities are a purpose-built congregate care option for individuals with complex, sometimes unpredictable medical needs who require 24-hour on-site registered nurse care and/or treatment. These facilities may be called nursing homes, auxiliary hospitals, special care homes, or personal care homes. When used appropriately, continuing care facilities fill an important need for older adults and their families. Just over half of continuing care residents are aged 85 years or older (Turcotte & Schellenberg, 2007). There are more than twice as many women as men residing in continuing care facilities. In part, this is because women live longer than men (on average) and thus may reach their older-old years (85 years of age and older) and require the care provided by continuing care facilities.

Inability to perform activities of daily living (ADLs) is one of the main reasons for moving to a continuing care facility, and most very elderly adults require significant assistance with ADLs and instrumental activities of daily living. Another reason older adults enter continuing care facilities is due to the presence of cognitive

impairment. More than two-thirds of the residents are cognitively impaired. Not only does cognitive impairment impact the ability of elderly individuals to care for themselves, but also the incidence of dementias increases significantly as individuals age (as noted in Chapter 2). It is no wonder then, that many individuals who enter continuing care facilities are very old.

Himes, Wagner, Wolf, Aykan, and Dougherty (2000) investigated whether the differentials (e.g., age, sex) in continuing care facility entry are attributable to variations in family composition between facilities in the United States and Germany. Results suggested that the correlates of entry are similar in the two countries. Family composition is an important factor, because marriage is associated with lower rates of continuing care facility admission for both men and women. Among women, childlessness leads to higher rates of entry, although this finding was not statistically significant.

While older adults relocate, as needed, into continuing care facilities (from less restrictive to more supervised settings), on occasion, older individuals may relocate from a *more* restrictive environment to a *less* restrictive environment. This sometimes occurs when a family removes an elder from a nursing home and brings the individual home to live with them. However, as a unique twist on the usual movement from an assisted living facility into a continuing care facility, such as a nursing home, Hutchings and colleagues (2011) reported on the relocation of older adults with dementia from a nursing home setting to an assisted living facility. They interviewed 10 family members of eight older adults on their experiences of the relocation. They reported that the client-centered care resulted in positive outcomes for both the older adults and their family members. The older adults and their family members were more contented with the assisted living placement, appreciated the privacy offered by the new environment, and some family members suggested that their older family member experienced improvement in functional abilities (Hutchings et al., 2011). We should note that this kind of reversal in the level of care (from more restrictive to less restrictive) is rare.

Hospice

The term *hospice* refers to more than just a site of care, hospice is also a philosophy of care. Palliative care offered within stand-alone hospices or within designated units in nursing homes offers services to help relieve suffering and improve quality of life for people with a life-limiting illness, as well as those grieving the impending death of a loved one.[1] Making the transition to hospice care can be difficult for individuals and their families. This type of housing arrangement will be discussed in length within Chapter 6 and touched upon in Chapter 8.

[1] There are differences in understanding of the terms *hospice* and *palliative care*. These concepts will be defined more clearly within Chapter 6.

THEORY AND RESEARCH THAT UNDERLIES OUR UNDERSTANDING OF TRANSITIONS

The Decision to Relocate

As individuals age and their family situation changes (e.g., children leave home), and their physical status changes, a relocation from the family home is often considered. However, for most people, relocation is a major decision. Older adults in urban areas may find that they are living in unfamiliar areas because the neighborhood around them has now changed. For example, some older adults may have originally settled in an area that was settled by people of the same ethnic background. Over time, the ethnic composition may have changed and thus the sense of shared culture and background may be lost. For adults in rural areas, the geographic distance and lack of supportive services may lead to serious consequences, especially if they are functionally impaired.

The housing transition decision, in other words relocation, of older adults is a relatively new area of investigation. A review of the literature identified the following traits:

- Older adults make up a small fraction of movers.
- Nearly one-half of older adult movers are married.
- Widowed older adults are more likely to move than their married counterparts.
- Death of a spouse reduces the chances of moving (from one house to another).
- Most older adults downsize their owned family home to rent (Lin, 2005).

Often physical or mental health influences the decision to relocate. Stoeckel and Porell (2010) examined the relationship between the occurrence of falls and the expectations older adults have about making future residential moves. Data from the 2002 Health and Retirement Study (HRS) was used to analyze self-reported probabilities of moving among a nationally representative sample of non-institutionalized adults aged 65 and older. The results revealed that falls were predictive of anticipation of housing relocation as indicated by more than 50 percent of respondents; these individuals reported a probability of moving within the next two years. The results suggest that consideration of housing relocation is greater among older adults who experience tangible events indicative of a trajectory of deteriorating health. Weeks, Keefe, and Macdonald (2012) examined contextual factors that might influence the older adult's decision to relocate. The findings of their quantitative study indicated that gender, age, household income, province of residence, driving status, whether the current home met the older adult's needs, and unmet heavy cleaning needs were significant influences. To elaborate, lower income older adults were less likely to consider relocation, because of reduced affordable options. Older adults who did not drive were less likely to consider moving, while challenges with heavy cleaning was a motivation for relocation.

As with many transitions, there are both potential negative and positive outcomes to moving residences. Overall, research indicates that relocation is associated with increased morbidity and mortality, but it does not always result in serious effects on mental or physical health. For instance, Capezuti, Boltz, Renz, Hoffman, and Norman (2006) examined the physical and mental health characteristics of 120 residents three months following their transfer from one nursing home to another facility. While there was a statistically significant increase in the number of residents who fell during the post-transfer (76.9%) compared to the pre-transfer (51.2%) period, overall, there were few changes noted. Residents did not demonstrate any other significant physical or mental health changes during the three months following the involuntary transfer when compared with their pre-transfer status. Similar findings were reported by Walker, Curry, and Hogstel (2007). They interviewed eight nursing home residents and eight assisted-living facility residents two to 10 weeks after admission, when symptoms of relocation stress are most likely to appear. Findings from these studies indicate that the incidence of relocation stress may be overestimated.

However, research suggests that individuals are better able to meet the challenges of relocation if they have a sense of control over the circumstances and have the confidence to carry out the needed activities associated with a move. Self-efficacy, defined as the individual's judgment about being able to perform a particular activity, may be an important variable in positive adjustment to relocation. The Self-Efficacy Relocation Scale (SERS), developed by Rossen and Gruber (2007), can be used to assess self-efficacy in individuals who are relocating, identify potential pre-relocation adjustment issues, and guide interventions to promote positive relocation outcomes.

Relocation Trauma

A variety of terms have been used to describe the results of relocation: *relocation trauma, relocation shock, translocation shock,* and *transfer trauma. Relocation trauma* describes a stressful move from one environment to another. If you have moved from one city to another, you will understand the stress of this transition. It takes time to adjust to any move. During a move, an older adult may have less personal energy available than a younger adult to cope with the stress of the move. Not only do aging individuals have less energy than younger individuals, older adults may be already using a considerable amount of energy to cope with some of the chronic conditions that they may be experiencing, such as chronic obstructive pulmonary disease or the residual effects of a cardiovascular accident. If an acute condition (whether a move, or an acute experience of the flu) requires additional coping strategies, then the older adult will find that his coping skills may be exhausted. This may make the move seem insurmountable. Thus the transition from one setting to another may be termed *relocation trauma.*

Relocation is a stressor, and sometimes a crisis, for the older adult and the family. Relocation to a continuing care facility is one of the more stressful kinds of relocations and one that many older adults dread. The dramatic change in both physical and social demands as a result of continuing care placement has been widely discussed in the literature as a life stress event for older adults. Accordingly, researchers have attempted to untangle the challenges older adults encounter in making the transition from home on the "outside" to life in a continuing care facility. It is frequently identified that older adults experience feelings of abandonment, a lack of privacy within the continuing care facility (such as a nursing home), and decreased opportunities for contact with family and friends. These different losses experienced upon continuing care facility placement generate much suffering for these older adults. The problems associated with the public nature of continuing care facility life and with the restrictions involved in complying with the rules and regulations can cause major concerns to older adults. The presence of sick and confused people is a constant source of threat to the newly admitted older adult who feels his health may similarly deteriorate.

The term *relocation stress syndrome* is seen within the healthcare literature. Relocation stress syndrome is a nursing diagnosis characterized by symptoms such as anxiety, confusion, hopelessness, and loneliness. It usually occurs in older adults shortly after moving from a private residence to a continuing care facility (Walker et al., 2007).

Consequences of Relocation: Health Decline

Some researchers have theorized about the reasons behind the decline in health status of some older adults who have been relocated. Their theories can be divided into three main foci: older adult (patient/client), transfer, and facility effects. Research on older adult effects has focused on their direct experience of the relocation. Hypotheses have changed over time in attempts by researchers to determine how older adults' experience changes in environments. One hypothesis is that those who are relocated are more ill compared to those who are not relocated and that the illness itself is the reason for the transfer. The underlying assumption of this hypothesis is that the relocation did not cause illness, but rather the illness in essence caused the relocation.

Another theory addressing the impact of relocation upon the older adult is the stress hypothesis. This hypothesis focuses on a lack of personal control an individual can experience when being relocated. A change in environment can cause an individual to experience high levels of stress before and after the move (Ewen & Kinney, 2013; Walker et al., 2007).

The transition theory hypothesis focuses on the impact of the transfer upon older adults, specifically, the varying levels of care and support received by older adults through the transfer. The underlying hypothesis in this theory is

that the quality of transfer differs between older adults; there are varying levels of care at facilities, and some provide better individualized care and attention than others. How well the individual is received and helped in the transition then impacts how well the older adult transitions to the new facility (Walker et al., 2007).

It should also be noted that the characteristics of the transfer itself can influence the impact relocation has on older adults. Thorough preparation can contribute to the success of the relocation. Preparation for the physical transfer involves anticipating and allowing for adequate time for necessary preparations to be put into place. (Sometimes transfers are so rushed that important details to be communicated between healthcare professionals maybe missed). Research has highlighted the importance of proper patient monitoring and being sufficiently prepared for adverse events are essential to making a patient transfer successful.

Transitions within and between Healthcare Facilities and Home

Relocation transitions can have negative physical and psychological effects on all clients/patients regardless of age and type of facility. These effects are more pronounced in those over 80 years, particularly those who are frail, as well as for continuing care residents. Acute care patients and continuing care residents are at an elevated mortality risk when they are relocated. Studies examining the effect of transferring (relocating) different patient groups between institutions have found that transferred patients were at an elevated mortality risk between 1.99 and 3.76 times greater than those patients who were not transferred (Robinson, 2002). Contradictory studies that have not found an increased mortality risk for transferred patients often have methodological problems. Some of the methodological concerns include small sample sizes, inadequate statistical power, and a lack of control groups.

Evidence from the United States indicates that transfers between care settings are frequent in the last few months of life but may produce little improvement in symptom or pain control (Van den Block, Deschepper, Bilsen,Van Casteren, & Deliens, 2007). Hanratty and colleagues' (2012) study was designed to explore the experiences of older adults as they moved between places of care at the end of their lives. In depth qualitative interviews were conducted with 30 adults between the ages of 69 and 93 years of age. All were identified by their physicians as being in the last year of their lives. Four themes were identified: the prioritization of institutional processes, support across settings, the importance of being heard, and being treated with dignity. As they moved between different care settings, much of the care received by these adults was characterized by inflexibility and a failure of care professionals to listen. Liaison between and within services was not always effective, and community support after a hospital admission was perceived to be,

on occasion, absent, inappropriate, or excessive. The findings highlight the need for continued attention to the basic aspects of care and communication between healthcare professionals and with patients.

Loeher, Bank, MacNeill, and Lichtenberg (2004) investigated whether transition to a continuing care facility after rehabilitation was significantly related to increased depressive symptoms at baseline and at periodic followup. All patients lived alone prior to their medical rehabilitation. Those returning to live alone were compared to those discharged to live with others, or to a continuing care facility. Patients discharged to live alone reported the lowest levels of depressive symptoms followed by those living with others. Patients discharged to a continuing care facility indicated higher levels of depressive symptoms. It may be, however, that longitudinal illness and a loss of independence may significantly impact geriatric depression levels.

Transitions during the course of hospitalization can be problematic for older patients. Minimizing the number of transfers from unit to unit during a single hospitalization is associated with more consistent nursing care, fewer adverse incidents (e.g., healthcare associated infections, falls and medication errors), shorter hospital stays, and lower overall costs (Kanak et al., 2008).

Making the transition from hospital to home can be challenging for many older adults. Fabbre and associates (2011) analyzed interviews with clinical social workers to identify salient themes relevant to care transitions. The return home, although often eagerly anticipated, can be fraught with surprises for aging adults, and for social workers who follow them (Fabbre, Buffington, Altfield, Shier & Golden, 2011). The transition from hospital to home can pose heightened risk for problems, especially for older adults who have multiple health concerns (Naylor & Keating, 2008). A poor transition is often marked by medication errors, noncompliance issues, continuing care facility placement, increased caregiver burden, and increased health costs (Coleman, Parry, Chalmers, & Min, 2006). Awareness of these consequences has grown substantially in the past decade among healthcare providers, administrators, and third-party insurers. Several randomized control trials have studied the effectiveness of specific interventions to enhance the transition process.

Another important aspect of relocation involves the effect of facilities upon the health outcomes of older adults. In essence, this entails the "fit" between the older adult and a new facility. The new facility must be able to handle the medical requirements of the transfer patient, especially if it is possible that his health status could decline upon transfer. For instance, can a facility handle issues related to a mental illness of the older adult, or can the facility manage issues related to an older adult's extreme obesity (Lane, 2007)? It has been documented that those older patients who experience an easy adjustment to their new environment fare better than patients who have a difficult transition.

Continuing Care Facility Placement

Although there is a body of literature addressing older adults' post-placement challenges, less is known about the actual *process* of how these older adults handle these challenges and adjust after continuing care facility placement. The transition, as we earlier termed *relocation*, into a continuing care facility is a common and significant event for older adults. And as noted within this chapter, the transition to a continuing care facility, such as a nursing home, can be very difficult for older adults. In 1963, the first study on the effects of relocation from one continuing care facility to another stirred much attention with its findings that a high mortality rate was associated with the move (Aldrich & Mendkoff, 1963). Yet, the picture is not as bleak as perhaps revealed in the aforementioned study; there are benefits of admission. Quinn and colleagues (2009) examined the influence of admission upon procedures related to diabetes mellitus for residents with dementia. Results indicated that these newly admitted residents experienced higher rates of procedures in the year after admission than they had experienced in the year before admission. The implication is that the policies of the facility may have contributed to resident health through regular monitoring. Other researchers have documented psychological benefits in the form of increased friendships (Wolff, 2013) and reduction in psychiatric symptoms (Bakker et al., 2011).

What do older adults experience when transitioning to a continuing care facility? Generally speaking, the initial transition period is the most difficult. Older adults may experience sadness, anger, loneliness, betrayal, and fear (Brandburg, 2007; Heliker & Scholler-Jaquish, 2006; Iwasiw, Goldenberg, MacMaster, McCutcheon, & Bol, 1996; Wiersma, 2010). During the first six to eight weeks, they may feel overwhelmed, homeless (Heliker & Scholler-Jaquish, 2006), and in a state of disorganization (Brooke, 1989). However, as noted by researchers, many older adults move toward acceptance during the first year. For instance, Wilson (1997) interviewed newly admitted older adults 24 hours after admission, every second day for two weeks post admission and one month after admission. She postulated that the transition into a nursing home involved three phases: overwhelmed phase, adjustment phase, and initial acceptance phase (Wilson, 1997). Similarly, Lee and colleagues (2002) reported that Hong Kong Chinese residents went through four stages in adjusting to continuing care and trying to regain some semblance of normalcy in their lives: orienting, normalizing, rationalizing, and stabilizing. The implication is that while the initial transition to continuing care facilities can be traumatic, aging adults may adapt to this new setting and regain their stability.

The Family Lens

There is consensus within the literature that placing a loved one into a continuing care facility is a painful and stressful experience for some family members

(Park, Butcher, & Maas, 2004). The decision to place a loved one has long been considered one of the most difficult decisions that family members will make. Indeed, most caregivers prefer to take care of their family members with chronic conditions at home and regard the continuing care facility placement as the last resort (Liu & Tinker, 2001).

When placing an older adult, family members may experience very strong, yet ambivalent emotions, including sadness, grief, guilt, anxiety, and relief (Dellasega & Nolan, 1997; Johnson, Morton, & Knox, 1992; Kao, Travis, & Acton, 2004; Kellett, 1999; Reuss, Dupois, & Whitfield, 2005). Relocation experiences are perceived more negatively when family members feel that they have had to make the placement decision on their own (with little support from professionals (Davies & Nolan, 2003), and when they believe staff members lack compassion or empathy with their situation (Strang, Dupuis-Blanchard, Donaldson, Nordstrom, & Thompson, 2006). It is important to note that placement of an older adult may decrease some stress, and yet evoke other stresses. For instance, Ryan and Scullion (2000) reported that family carers experienced relief from the physical exhaustion of caregiving, yet the emotional turmoil of placement continued long after the admission of an older member to a continuing care facility.

We also believe that a cultural lens needs to be applied to the relocation experience. Specifically, what precipitating events tend to lead to placement of elders from various ethnicities, such as Asian older adults? This is a particularly salient question as in the past, Asian families were less likely to place their older adults. In one study, Chinese family caregivers (living in Taiwan) began to consider placement when their older members displayed disturbing, destructive, or risky behaviors (Chang & Schneider, 2010). The aforementioned study examined placement decisions in relation to Asian Chinese within an overseas context; however, studies that examine the relationship of housing and ethnic minorities living *within* Canada are sparse. As an exception, Weeks and LeBlanc (2010) examined the housing concerns of Aboriginal elders and older adults from visible minorities. Aboriginal individuals are considered one of the most poorly housed groups within Canada (Weeks & LeBlanc, 2010). The researchers concluded that many minority older adults (including those who are Aboriginal, have disabilities such as developmental disabilities, or are from another ethnic minority) have concerns about the costs of housing (including renting), the possibility of relocating due to an inability to afford their current housing, the inappropriateness of their current location (e.g., house too small, heating problems, not enough bedrooms, difficulty in using stairs, lack of security related to power outages), a lack of housing options, in particular, low-cost housing options (long waiting lists) and the importance of cultural appropriateness. For instance, older Aboriginal adults and those from other ethnic minorities felt that they were not accepted in the dominant culture of their neighborhoods (Weeks & LeBlanc, 2010).

Family members will need considerable support when an older person moves into a continuing care facility. In particular, family members desire emotional support and good communication with staff caring for the older members (Davies, 2005; Strang et al., 2006). We cannot stress the importance of emotional support enough; no matter how extenuating the circumstances, or how rational the placement decision, family members often feel that they have in some way failed the older adult. And this sense of failure leads to guilt and much grief.

INTERVENTIONS TO PROMOTE POSITIVE TRANSITION EXPERIENCES

In order to facilitate positive transition experiences, conversations with the older adult (and possibly family members) should take place in order to explore what type of housing option is most suitable. Knowledge of the various kinds of housing options is important, especially for aging adults who are vulnerable, including those from different ethnicities, impoverished individuals and those with significant physical or mental illness/disabilities.

For example, if it is determined that an appropriate option is assisted living, then it is important to get a written outline of what services are or are not available from the facility. The older adult will also want to inquire into the staffing, security features, exit processes (e.g., if an individual's health deteriorates, can she access staff to assist her, or is she obligated to move out of the residence?). She will also want to know specific details about the size of the suite, how many bedrooms, and other particulars, so that she knows what belongings she can bring from her current home.

In order to assist older adults with relocation decisions and adjustment, nurses and other professionals should be aware of resources available to the older person, assess the older adult's relocation needs, individualize a realistic relocation plan, promote coping while making a relocation decision, assist with pre-move preparation, and facilitate continuity of care. Post-relocation, nurses and other professionals should tailor interventions to the older adult's values and preferences; promote the individual's sense of control, autonomy, and mastery; provide social support and activities; promote coping with relocation; orient the person to his new surroundings; maintain continuity of care; and ensure that physical and psychosocial needs are met.

Thinking about Shared Housing

Nurses and other professionals should be familiar with the variety of housing options in their communities and be knowledgeable about the rights of tenants of assisted living facilities, low cost seniors' complexes, or other facilities. They may

Questions that might be asked of family members and the older adult:

- What are the needs of the new household member and of the family?
- Where will space be provided for the new member?
- What space will be provided to the older member?
- How will the new member be included in existing family patterns?
- How will responsibilities be shared?
- What resources in the community will assist in the adjustment?
- Is the environment safe for the new member?
- How will family life change with the older member?
- How does each family member feel about the addition of the new member?
- What are the differences in the routines of the new member and the current household pattern?
- What are the older person's expectations?
- Will there be a change in household roles and responsibilities?
- Will the older member be making a contribution to household expenses?

Figure 1: Thinking about adding an older family member to one's home.

also have to initiate or answer questions from family members about when it is suggested that an older adult move into the home of an adult child. This can feel uncomfortable for the nurse or professional, particularly if the older adult and family members disagree on the course of action. The following questions may guide the conversation.

Addressing these questions *prior* to older adults moving into family members' homes may prevent uncomfortable conversations *after* the move has taken place.

Improving Transitions across the Continuum of Care

Nurses in hospitals, the community, and continuing care facilities frequently care for older adults who have experienced relocation. They therefore have a responsibility to help older adults and their family members to understand the impact of relocation and to help facilitate the adjustment to this transition. The first issue to address in any move is whether it is necessary and whether it will provide the least restrictive lifestyle appropriate for the individual. For older adults who are not functioning or safe within their homes, nurses or other professionals may need to refer their clients to home care for an assessment to determine the level of placement required. Home care professionals can then place these individuals on a wait list, if placement is deemed appropriate. Additional nursing or professional interventions include the need to assess the impact of relocation

and determine how to mitigate any negative reactions. This can involve providing information to aging adults and their family members, as well as extending emotional support. As will be discussed in Chapters 6 and 7, this may also involve "standing with" family members as they try to make sense of how to relate to the aging individual, as well as their siblings, as they navigate this transition.

It is important that nurses and other professionals recognize the complexity of the healthcare needs of older adults and are aware that aging individuals often require care in multiple settings across the continuum. Thus, they experience multiple care transitions. Care transition refers to movement of patients from one healthcare practitioner or setting to another as their condition and care needs change. Transitional care requires that nurses and other professionals utilize a set of clinical and communication activities to facilitate the moves of older adults from one care setting to another. To illustrate, an older adult may be treated by a family practitioner, hospitalized and treated by a nurse practitioner, discharged home or to an assisted living facility where the family practitioner may or may not continue to follow him or her. (Many healthcare providers practice in only one setting and are not familiar with the specific requirements of other settings). As a result, there are often significant misunderstandings and criticism of care in the different settings across the continuum.

In order to address the often complexity of care transitions experienced by older adults, intervention strategies have been developed. In a review of the literature, four well-developed transitional care intervention strategies were located. The Transitional Care Model (Naylor et al., 2010), Project RED [Re-Engineered hospital Discharge] (Jack et al., 2009), the Care Transitions Intervention (Coleman et al., 2004) and BOOST [Better Outcomes for Older adults through Safe Transitions] (Society of Hospital Medicine, 2011) all serve the hospitalized older adult population with a goal of decreasing readmissions while maintaining a high level of patient satisfaction. Secondary goals common to all the programs include increasing the patient's ability to self-manage healthcare.

However, there are several programmatic differences among these transition programs. Some programs are limited to hospital based interventions and contact, whereas others follow the patient into the post-discharge environment. Another difference is the professional identified to provide the interventions. The Transitional Care Model and the Care Transitions Intervention provide advance practice nurses and nurse transition coaches to coordinate and provide the interventions both in hospital and after discharge. Home visits and followup phone calls are used by both these programs to provide education on disease management and to reinforce adherence to care plans. In contrast, Project RED and BOOST focus on interprofessional hospital care teams to implement the intervention.

Not all transitional care models utilize nurses, however. Watkins, Hall, and Kring (2012) reported on the results of a study designed to evaluate a social worker

navigator transitional care model for at risk older adults being discharged from hospital to home. The purpose of their study was to evaluate the effectiveness of an innovative Hospital to Home transition program that used a social worker navigator who identified frail elders at risk for readmission during their hospitalization and followed them into their home environments. The navigator focused not only on health-related needs but also on instrumental activities of daily living (IADLs) to ensure a successful transition. Their results demonstrated the importance of extending social support and health education into the home after discharge from hospital. The navigator reinforced medical management and connected participants to appropriate community resources in order to remain safe at home.

When the Transition is to a Continuing Care Facility

Nolan and colleagues (1996) proposed a four-stage typology that describes how admission to a continuing care facility occurs (the process). The typology ranges from an ideal type of admission into continuing care to a less desirable kind of admission. The best kind of admission process is termed a *positive choice*. This occurs when an admission is planned and the older member is fully involved in the discussion and decision making process. The second type of admission is the *rationalized alternative*. This is the most frequent form of admission. While there is less choice on the part of the older adult, the aging individual is still able to create and sustain a perception that the admission is legitimate and/or reversible. The third type of admission is the *discredited option*. This type starts as a positive choice or rationalized alternative but after admission, the resident finds that the situation is not as was expected. For instance, she may have expected a private room but upon admission, finds that this is not possible. The *fait accompli* is the worst-case scenario where virtually all the basic conditions for an acceptable move are absent. The older adult did not anticipate the move, others may have made the decision, and there was no opportunity to explore alternatives and prepare emotionally for the move (Nolan et al., 1996). When at all possible, nurses and other professionals, as well as family members, should aim to facilitate transitions to continuing care facilities that fall within the positive choice category (Nolan et al., 1996), whereby aging adults are involved in the process of decision making.

Unfortunately, it is not always possible to involve older adults in the decision-making process. However, on a more pragmatic level, there are simple interventions that nurses and other professionals can do to promote positive adaptation to relocation to a continuing care facility. For instance, on the first day of the move for the older adult, stimulation and the introduction of new activities and people should be limited. The older adult can be oriented to the environment slowly so that he can incorporate new ideas and routines gradually and at a pace that he feels comfortable with. For example, on the first day, limit introductions to only those key people and places that are necessary; for an aging individual just admitted to a

facility, the only important place to show might be the dining room. Nurses and other professionals can seek out ways to help the older adult make connections between the old environment and the new one. The more familiar the older adult is with the new environment, the easier the transition will be.

It is important to note that family also require support during any relocation, but most noticeably when an older member is admitted into continuing care. Sussman and Dupuis (2012) noted that when families were not given the opportunity before the move to emotionally accept the placement decision, they tended to experience more adjustment issues in the period following admission. This bears witness to the fact that nurses and other professionals work with two clients—the older adult and the family.

SUMMARY

Within this chapter we provided an overview of the housing options available to older adults. Basic guidelines for housing of older adults includes facilitating as much personal decision making as possible, selecting the least restrictive environment, and providing support for older adults and family members prior to the transition, during the transition and after the relocation. Continuing care facilities and other healthcare housing options for older adults are currently undergoing major changes, and these changes are likely to continue well into this century. We suggest that changes need to continue in order to facilitate appropriate housing for older adults, particularly those who are most vulnerable. Some suggested changes will be offered in Chapter 8 (Future Directions).

Critical Thinking Activities

- Ask an older family member what items within the home are significant and why. Consider what item you might select from your own personal environment if you were entering an assisted living facility or a continuing care environment.
- In your clinical experience, what settings have you encountered? Explore with colleagues how the environment might influence the older adult, his or her family, and your own professional role.
- Design your ideal home, recognizing that aging brings physical, functional, psychological, spiritual, and other changes.

REFERENCES

Aldrich, C., & Mendkoff, E. (1963). Relocation of the aged and disabled: A mortality study. *Journal of the American Geriatrics Society, 11*, 185–194.

Aminzadeh, F., Dalziel, W. B., Molnar, F. J., & Garcia., L. J. (2009). Symbolic meaning of relocation to a residential care facility for persons with dementia, *Aging and Mental Health, 13*(3), 487–496. doi:10.1080/13607860802607314

Bakker, T. J., Duivenvoorden, H. J., van der Lee, J., Rikkert, M. G., Beekman, A. T, & Ribbe, M. W. (2011). Integrative psychotherapeutic nursing home program to reduce multiple psychiatric symptoms of cognitively impaired patients and caregiver burden: Randomized controlled trial. *American Journal of Geriatric Psychiatry, 19*(6), 507–520. doi: 10.1097/JGP.0b013e3181eafdc6.

Bekhart, A., Zauszniewski, J. A., & Nakhala, W. E. (2009). Reasons for relocation to retirement communities: A qualitative study. *Western Journal of Nursing Research, 31*(4), 426–479. doi:10.1177/0193945909332009

Bellantonio, S., Kenny, A. M., Fortinsky, R., Kleppinger, A., Robison, J., Gruman, C., Kulldorff, M., & Trella, P. (2008). Efficacy of a geriatric team intervention for residents in dementia-specific assisted living facilities: Effect on unanticipated transition. *Journal of the American Geriatrics Society, 56*(3), 523–528. doi:10.1111/j.1532-5415.2007.01591.x.

Brandburg, G. L. (2007). Making the transition to nursing home life: A framework to help older adults adapt to the long-term care environment. *Journal of Gerontological Nursing, 33*(6), 50–56.

Brooke, V. (1989). How elders adjust. *Geriatric Nursing, 10*(2), 66–68.

Cangelosi, P. R., & Sorrell, J. M. (2010). Walking for therapy with man's best friend. *Journal of Psychosocial Nursing & Mental Health Services, 48*(3), 19–22.

Capezuti, E., Boltz, M., Renz, S., Hoffman, D., & Norman, R. G. (2006). Nursing home involuntary relocation: Clinical outcomes and perceptions of residents and families. *Journal of the American Medical Directors Association, 7*(8), 486–492. doi:http://dx.doi.org/10.1016/j.jamda.2006.02.011

Chang, Y. P., & Schneider, J. K. (2010). Decision-making process of continuing care facility placement among Chinese family caregivers. *Perspectives in Psychiatric Care, 46*(2), 108–117. doi: 10.1111/j.1744-6163.2010.00246.x

Chappell, N. L., Havens, B., Hollander, M., Miller, J. A., & McWilliam, C. (2004). Comparative costs of home care and residential care. *The Gerontologist, 44*(3), 389–400. doi: 10.1093/geront/44.3.389

Coleman, E. A., Parry, C., Chalmers, S., & Min, S. J. (2006). The care transitions intervention: Results of a randomized controlled trial. *Archives of Internal Medicine, 166*(17), 1822–1828. doi:10.1001/archinte.166.17.1822

Coleman, E. A., Smith, J. D., Frank, J., Min, S., Parry, C., & Kramer, A. M. (2004). Preparing patients and caregivers to participate in care delivered across settings: The Care Transitions Intervention. *Journal of the American Geriatrics Society, 52*(11), 1817–1825.

Davies, S. (2005). Meleis' theory of nursing transitions and relatives' experiences of nursing home entry. *Journal of Advanced Nursing, 52*(6), 658–671. doi: 10.1111/j.1365-2648.2005.03637.x

Davies, S., & Nolan, M. (2003). 'Making the best of things: relatives' experiences of decisions about care-home entry. *Ageing & Society, 23*(4), 429–450. doi: http://dx.doi.org/10.1017/S0144686X03001259

Dellasega, C., & Nolan, M. (1997). Admission to care: Facilitating role transition amongst family carers. *Journal of Clinical Nursing, 6*(6), 443–451. doi: 10.1111/j.1365-2702.1997.tb00341.x

Ewen, H. H., & Kinney, J. (2013, January 30). Application of the model of allostasis to older women's relocation to senior housing. *Biological Research for Nursing.* doi:10.1177/1099800412474682

Fabbre, V. D., Buffington, A., Altfeld, S. J., Shier, G. E., & Golden, R. L. (2011). Social work and transitions of care: Observations from an intervention for older adults. *Journal of Gerontological Social Work, 54*(6), 617–625. doi: 10.1080/01634372.2011.589100

Fox, A. (2010). HomeShare—An intergenerational solution to housing and support needs. *Housing, Care and Support, 13*(3), 21–26. http://dx.doi.org/10.5042/hcs.2010.0707

Furlotte, C., Schwartz, K., Koornstra, J. J., & Naster, R. (2012). Got a room for me? Housing experiences of older adults living with HIV/AIDS in Ottawa. *Canadian Journal on Aging, 31*(1), 37–48. doi: http://dx.doi.org/10.1017/S0714980811000584

Gillsjo, C., & Schwartz-Barcott, D. (2011). A concept analysis or home and its meaning in the lives of three older adults. *International Journal of Older People Nursing, 6* (1), 4–12. doi: 10.1111/j.1748-3743.2010.00207.x

Hanratty, B., Holmes, L., Lowson, E., Grande, G., Addington-Hall, J., Payne, S., & Seymour, J. (2012). Older adults' experiences of transitions between care settings at the end of life in England: A qualitative interview study. *Journal of Pain and Symptom Management, 44(*1), 75–83. doi: 10.1016/j.jpainsymman.2011.08.0

Heliker, D. M., & Scholler-Jaquish, A. (2006). Transition of new residents: Basing practice on residents' perspective. *Journal of Gerontological Nursing, 32*(9), 34–42.

Himes, C. L., Wagner, G. G., Wolf, D. A., Aykan, H., & Dougherty, D. D. (2000). Nursing home entry in Germany and the United States. *Journal of Cross-Cultural Gerontology, 15*(2), 99–118.

Hollander, J. (1991). The idea of a home: A kind of space. *Social Research, 58*(1), 31–49.

Hutchings, D., Wells, J. L., O'Brien, K., Wells, C., Alteen, A.M., & Cake, L. J. (2011). From institution to 'home': Family perspectives on a unique relocation process. *Canadian Journal on Aging, 30*(2), 223–232. doi: http://dx.doi.org/10.1017/S0714980811000043

Imber-Black, E. (2009). Snuggles, my cotherapist, and other animal tales in life and therapy. *Family Process, 48*(4), 459–461. doi: 10.1111/j.1545-5300.2009.01295.x

Iwasiw, C., Goldenberg, D., MacMaster, E., McCutcheon, S., & Bol, N. (1996). Residents' perspectives of their first 2 weeks in a long-term care facility. *Journal of Clinical Nursing, 5*(6), 381–388. doi: 10.1111/j.1365-2702.1996.tb00271.x

Jack, B. W., Chetty, V. K., Anthony, D., Greenwald, J. L., Sanchez, G. M., Johnson, A. E., & Culpepper, L. (2009). A reengineered hospital discharge program to decrease rehospitalisation: A randomized trial. *Annals of Internal Medicine, 150*(3), 178–187.

Johnson, M. A., Morton, M. K., & Knox, S. M. (1992). The transition to a nursing home: Meeting the family's needs. *Geriatric Nursing, 13*(6), 299–302. doi: http://dx.doi.org/10.1016/S0197-4572(05)80373-8

Kaida, L., Moyser, M., & Park, S. Y. (2009). Cultural preferences and economic constraints: The living arrangements of elderly Canadians. *Canadian Journal on Aging 28*(4), 303–313. doi: http://dx.doi.org/10.1017/S0714980809990146

Kanak, M., Titler, M., Shever, L., Fei, Q., Dochterman, J., & Picone, D.M. (2008). The effects of hospitalization on multiple units. *Applied Nursing Research, 21*(1), 15–22. http://dx.doi.org.ezproxy.lib.ucalgary.ca/10.1016/j.apnr.2006.07.001

Kao, H. F., Travis, S. S., & Acton, G. J. (2004). Relocation to a long-term care facility: Working with patients and families before, during and after. *Journal of Psychosocial Nursing & Mental Health Services, 42*(3), 10–16.

Keene, J. R., & Batson, C. D. (2010). Under one roof: A review of research on intergenerational coresidence and multigenerational households in the United States. *Sociology Compass, 4*(8), 642–657.doi:10.1111/j.1751-9020.2010.00306.x

Kellett, U. M. (1999). Transition in care: Family carers' experience of nursing home placement. *Journal of Advanced Nursing, 29*(6), 1474–1481. doi:10.1046/j.1365-2648.1999.01035.x

Kennedy, C. (2010). The city of 2050—An age-friendly, vibrant, intergenerational community. *Generations, 34*(3), 70–75.

Lane, A.M. (2007). *The social organization of placement in geriatric mental health.* Unpublished doctoral dissertation, University of Calgary.

Lane, A. M., Hirst, S. P., & Reed, M. B. (2013). Housing options for North American older adults with HIV/AIDS. *Indian Journal of Gerontology, 27*(1), 55–68.

Lee, D. T. F., Woo, J., & Mackenzie, A. E. (2002). The cultural context of adjusting to nursing home life: Chinese elders' perspectives. *The Gerontologist, 42*(5), 667–675. doi: 10.1093/geront/42.5.667

Lin, J. (2005). The housing transitions of seniors. *Canadian Social Trends,* Catalogue No. 11-008, 22–26.

Liu, L. F., & Tinker, A. (2001). Factors associated with nursing home entry for older people in Taiwan, Republic of China. *Journal of Interprofessional Care, 15(3)*, 245–255.

Loeher, E., Bank, A. L., MacNeill, S. E., & Lichtenberg, P. A. (2004). Continuing care facility transition and depressive symptoms in older medical rehabilitation patients. *Clinical Gerontologist, 27*(1/2), 59–70. doi:10.1300/J018v27n01_06

McGarry, P. (2012). Good places to grow old: Age-friendly cities in Europe. *Journal of Intergenerational Relationships, 10*(2), 201–204. doi: 10.1080/15350770.2012.672123

Naylor, M. D., Brooten, D., Campbell, R., Jacobsen, B. S., Mezey, M. D., Pauly, M. D., & Swartz, S. J. (2010). Comprehensive discharge planning and follow-up of hospitalized elders: A randomized clinical trial. *Journal of the American Geriatric Society, 281*(7), 613–620. doi:10.1001/jama.281.7.613.

Naylor, M., & Keating, N. (2008). Transitional care: Moving patients from one care setting to another. *American Journal of Nursing, 108*(9 Suppl), 58–63. doi: 10.1097/01.NAJ.0000336420.34946.3a

Nolan, M., Walker, G., Nolan, J., Williams, S., Poland, F., Curran, M., & Kent, B. C. (1996). Entry to care: Positive choices or fait accompli? Developing a more proactive nursing response to the needs of older people and their carers. *Journal of Advanced Nursing, 24*(2), 265–274. doi: 10.1046/j.1365-2648.1996.01966.x

Oxford dictionary. (-). Retrieved February 10, 2013, from www.oed.com

Park, M., Butcher, H. K., & Maas, M. L. (2004). A thematic analysis of Korean family caregivers' experience in making the decision to place a family member with

dementia in a long-term care facility. *Research in Nursing & Health, 27*(5), 345–356. doi:10.1002/nur.20031

Parker-Pope, T. (2009, December 14). The best walking partner: Man vs. dog. *The New York Times.* Retrieved March 22, 2013, from http://well.blogs.nytimes.com/2009/12/14the-best-walking-partner-man-vs-dog/?emc=etal

Perkins, M. M., Ball, M. M., Whittington, F. J., & Hollingsworth, C. (2012). Relational autonomy in assisted living: A focus on diverse care settings for older adults. *Journal of Aging Studies, 26*(2), 214–225.

Perks, T., & Haan, M. (2010). The dwelling-type choices of older Canadians and future housing demands: An investigation using the aging and social support survey (GSS16). *Canadian Journal on Aging, 29*(3), 445–463. doi:http://dx.doi.org/10.1017/S0714980810000413

Public Health Agency of Canada. (2008). *Age-friendly communities.* Retrieved March 3, 2013 from www.phac-aspc.gc.ca/seniors-aines/afc-caa-eng.php

Quinn, C. C., Gruber-Baldini, A. L., Port, C. L., May, C., Stuart, B., Hebel, J. R., Zimmerman, S., Burton, L., Zuckerman, I. H., Fahlman, C., & Magaziner, J. (2009). The role of nursing home admission and dementia status on care for diabetes mellitus. *Journal of the American Geriatrics Society, 57*(9), 1628–1633. doi: 10.1111/j.1532-5415.2009.02382.x

Redfoot, D., & Gaberlavage, G. (1991). Housing for older Americans: Sustaining the dream. *Generations, 15*(3), 35–38.

Reuss, G., Dupuis, S. L., & Whitfield, K. (2005). Understanding the experience of moving a loved one to a long-term care facility. *Journal of Gerontological Social Work, 46*(1), 17–46. doi:10.1300/J083v46n01_03

Robinson, V. (2002). *A brief literature review of the effects of relocation on the elderly.* Prepared for The Hospital Employee Union of British Columbia.

Rossen, E. K., & Gruber, K. J. (2007). Development and psychometric testing of the Relocation Self-Efficacy Scale. *Nursing Research, 56*(4), 244–251. doi: 10.1097/01.NNR.0000280609.16244.de

Ryan, A. A., & Scullion, H. F. (2000). Continuing care facility placement: An exploration of the experiences of family carers. *Journal of Advanced Nursing, 32*(5), 1187–1195. doi: 10.1046/j.1365-2648.2000.01589.x

Schafer, R. (2000). *Housing America's seniors.* Cambridge, MA: Joint Center for Housing Studies at Harvard University.

Scharlach, A.E. (2009). Creating age-friendly communities. *Generations, 33*(2), 5–10.

Society of Hospital Medicine. (2011). Project BOOST: Better outcomes for older adults through safe transitions. Retrieved February 14, 2013, from www.hospitalmedicine.org/AM/Template.cfm?Section=Home&Template=/CM/HTMLDisplay.cfm&ContentID=27577

Steinisch, M. (2007). Senior homesharing a win-win. Retrieved April 27, 2013, from http://hffo.cuna.org/12433/article/1802/html

Stevenson, D. G., & Grabowski, D. C. (2010). Sizing up the market for assisted living. *Health Affairs, 29*(1), 35–43. doi: 10.1377/hlthaff.2009.0527

Stoeckel, K. J., & Porell, F. (2010). Do older adults anticipate relocating? The relationship between housing relocation expectations and falls. *Journal of Applied Gerontology, 29*(2), 231–250. doi: 10.1177/0733464809335595

Strang, V., Dupuis-Blanchard, S., Donaldson, C., Nordstrom, M., & Thompson, B. (2006). Family caregivers and transitions to long term care. *Clinical Nursing Research, 15*(1), 27–45. doi: 10.1177/1054773805282356

Strohschein, L. (2012). I want to move, but cannot: Characteristics of involuntary stayers and associations with health among Canadian seniors. *Journal of Aging and Health, 24*(5), 735–751. doi:10.1177/0898264311432312

Sussman, T., & Dupuis, S. (2012). Supporting a relative's move into long-term care: Starting point shapes family members' experiences. *Canadian Journal on Aging, 31*(4), 395–410. doi: 10.1017/S0714980812000384

Thorpe, R. J., Simonsick, E. M., Brach, J. S., Ayonayon, H., Satterfield, S., Harris, T. B., Garcia, M., & Kritchevsky, S. B. (2006). Dog ownership, walking behavior, and maintained mobility in late life. *Journal of the American Geriatrics Society, 54,* 1419–1424. doi: 10.1111/j.1532-5415.2006.00856.x

Torgusen, B. L., & Kosberg, J. I. (2006). Assisting older victims of disaster: Roles and responsibilities for social workers. *Journal of Gerontological Social Work, 47* (1/2), 27–44. doi: 10.1300/J083v47n01_04

Tsemberis, S. J., Gulcur, L., & Nakae, M. (2004). Housing First, consumer choice, and harm reduction for homeless individuals with a dual diagnosis. *American Journal of Public Health, 94* (4), 651–656.

Tsemberis, S. J., Moran, L., Shinn, M., Asmussen, S. M., & Shern, D. L. (2003). Consumer preference programs for individuals who are homeless and have psychiatric disabilities: A drop-in center and a supported housing program. *American Journal of Community Psychology, 32* (3/4), 305–317. doi: 10.1023/B.AJCP.0000004750.66957.bf

Turcotte, M., & Schellenberg, G. (2007). *A portrait of seniors in Canada, 2006.* (Statistics Canada Catalogue, No. 89-519-XIE). Ottawa, ON: Statistics Canada.

Van den Block, L., Deschepper, R., Bilsen, J., Van Casteren, V., & Deliens, L. (2007). Transitions between care settings at the end of life in Belgium. *Journal of the American Medical Association, 298*(14), 1638–1639.

Walker, C. A., Curry, L. A., & Hogstel, M. A. (2007). Relocation stress syndrome in older adults transitioning from home to a long-term care facility: Myth or reality? *Journal of Psychosocial Nursing Mental Health Service, 45*(1), 38–45.

Walsh, F. (2009). Human-animal bonds 1: The relational significance of companion animals. *Family Process, 48*(4), 462–480. doi: 10.1111/j.1545-5300.2009.01296.x

Watkins, L., Hall, C., & Kring, D. (2012). Hospital to home: A transition program for frail older adults. *Professional Care Management, 17(3),* 117–123. doi: 10.1097/NCM.0b013e318243d6a7

Weeks, L. E., Keefe, J., & Macdonald, D. J. (2012). Factors predicting relocation among older adults. *Journal of Housing for the Elderly, 26*(4), 355–371. doi 10.1080/02763893.2011.653099

Weeks, L. E., & Leblanc, K. (2010). Housing concerns of vulnerable older Canadians. *Canadian Journal on Aging, 29*(3), 333–348. doi: http://dx.doi.org/10.1017/S0714980810000310

Wiersma, E. C. (2010). Life around . . .: staff's perceptions of residents' adjustment into long-term care. *Canadian Journal on Aging, 29*(3), 425–434. doi:http://dx.doi.org/10.1017/S0714980810000401

Wilson, S. A. (1997). The transition to nursing home life: A comparison of planned and unplanned admissions. *Journal of Advanced Nursing, 26*(5), 864–871. doi: 10.1046/j.1365–2648.1997.00636.x

Wolff, F. C. (2013). Well-being of elderly people living in nursing homes: The benefits of friendship. *KYKLOS, 66(*1), 153–171.

World Health Organization (WHO). (2007). Global age-friendly cities: A guide. Retrieved February 5, 2013, from www who int/entity/aging/publications/Global_age_friendly_cities_Guide_English pdf

Chapter 5

EXISTENTIAL TRANSITIONS

To be human is to keep rattling the bars of the cage of existence, hollering, "What's it all for?"
(Robert Fulghum, in Poor & Poirrier, 2001, p. 113)
(American author)

Reflective Questions

- How is a sense of personhood developed?
- How do life's changes affect that sense of self?
- How can personhood remain intact through the transitions of old age?
- What can healthcare professionals do to validate personhood in each older person that they work with?

What does the term *existential* mean? In its most basic definition, *existential* refers to that which deals with existence (Free Online Dictionary, 2012). However, in its operational form, *existential* usually refers to issues about meaning and purpose in life and is intricately tied into individuals' sense of self or personhood. As Robert Fulghum noted in the quote above, most humans cry out at some point, even at many occasions in their lives, "What is this all about?" To try to address these essential questions about the meaning in life, many individuals seek to find meaning and purpose in activities, goals, and values. For some, an inability to find meaning can lead to great emotional distress and even lead to actions that nullify personhood—suicide (Hunter, 2007–2008; Moore, 1997).

The "bars of the cage of existence," or issues of meaning and purpose, become more pronounced as one gets older (Dwyer, Nordenfelt, & Ternestedt, 2008). The "I," the sense of personhood, which was likely once built upon a foundation of occupation, family, and friends, becomes threatened with the passing of years, retirement, and death of family members, as well as the final transition: death.

Within this chapter we will discuss personhood, briefly exploring the formation of a sense of personhood. Primarily, we grapple with what *existential* means and focus upon the existential transitions of aging. We address interventions within the family and healthcare system that help maintain that sense of personhood. Further, we encourage healthcare providers to do their own existential work. Finally, we

allude to ethical issues that will become pressing as our population ages (see also Chapter 8). It is our goal that, for the reader, the bars of the cage of existence will be rattled: *"What's it all for?"* (Fulghum, in Poor & Poirrier, 2001, p. 113).

DEVELOPMENT OF PERSONHOOD

Definition

What is personhood? In its most basic form, *personhood* can be defined as "the state or condition of being a person" (Free Online Dictionary, 2012). This can be understood to primarily reflect the physicality of an individual. However, *personhood* means much more: meaningful self-expression, self-determination, conscience, empathy, passion, and an individual's values (Hirst, Lane, & Reed, 2013). Although Gress and Bahr (1984, p. 20) distinguish between "person" and personhood, stating that "person" refers to the totality of one's being and that "personhood" describes the lifelong growth of that multifaceted being, the literature tends not to split these two concepts, and so we purposefully have kept the two together.

In spiritual/religious terms, the ethereal part of the person is termed *soul* or *spirit*.[1] A person's spirit is his "energy and power" (May, 1982, p. 7), "the essence of self" (Ley, 1992, p. 209). Power (2006) deemed personhood and spirit to be synonymous. It is what it means to be truly human—so often expressed to this palliative chaplain (MBR) by family members as they are standing around the bedside of a loved one who has just passed: "She's gone now; the body is just the shell."

The terms *existential* and *spiritual* are used consistently throughout this chapter. They are related in that both refer to the experience of an individual—"felt" in the inner being and observable by others. They are typically used in the context of life meaning and purpose; hence the existential and spiritual often come to the fore in times of transition. The two terms differ in that *existential* has the connotation of being "factual" and "demonstrable" and "objective" (Merriam-Webster Online Thesaurus, 2012); *spiritual* tends to be understood as being subjective. The expression of the spiritual may be understood to be a response to that which is existential.[2] While having different nuances, *existential* and *spiritual* are inextricably tied to the experience of "personhood."

---

[1] Jewish and Christian theologians will often distinguish between soul and spirit; soul being understood to be the "source of human genuineness, depth, emotion" (Walsh, 2009, p. 6), with the spirit being the "image of God" within (Genesis 1:27). See Walsh (2009), for a succinct distinction between the two terms. (For the purpose of this text, soul and spirit will be used interchangeably, as they are overlapping constructs, and this seems to be the common usage today).

[2] It could be argued that the *effects* of spirituality are demonstrable. For example, the altruistic work done by people such as Mother Teresa and Mahatma Gandhi have very spiritual motivation.

Initial Formation of Personhood

When a baby enters the world, he comes with a specific set of needs. The person within that 7-pound bundle of joy demands to be fed, changed, and comforted. While in utero, the fetus had all his needs met; he was warmed and sheltered, he was fed, and his bodily functions were taken care of by his mother's body. But birth into this world—a harrowing journey in and of itself—now means that his basic requirements are not automatically fulfilled. He is apart from his mother and part of a larger system that may, or may not, meet his needs. The vulnerability of the little one, coupled with his lack of ability to communicate on an adult level, leads to the piercing expression of need: crying.

It is in these early days of development that an infant learns that she is distinct; she is not her parent or the environment around her. A sense of personhood is in its early stages. She recognizes that she is dependent upon others for her survival. Her understanding of the world as safe or not safe (or somewhere in between) begins to be formed. If her physical needs are taken care of, and if she is held and cuddled and cooed to, she will grow. The "soul's" requirements—including touch, emotional stimulation, hearing one's name spoken in love, for example—have been highlighted in the literature repeatedly, beginning with Bowlby's seminal pamphlet, *Maternal Deprivation.*[3] Cuddling by parents, or a consistent parent substitute, leads to physical and psychological health (Ainsworth, 1967; Bowlby, 1999; Coila, 2011). The baby "attaches" on a visceral level to her significant others. From this secure place of connection, she is able to explore her limited world safely, returning to the parents for comfort regularly. This prepares her to form later attachments with the outer world.

Lifelong Development of Personhood

From this basis of security—"I am!" "I matter!"—comes a greater understanding of who one is in relation to others. A child begins to understand who she is—gender, abilities, passions, and self-determination. She begins to form ideas about what she would like to do in the world—what will bring her meaning—based upon her interests and talents. And, if the development of personhood is healthy, this child will understand that she *is* in a world where others *are.* While "I" matters, "thou" matters too![4] Hence the moral development of the child begins.

---

[3] *Maternal Deprivation* was written for the World Health Organization, at the request of the United Nations, and based upon Bowlby's observations of orphaned children following World War II. This began what later was, through much more research, Bowlby's "attachment theory." *Maternal Deprivation* is available in print today in the book *Child Care and the Growth of Love.* See reference list (Bowlby, 1953).

[4] Martin Buber's (1958) construct of "I-thou" relationship will be referred to throughout the chapter. When used to refer to this construct, the words will be italicized.

In early childhood, a child functions with primarily an external locus of moral control. "Don't!" says the parent as a child puts his hand on the hot stove. As children grow older, this external locus needs to shift to an internal one. The home, school, and community (and sometimes a faith community) give guidance to aid in this process. "How must Billy have felt when you hit him?" External rules gradually are replaced by internal motivations of respect for others, the welfare of the community, and other considerations. The development of empathy is vital.[5]

The healthy sense of self recognizes that both *I* and *thou* have inherent value. Buber speaks of this relationship as being of subject to subject. A person, out of his own sense of self, *relates to* another—the *thou*. Thou can be other human beings and it can be God (*the eternal Thou*, as noted by Buber). The respectful relationship is mutual and leads to growth in each party. Personhood involves the continual development of self over a lifetime (Gress & Bahr, 1984; Hirst et al., 2013).

Within Buber's (1958) construct, the *using of* others is termed *I—it*—from subject to object. This is a malformation of the human personality. Relationships are characterized by exploitation and control. The *I* lacks conscience, empathy, and concern for others. Rather than relate to others in a healthy manner, people are treated as commodities to be used. "Where there is no empathy . . . the seeds of violence are there" (Cram, 2003, pp. 56, 61).

While the basic sense of personhood is formed early in life (Ainsworth & Bowlby, 1991), throughout the human journey, there will be significant shaping of the human soul. Transitional milestones, such as marriage or the birth of a child, will change an individual's identity and role. These milestones will stretch the inner capacities of soul—as any parent awake at 2 A.M. feeding an infant with colic will attest. The development of these inner capacities is often referred to as *character* and *maturity*—essential in the lifelong growth of personhood. The parent is able to look beyond his or her own needs to an extent greater than imagined—setting aside personal "rights" to look after the welfare of another. Qualities such as *hope* and *resilience*, highlighted in this text, are developed in these stretching experiences.

Cognitively, a person's existential/spiritual views will develop throughout his or her life (Hood, Spilka, Hunsberger, & Gorusch, 2003; Walsh, 2009; Worthington, 1989). A fully developed person will mature morally and spiritually

---

[5] Moral development—essential to a healthy sense of self—is not automatic with chronological age. Kohlberg's Stages of Moral Development, Levels 1 and 2 (Preconventional Morality and Conventional Morality) elucidates a morality that is based (in Level 1) in a fear of punishment or (in Level 2) upon an obedience to outer authority, regardless of whether it is moral. While an internal locus of motivation, based upon universal principles of justice and respect (Level III: Postconventional Morality, Stage 6: Universal Principles, on Kohlberg's Scale) is a preferable guide for behavior, laws provide an essential external protection for the physicality of personhood. (See reference list for Munsey, 1980). Martin Luther King Jr. wryly noted "It may be true that the law cannot make a man love me . . . But . . . it keeps him from lynching me, and I think that's pretty important also" (1962).

over time; he will process life, consciously revising and being revised by ideas and experiences. As part of his existential work, he will integrate his experiences and beliefs. If his beliefs and experiences do not align, the sharp discrepancies will lead to cognitive and spiritual dissonance. In times of transition, the "bigger questions" will be asked:

- Who am I?
- What is this all for?
- Will I make it?
- What do I *really* believe?
- Is there an afterlife?

A person's philosophy, or paradigm, has a major impact on how he copes throughout life and particularly, in the transitions of older adulthood.

Spirituality and Personhood

> Man lives in three dimensions: the somatic, the mental and the spiritual. The spiritual dimension cannot be ignored, for it is what makes us human. (Frankl, 1986, pp. xv–xvi)

As alluded to earlier in the chapter, the noncorporeal aspects of personhood often are captured by the words *soul* and *spirit*. Using this terminology, then, the life of the human spirit—personhood—is expressed through a person's spirituality. The expression of spirit is all about finding meaning and making meaning in the world; it is about inner wholeness (Walsh, 1999, pp. 3, 4) and connection with others (Walsh, 1999; Weingarten, 1999)—*I–thou* relationships.

Spirituality and religion are not synonymous. The differences have been highlighted by a number of researchers (Anandarajah & Hight, 2001; Benner Carson & Koenig, 2004; Hawley, 1993; McKernan, 2005; Wright, 2005) and may be summarized as follows: Religious faith tends to involve a group of people (community) with a codified set of beliefs; it involves codes of conduct and has incorporated into it standard rituals and practices for the transitions of life. Spirituality tends to be more private in nature, with widely varying individual beliefs, containing aspects common to all religions: kindness, charity, and so on. It involves "an awareness of relationships with all creation, an appreciation of presence and purpose that includes a sense of meaning" (VandeCreek & Burton, 2001, p. 82). The practice of religion is one way of conceptualizing and expressing one's spirituality (Benner Carson & Koenig, 2004; Hamilton, 1998; Mount, 1993). From this perspective, religious practice is one aspect of the expression of spirit, or personhood. "Religion, at its best, provides a home for the nourishment and development of the spiritual life" (Wright, 2005, p. 5).

The question is often asked: "Can a person be spiritual, without being religious?" Based upon the aforementioned criteria, most certainly. An individual can

have an internal system of beliefs and ideals (a worldview, a philosophy) practicing those principles in day-to-day life, without ever setting foot into a religious institution. Reciprocally, "Can an individual be religious, without being spiritual?" Again, yes. An individual can practice a religion without ever meaningfully integrating those beliefs into personhood. Her religious commitment to a set of ideals may not be adequately internalized, integrated into her soul.[6] As the expression of the spirit is about meaning, profound transcendent experiences of joy and awe happen to those who practice religious faith and those who do not (VandeCreek & Burton, 2001).

To summarize, personhood encompasses much more than the physical; it also involves those intangible elements of being. A person's essence and philosophy are expressed through her spirituality. The characteristics of a well-developed personhood—such as maturity, hope, and resilience—are the tools an individual uses to survive, even thrive, when the transitions of older adulthood challenge the very core of the being. Older adulthood can whittle away at a sense of person; conversely, the sense of person can continue to grow, leaving a lasting legacy to those who follow.

EXISTENTIAL TRANSITIONS IN OLDER ADULTS

Integrity versus Despair

Erik Erikson, a psychologist and psychoanalyst, delineated stages of psychosocial development for individuals across the lifespan (Erikson, 1982). For older adults, attaining integrity (instead of despair) refers to the process of older adults reviewing their lives and deriving a sense of meaning and achievement (Thomas & Cohen, 2006). If aging individuals review their lives and come to the conclusion that their lives were meaningless and futile, they will often feel great emptiness and despair. Ron was a rugged individualist for whom self-actualization was a primary motivator. Hence, he had packed into his long life many interesting experiences. These expeditions and events were chronicled in scrapbooks, a feature in the local newspaper occasionally, and a significant collection of memorabilia. At the end of his life, his reflection did not lead to Erikson's *integrity* however; rather, it led to *despair*. He felt that he had missed some vital components to his existence: long-term relationships, intimacy, an understanding of "ultimate meaning" that he could take with him to the grave. There had been much *I*, but, not enough *thou*. For many, however, the life review process can be profoundly affirming.

---

[6] Gordon Allport (1967) distinguished between extrinsic religion and religion that is intrinsic. Extrinsic faith is characterized by what religion can do for an individual, such as church attendance providing social or business contacts. Intrinsic religion is faith that is internalized—integrated into one's being, "lived" from the inside out. See Allport and Ross (1967).

"My life has been meaningful!" *I*, in relation to *thou* (and perhaps *Thou*), have made a difference!

Informally, family members listening to stories from their older adults are providing opportunities for life review. As has been explicated throughout this text, the challenges of our fast-paced lifestyle, of geographical distances, of institutionalized care (rather than elders living in the home of adult children) have reduced the occasions for this type of interaction. While these sociological realities have impoverished the elderly, depriving them of doing the work to achieve *integrity*, many would say that the generations that follow them are losing out as well (Byock, 1997).

Moving from "Doing" to "Being"

Thus far in this text we have enumerated the numerous transitions of old age. *Loss* is one word that captures what so many older adults feel as they move from being active to less active, to being cared for rather than caring for others, from being a *thou* in relationships to feeling like an *it*. As individuals, and as a society, we value ourselves, and others, on the basis of the contribution made, not on the inherent worth of humans.

This feeling of lack of worth—*within* the older adult population and *toward* the older adult population—is a phenomenon found in developed countries. In some ancient societies and eastern countries, old age—with all of its transitions—is venerated. An older adult has a position of influence and respect and is often physically situated in the midst of the family, irrespective of physical or psychological capacities. The older an individual becomes, the more respect that may be received; the older adult becomes the "patriarch" or "matriarch" of the family—not because of what he or she can do, but because of who he or she was and is currently. That person's identity is firmly situated within the family construct: "*I am* because *we are*" described African theologian John Mbiti (quoted in Walsh, 2009, p. 24; italics ours).

The term *ageism*—referring to discrimination against the elderly—originated with Butler (1969). Ageism is widespread within our society, impacting older adults in the western world in the areas of work, healthcare, and, sometimes even within the family setting, with elder neglect/abuse. Within the realm of work, discrimination of older adults is widespread (Caldwell & Caldwell, 2010). Dennis and Thomas (2007) reported that most complaints regarding age-related prejudice in the workplace are dismissed without action. Within healthcare, ageism is understood to negatively impact the care, as well as the well-being of the elderly patient (Reyna, Goodwin, & Ferrari, 2007). Within the media, as well as within some religious circles (Caldwell & Caldwell, 2010), youth—with physicality and sexuality being prominent—are venerated. The virtues of aging—wisdom, experience, and honor—are not. This social construct of aging "does not allow the paradoxes of later life: aging is a source of wisdom *and* suffering,

spiritual growth *and* physical decline, honor *and* vulnerability" (Stoneking, 2003, p. 70, italics hers). The older adult can feel like an *it*, rather than a *thou*, in Buber's construct.

How does an individual value self when her capacities have declined? How is personhood maintained, even enhanced? First, it is vital that an individual, and her loved ones, prepare for the transitions of her old age (Kind, 2010). This preparation can come gradually, if the losses of aging come one at a time and will involve medical decisions, lifestyle choices, and financial options. For instance, the individual who begins to develop plans and hobbies for retirement will be better prepared to face the changes of this particular transition. Such plans need to be specific to the person herself and must be personally meaningful. While traveling may be soul-enriching to one, it may not be to another. Over time these plans continue to be revised as needs change. If an older adult can no longer run due to arthritis, then taking to the pool for both exercise and the hot tub can aid both body and soul.

It is not simply the tangible preparations for change that are important, but also the soul preparations. It is well-documented in the literature that during the changes of mid- to later life, people wrestle with the issues of life's meaning (Erikson, Erikson, & Kivnick, 1986; Walsh, 2009). Past experience with significant transitions, coupled with the necessary spiritual work to develop inner resources (such as resilience) to negotiate these transitions, pay dividends. Wilma was a palliative care patient; in my work with her, I (MBR) wondered if she possessed the resources needed to face into her death. She continued to resist the obvious physical transitions occurring as her demise neared; she was "dressed to the nines" in her hospital bed. In her struggle to face into her imminent passing, she wrestled with despair; her sense of personhood—her very being—was being threatened. I asked her about the tools she had used in the past to get her through difficult times. A lengthy silence ensued. Upon reflection, she could not identify one coping skill: "Perhaps I've had too easy a life!" she proclaimed. In Wilma's situation, the blessings of an "easy" life did not help address existential issues as she faced death.

In popular psychology and in palliative care, the construct of *human being* vs. *human doing* is often referred to (Byock, 1997; Hemfelt, Minirth, & Meier, 1991). For the human being, self-worth resides within; what she achieves in life comes from the security of her own personhood. For the human doing, worth must consistently be proven to the self and to the world through ongoing achievement. This is necessary to prop up a fragile sense of self. When achieving—with its internal and external rewards—is no longer possible, a critical point in personhood is encountered. For the individual facing such an existential crisis, deep spiritual work needs to occur. This labor involves the understanding of recognizing personal losses, accepting that what could be done before is no longer possible, grasping that he or she still has value, and tapping into deep spiritual resources that will allow that revelation in the soul to take hold. In our North American culture

that eschews illness and denies death, this process can seem morbid. Byock (1997) spoke of Douglas, a relatively young man facing into his death. The following quote captures his journey of diminished capacities and yet the maintenance, even growth, of personhood. Douglas moved from a *human doing* to a *human being* through the crisis of cancer.

> In accepting his sadness, Douglas reconnected with parts of himself that were threatened by his impending demise. . . . By acknowledging his losses, he had, paradoxically, become more whole. The exhilaration he expressed typifies the experience of personal growth, the sense of mastery, in a changed life situation. (pp. 79–80)

For the aged person living alone, this existential transition from doing to being can be very difficult. The philosophical foundation of the value of human life is essential. Suicide rates among older adults are significant (Statistics Canada, 2009).[7] Lessening physical, mental, and emotional capacities may lead to what Holocaust survivor Frankl (2006) called "an existential vacuum" (p. 106): a state of inner emptiness, a void within self. The loss of a partner, a change in social roles (through retirement, for example), and social isolation add to that sense of emptiness and are considered to be risk factors for suicide (American Association of Suicidology, 2009). The initial formation of personhood, as well as the existential work done throughout life, girds the older adult through losses of capacity, a spouse, poor health, retirement, social isolation. The inner resources of maturity, resilience, and patience are tools to access this foundation and rest upon it.

But as the infant described at the beginning of the chapter is vulnerable, so the older adult is vulnerable. He needs family and community to reinforce that sense of personhood as he navigates the transitions. Just as the infant required more than simply physical care, so the older adult needs "soul care" to thrive. This involves time and attention from adult children or other relatives—a challenge in our fast-paced society (Hirst et al., 2013). It involves meaningful connection with family members and community.

In this "sandwich generation," few things conjure more guilt in adult children than the message that aging parents have increased needs. The sense of responsibility can be overwhelming and can lead to existential crises in family members (MacMillan, Peden, Hopkinson, & Hycha, 2000). That "What about my dreams

---

[7] This is particularly true for men. While suicide rates for Canadian women over 65 were at or below the national average of 5.3 deaths/100,000 population, for Canadian men, the rates of this same demographic were startlingly high. The average suicide rate in Canada for men was 17.9 deaths/100,000 population. For men over 65, this rate varied from 16.4 deaths/100,000 population to 30.6 deaths/100,000 (in the 80–85 years of age category) (Statistics Canada, 2009).

for the future?" and "What does this all mean?" are questions agonized over by older adults in transition is readily understood. However, it is often not acknowledged that their family members may face the same crisis of meaning.[8] The bars on the cages of their existence are rattled, too.

Dr. Ira Byock (1997), a well-known palliative care physician, encouraged family members to face into the challenge, and he openly spoke of the *family's need* to care for their loved one. While the transitioning older adult needs physical and emotional attention, *the family needs to give this.* Through caregiving, family members can grow in personhood; they have the opportunity do their own existential work. Caregiving can be spiritually enriching for both the older adult receiving care and the family that care for him (Walsh, 2009).

Meaning is often found in unexpected places. The transitioning older adult needs his family—and his family needs him! Embraced for millennia by eastern societies, this existential understanding is slowly being acknowledged in North America. The perception of meaning in the older adult's life is inextricably tied to self-acceptance (Hughes & Peake, 2002).

Resolving Inner Conflicts

Throughout a person's life, there will be questions of meaning. A paradigm that sufficed and worked in one's 20s may no longer be adequate later on, as life's experiences challenge previously held beliefs. As the goal of human being is integration of beliefs with life experiences, there will be times of inner tension. Frankl (2006) articulated this eloquently when he stated that mental health is based upon some inner tension:

> . . . the tension between what one has already achieved and what one still ought to accomplish, or the gap between what one is and what one should become. Such a tension is inherent in the human-being and therefore is indispensable to mental well-being. (pp. 104–105)

The recognition of this tension and the existential work to resolve it is a sign of soul health. For many people, however, this inner tension is ignored in the business and busyness of life. The bigger existential issues of life purpose and growth can get silenced in the routines of daily living. Sometimes these issues lie dormant

---

[8] Bioethicist Viki Kind used the term *care-grieving* to describe some of the struggles that adult children of dying parents experience. Besides the putting aside of work, hobbies, etc., to care for an elderly parent, these adult children experience anticipatory grief. The "I don't know if I can handle this" response—very common in family members—produces a great deal of guilt (Kind, 2010, pp. 105–107). Normalizing these feelings to families can be profoundly helpful. (More will be discussed on *care-grieving* in Chapter 6).

until older adulthood, when the many transitions impinge upon personhood, and these unresolved inner conflicts come to the surface.

The details of these inner conflicts can be many—however, they often center on a severance of relationship, of connection (Weingarten, 1999)—with self, with others, and with the Transcendent. This brokenness can be buried in guilt and shame. A sense of "regret" is how these disconnections usually manifest themselves.

Disconnection with Self

In the challenges of daily life, and often in the course of a lifetime, a person can become disconnected with her soul, her essence, her passion. The job that puts food on the table can be mind-numbing and soul-crushing. It is not always possible to do what we want to do, to grow in every aspect of our lives. Over the course of time, however, a person may become very detached from who she really is. One woman captured this beautifully: "I feel like I am on the outside of the glass, looking in at life. I don't know who I am."

For the older adult, this may be particularly pronounced. The mother and grandmother who put aside all her dreams to focus on her children and then her grandchildren may feel that she has never realized her own dreams. She may no longer know what she wants and what she needs. The transitions of her adult children (such as moving out of geographic proximity for the sake of employment, taking the grandchildren with them) may thrust her into a crisis of being—a crisis that has opportunity for growth. Here, she may go back to the interests of her pre-children days—beginning to paint again, or pursuing the university degree she never attained.

In studies examining life regrets in older adults, some of the common regrets, besides ruptures in relationships, often involve decisions regarding work, such as not taking risks at work or making the most of opportunities, as well as not pursuing more education (Timmer, Westerhof, & Dittmann-Kohli, 2005). As some of these regrets involve decisions that were time specific (e.g., work decisions), it becomes difficult to resolve these regrets; an older adult cannot return to young adulthood and choose a different career, for example. However, as will be described in greater length in Chapter 8, there are options for some older adults who regret not getting a university degree.

Further, ways in which to address lifetime regrets can be very individual and creative. A family story speaks of this. My (MBR) spouse had a grandmother who fulfilled the role of wife, grandmother, churchgoer, and volunteer faithfully. She dressed in somber hues and lived within the defined parameters of her roles for decades. When she was in 80s, her spouse passed; she grieved the loss greatly. However, she knew that she still had living to do; so she learned to drive, took a helicopter trip, listened to rock music, and dressed in vivid colors! She tapped in to who she really was—affirming personhood—and then enjoyed *her-self* !

Disconnection with Others

Severed relationships can cause profound dis-ease within the human spirit. The transitions of older adulthood—such as the loss of friends due to death—bring this dis-ease to the surface. The older adult may have more time on his hands, but fewer friends (due to death or relocation). He may regret the loss of relationships that were dropped due to busyness or conflict. On a deeper level, he may be re-evaluating his priorities; although work previously took priority, now that he is retired, he may be rethinking what is most important to him. "What was it all for?" he may be thinking and saying.

Disconnection with God

Many individuals wrestle, in their older adult years, with faith that has been lost, or, at least, "set aside." Disappointment with organized religion, the inability to bring together previously held beliefs with difficult life experiences, and—sometimes—a life that has gone "too smoothly" (to need a power greater than self), all can lead to this sense of disconnection with the Divine.

When the transitions of older adulthood occur, many find their inner resources insufficient, and (re)turn to a religious expression of spirituality (Floriani, 1999; Hamilton, 1998; Speck, 1998; Sutterly, 2001; VandeCreek & Burton, 2001). Some seek out new experiences in religion and/or spirituality (Speck, 1998). In my experience as a palliative care chaplain (MBR), more people tend to return to the spirituality, faith or rituals of their childhood.[9] In one case, a Sikh gentleman came to Canada, got married here, and had a family. His wife was a Christian, and so he attended church with her and their children for many years. In his dying, he requested Sikh rituals—a return to the religious expression of his youth—as well as a church funeral![10]

North American researchers are not surprised by this phenomenon. Religion is understood to be culturally present and accessible. For example, a 2011 Gallup poll indicated that 92 percent of Americans believe in God or a universal spirit (Newport, 2011); sociologist Reginald Bibby (2012) noted that for two in three Canadians, religious and spiritual beliefs are important.[11] What about in very

---

[9] See "Anne's garden: A journey of the human spirit" for a powerful example of one woman's spiritual journey back to the symbols of her youth (Hall, McCarney, Hamilton, Robertson, & Yates-Fraser, 1996).

[10] Along the same lines, Carol Milardo Floriani, RN, spoke of a Cambodian man who converted to Christianity during his life in the United States. In his dying, he needed to reconnect with his Buddhist roots/practices, and so the spiritual care he received was both Christian and Buddhist (see Floriani, 1999).

[11] While spiritual beliefs and practices are still significant to North Americans, regular attendance at religious institutions tends to be lower. Canadian sociologist Reginald Bibby (2012) reported that while one in two Canadians engage in a religious or spiritual practice at least once a month, only 30 percent of Canadians attend a religious institution *once a month*. In the United States, *weekly* religious service attendance has been estimated to be between 40 and 50 percent by Gallup polls

secular societies? la Cour (2008) studied religious and spiritual expression among those admitted to Danish hospitals. For those with less severe or short-term issues, little or no change was noted in religious and spiritual expression. But severity of illness was correlated with greater expression of spiritual and religious activity among patients, despite the fact that religion is less culturally present there. The existential crisis of severe illness prompted a (re)connection of spiritual and religious expression.

The Ties that Support and that Bind: The Place of Religious Faith in Dealing with Inner Conflicts

As has been emphasized throughout this chapter, religious expression is one form of the expression of the spirit. As a subset of spirituality, it is about having and making meaning in the world. Much has been said about its benefits in difficult life transitions. "When (one) stands on the firm ground of religious belief, there can be no objection to making use of the therapeutic effect of his religious convictions and thereby drawing upon his spiritual resources," said Frankl (2006, p. 119). People of faith often attach a "higher meaning" to their crisis, which takes away the sense of randomness. "If a man knows the wherefore of his existence, then the manner of it can take care of itself . . ." stated German philosopher Nietzsche (1911, p. 2).[12] Frankl (2006), spring boarding off of this concept, spoke of the necessity of a higher purpose for those imprisoned in World War II.

> We had to learn ourselves, and, furthermore we had to teach the despairing men, that *it did not matter what we expected from life, but rather what life expected of us.* (p. 77, italics his)

For some, in the concentration camps, this meant living for family members. For others, it meant choosing to honor a power greater than the Nazis—God. Religious faith brought meaning to sacrifice (Frankl, 2006). "Faith fuels the resilient spirit," stated Walsh (2009, p. 24). Although the example of meaning in concentration camps may seem extreme, it is almost a "meta-example" for

---

and Barna reports, staying relatively consistent throughout the first decade of the new millennium. However, a number sources dispute this figure, saying that people in the United States overestimate church attendance. See The Barna Group (2009) and ReligiousTolerance.org (1999–2007). The data would seem to reveal significant personal spiritual practices in both countries, with less institutional involvement in religion. It is interesting to note the cultural differences between Canada and the United States, as well. This data suggests that Canada could be considered to be a more secular nation than the United States.

[12] This statement has been frequently quoted, many times in a slightly different fashion. When Frankl (2006) used this quote, he gave credit to Nietzsche, and phrased it this way: "He who has a *why* to live for can bear with almost any *how*" (p. 76, italics his).

all existential crises—including the deep inner conflicts that occur within older adults. For instance, many people in older adulthood experience regret over life choices. "If I could do it all over again . . ." is a common theme. The "what if's" and "if only's" torment the sensitive soul. Within the major religious traditions are vehicles for obtaining forgiveness for these regrets. Rituals designed to communicate God's forgiveness for wrongdoing, facilitate reconciliation between self and others, as well as reconnect with self can bring freedom from these regrets. Many people, during times of transition, will find meaning in these rituals, to "mark" that time and place—a physical action signifying a deep spiritual transaction. The teachings of religion and accompanying rituals can bring great peace (Walsh, 2009).

Although the ties of religion can support, they can also bind. In times of formation or transition, the belief system of an individual may not be appropriate or adequate for her circumstances, and thoughtlessly applied "truths" by others or self can be very damaging (la Cour, 2008; Purcell, 2008; Walsh, 2009). Rather than providing meaning and allowing the individual to incorporate the experience into her being—cognitively and spiritually—the belief system ties the person up, causing profound anguish of personhood, of spirit.

Dying individuals sometimes connect physical illness to sin, God's judgment, or bad karma. If an individual rigorously applies such theology to her circumstances, she will suffer profoundly. Many people, representing a good number of the world's major religions, have expressed such inner dissonance when trying to come to grips spiritually with why they, or their loved ones, are terminally ill. Letting go of the faith system upon which they have built their identity, their personhood, would be untenable, but believing what others have told them and what doctrines may have been emphasized within their faith tradition is equally so. This results in a double bind! Identity, religious faith, and family relationships can all be threatened. [13] For some, their future is in jeopardy, as they fear hell (Egan & Prud'homme Brisson, 2006). This is a crisis that is multifaceted and profoundly existential. Others thoughtlessly applying these types of beliefs to vulnerable souls (the young, the old, and everyone in between) has been understood by Purcell (2008) to be "spiritual abuse" and "spiritual terrorism."

---

[13] One situation stands out in my (MBR) experience. A man was dying of cancer. The family belief in faith healing—as a sign of God's favor—was so strong that any outcome other than total restoration of health meant that this fellow was not a Christian. The mother of this man feared that if her son were not healed, he was not a Christian and he would go to hell. (And then she would not see him again). The father of the terminally ill man believed so strongly in physical healing that he said that his wife (the dying man's mother) must be keeping the healing away with her "unbelief." Because of her unbelief, she was not considered to be a Christian by her own husband. In the death of her son, this mother—because of the belief system the family adhered to—stood to lose her son physically (to death), her faith (her husband no longer believed she was a Christian and she feared she was not), and the reunion of her family in heaven—if either her son or she herself were not Christians!

Religious faith can be a tremendous resource for older adults in coping with transitions. With deep conviction (from the depths of her soul!) one dear elderly lady experiencing major life transitions said, "My faith and prayer—they anchor me." At times it can complicate matters; dealing with this internal dissonance, from a professional perspective, will be touched upon later in this chapter. A guiding principle in this discussion is explicated beautifully by the twentieth-century theologian, William Barclay:

> The real test of religion is, does it make wings to lift a man up or a dead weight to drag him down? Is a man helped by his religion, or is he haunted by it? Does it carry him, or does he carry it?" (Barclay, in Blue, 1998, p. 86)

Resolving External Conflicts

As individuals age or approach death, there may be a need to repair damaged relationships with others, especially estranged family members. Older adults may seek to make contact with family members, ask forgiveness, and to some degree, restore the damaged relationship (McSherry, 2011). Or, some older adults may want to express to their loved ones how much they have loved them and what they have meant. This is part of the unfinished business of aging and dying and may bring meaning to individuals' lives as they approach death.

Significant repair of relationships may not be possible. As one adult child said, "He left our lives. An 'I'm sorry' won't restore all those years we lost." The dying parent's children did see him once before his death. After this meeting, the palliative patient said, "Sometimes it's just too late." There was no intervention that could erase the past. But what was significant, meaningful to both the dying father and his son, was the opportunity to say "I love you." Knowing one is loved is a basic need of personhood, and, even in a limited way such as this family's tenuous reunion, can enable a dying individual some peace and grieving adult children some solace.

Facing into an Unknown Future

Facing into an unknown future involves anticipating further physical decline and possible cognitive decline. Research reveals that some older adults fear memory loss (Corner & Bond, 2004; Dark-Freudeman, West, & Viverito, 2006). Older adults recognize "the bigger picture," that bodily decline ultimately leads to death. Although younger adults have greater fears about death than older adults, aging individuals still experience fear about death (Cicirelli, 2001). Fears can be related to fear of the dying process (Cicirelli, 2001); specifically, older adults may fear that they will experience overwhelming pain in the death process. This is common. With the palliative medications available today, that fear is generally unfounded

(Byock, 1997).[14] But an elderly adult facing into her death may remember the passings of her parents, perhaps in her living room, in profound pain. She carries these memories into her own process. Loss of control is another fear; being unable to toilet oneself, loss of "dignity" with the effects of medication, and losing the ability to make one's own decisions can factor in. In one study examining religious faith, fear of death, and advance care planning among chronically ill older adults, religious faith, as well as fear of death, was associated with advance care planning (living will) (Dobbs, Emmett, Hammarth, & Daaleman, 2012). It could be that these older adults feared the death *process*, rather than actual death, and that a completed living will enhanced feelings of control in this transition.

As discussed earlier, religious belief can be a great comfort; it can, however, complicate matters. Individuals may fear the coming afterlife (Egan & Prud'homme Brisson, 2006). I (MBR) have been asked many times, "What's it like on the other side?" Or, others may require reassurance that life does not end with the death of the physical body (Turesky & Schultz, 2010). They, or family members, express the need to know that personhood does not end with physical death; the hope of a reunion on "the other side" predominates. From a palliative perspective, stories of "death bed phenomena" abound;[15] I (MBR) will, from time to time, share what I have observed, to bring some peace to those afraid that personhood ends at death, or of what may lie beyond.

At times this anxiety about life after death is a deep-seated fear of hell (Egan & Prud'homme Brisson, 2006). A terminally ill person may have not practiced the religion she was raised with during her adult years. As mentioned earlier, when death approaches, people can reflect back upon the faith system in which they were raised; it is often "programmed onto the hard drive" of their souls. If this system (or respected people within the system) has emphasized punishment for wrongdoing, great fear can result. For some, the rituals of that background are enough to alleviate the trepidation. For example, a significant number of people who were raised Roman Catholic and are no longer practicing their faith will request a priest and the Sacrament of the Sick in their dying. Sometimes, more than this is needed. This chaplain (MBR), conscious of respecting all people's faith systems, has sometimes sought to gently work *with* an individual's personal theology that is "damning" (pun intended). If there is a theology of sin, it follows that there also be a

---

[14] Dr. Ira Byock (1997) said, "Physical suffering can *always* be alleviated" (p. xiv, italics his). But whether physical suffering can be totally eradicated is debatable. Palliative care makes an enormous difference in a dying person's end-of-life, but it does not mean that one will not experience physical symptoms at all. This topic will be discussed more in Chapter 6.

[15] There are many published stories of "near death" experiences. And, popular today, are stories of those who have been declared clinically dead who have "come back" and shared their experiences of the after-life. This would validate North America's interest in the spiritual. It also speaks much of the human "need" that personhood not be extinguished at death. This subject will be discussed more in Chapter 6.

theology of atonement/forgiveness from God and others—within the same faith system. To utilize one (forgiveness) to counteract the other (sin) can be helpful.[16]

Unfortunately, some have been raised with the stated or implied idea that "nothing is good enough." This is spiritual pain (caused by deep, internal shame), rather religious pain (caused by guilt) (Sutterly, 2001); an individual feels that his true self will be known by God, and that he (personhood) will be found lacking.

In such situations, a ritual is often not sufficient, as rituals tend to address guilt, rather than shame. Discussion about this shame and a counteracting of this, *within the person's paradigm,* can be beneficial; shame is counteracted by unconditional love (Sutterly, 2001). These are waters for a chaplain trained in palliative care to wade into (Benner Carson & Koenig, 2004; Coates, 1995; Koenig, 2001; Sulmasy, 2006)! For faith systems unfamiliar to the healthcare chaplains, a clergyperson from within the faith system can also be invaluable (Benner Carson & Koenig, 2004; Coates, 1995).

Legacy

Older adults often feel a need to leave a legacy. Legacy refers to the act (s) of leaving something behind for others after death (Hunter, 2007–2008). It is a tangible way of remembering the individual who has passed; while this person is physically gone, some aspect of him or her carries on. Legacies may be very personal and specific to individuals;[17] the common theme in legacies is that they bring meaning to life. Legacies can involve material objects, such as bequeathing personal belongings to the next generation. They can also be symbolic, in that persons may attach their names to things that will remain long after death. Legacies can also be related to values, in that individuals pass on their own beliefs and values to others (Hunter, 2007–2008).

For example, one woman, in her dying, was very concerned that her grandson be baptized. This was a value of hers, not her daughter's (the mother of the child). As this woman was dying, her daughter organized the baptism of her child in the palliative care facility, so that her mom could be present. This was truly a gift to her mom, so that she could pass in peace. ("Now every one of my family members

---

[16] For instance, a chaplain can stress to the suffering older adult the love of and forgiveness from God, to balance off the heavy emphasis upon sin. Rituals—such as prayer—can be utilized to bring forgiveness into the equation, to bring spiritual relief.

[17] Generally, legacies reflect what one has had in life. Occasionally, a legacy reflects what has been *missing* in an older adult's life. One woman, who had grown up in poverty and lived "hand to mouth" all her life, left a certain amount of cash to each grandchild. Because she had always been lacking in financial resources (a lifelong source of shame and grief for her), she wanted to be remembered by her grandchildren as someone who had and gave to them the material resources she possessed. It is quite likely that this legacy was more reflective of what was important to her than to *her* grandchildren, as each came from homes that were well off financially. However, it was an important part of her end-of-life work.

are in the fold!" she said to MBR). For this dying woman, the legacy she wanted to pass along to her children and grandchildren was her faith and the values and rituals associated with it. Her daughter recognized this, and, in essence, "received" this gift from her mom on behalf of herself and her son by having this young boy baptized.

When materials are passed on to family members, such as a dining room table or jewelry, the purpose behind the objects are more than material or monetary. Older adults often pass on these objects in hope that the recipient values the furniture or rings/pins etc. because they elicit memories about family members, and perhaps signify characteristics of the older adults, such as strength or resilience (Hinck, 2007).

Individuals can also pass down the legacy of knowledge. They may teach skills and provide knowledge about gardening to their children, who then enjoy the benefits of gardening in their adulthood, and can pass this on to their children. Not only does the activity provide a sense of enjoyment and productivity in the present, but there is the connection with the past (their parents' legacy) and hopefully, with the future through their children (Heliker, Chadwick, & O'Connell, 2001).

INTERVENTIONS TO ADDRESS EXISTENTIAL ISSUES IN OLDER ADULTS

Interventions with older adults involve working with them in one or more of the following areas, as needed by the elderly person: to validate personhood, helping them to reconnect with self, others and (possibly) the Transcendent; aiding the elderly to recognize and (if necessary) re-establish meaning and purpose in life; to help to restore hope, and aid the older adult in dealing with regrets, including doing the work of forgiveness. As such the following interventions target these various aspects of existential issues.

The Ministry of Presence

Not simply a "skill" or an intervention, the *ministry of presence* is about who the healthcare professional is and how he is with people. Benner Carson and Koenig (2004) used the term *ministry* in terms of professional ministry, as they spoke of spiritual care in healthcare settings. However, the term can and should be understood more broadly. *Ministry* can also mean "vehicle," "agency," and "instrument" (Merriam-Webster Online Thesaurus, 2013). The healthcare provider is a vehicle, an agent, an instrument of presence for the older adult and his family. It is less about *doing* to and more about *being* with the older adult and their family (Heyse-Moore, 1996).

Benner Carson and Koenig (2004) explained what this ministry of presence involves: active listening, empathy, being vulnerable, humble, and committed to the family one is working with. These characteristics and skills are explicated more fully in the interventions listed below. They are highlighted here to emphasize that they are not simply what is done *to* or *for* a family; they flow *out of* who the nurse, chaplain, or other healthcare or human service professional *is*. Her spirit "touches the spirit" of the person being cared for (Thompson O'Maille & Kasayka, 2005, p. 64): the *I–thou* relationship. Those who have been faced with life-threatening illness or death themselves or of a family member know which professional is simply practicing what is required of him or her and those from whom this presence flows. "You can tell he really cares," said one woman, of a physician that had seen her and her husband through one health crisis after another. "You just know." In this context, there is a *ministry* in a spiritual sense—from whatever nurse or professional is providing the care; his care comes with the scent of the sacred, and those who catch a whiff of that fragrance are ministered to!

Establish Rapport and a Trusting Relationship

For some, the existential issues surrounding aging, physical decline, dying, and death are very personal and private. Therefore, in order for nurses, chaplains, and other professionals to gain access to such concerns, a trusting relationship needs to be developed with older adults (Benner Carson & Koenig, 2004; Ryan, 2005). This involves genuine interest in older clients, patient listening to their concerns, and an acknowledgment that aging, dying, and death encompass more than just the body, but also concern individuals' entire lives and the meanings they attribute to the transitions (Ryan, 2005). It involves addressing concrete tasks of older adults (Egan & Prud'homme Brisson, 2006); perhaps the requests focus upon small, but significant concerns (e.g., contacting the pharmacy, helping to do something in a senior's home) that demonstrate to older adults the level of care professionals have toward all areas in their life.

Validating Personhood

Regardless of age, human beings need to feel a sense of value and worth as human beings. This sense of worth and dignity is essential to good mental health and quality of life. However, the process of aging, particularly if there is significant pain and physical disability, may preclude some from engaging in the very activities that enhance their sense of personhood and worth. The work of nurses and professionals in recognizing and validating personhood in older adults involves valuing individuals for their inherent worth and demonstrating that valuing, as well as tailoring interventions to the level of functioning of older adults.

Encouraging older adults to talk about what they did and who they were in the past is a first step. Before these elderly people needed extra care in the

home, transitioned to nursing home, or became residents within a hospice setting, they were agents of meaning and change within the world. They raised families, labored within the workforce, coached soccer teams, and were active members of Block Watch (for example). These activities revealed both abilities and character qualities, that can be affirmed and brought (to some degree) into the present. One gentleman, for whom painting had been a passion, was encouraged to have family members bring in some of his paintings into the hospice; these adorned the walls of his room. Although he could no longer paint large masterpieces, he still enjoyed "dabbling," and the volunteer artist at this hospice would paint together with him in one of the quiet spaces within the facility. Here, he was able to practice his craft (on a smaller scale), talk about his work with someone who had similar interest and talent (the volunteer artist), and enjoy the community's appreciation for his work. What begun as conversation about what a patient had liked to do in the past was really about valuing personhood; this led to him being able to express that same passion of his spirit within a different context: the hospice.

Within a hospice setting, the typical "rules" of institutions can be relaxed and valued attachments and activities are commonly made possible. Pets are allowed to visit; residents may be able to imbibe (with physician awareness), and guests are accommodated.[18] The purpose is to affirm that which has brought meaning and purpose and comfort to a resident.

The palliative experience of older adults and their family members tends to be shorter in length than the continuing care experience (e.g., nursing home). Hence, the gentleman in the aforementioned example was only able to paint for a short period of time before he was physically no longer able to engage in these person-affirming activities. Staff could and did continue to validate his personhood through conversation (including speaking about the picture on the wall), and treating him and his family with respect.

Living within a nursing home can pose challenges for self-expression, in part because of the numbers of older adults residing on units, as well as the duration of time the older adult spends within the institution. Certainly, in the past, being institutionalized could be demoralizing; the longer a person lived within the institution, the more challenging it was to maintain personhood (Goffman, 1961). However, there is a movement within nursing homes to shift toward a culture that values personhood and that recognizes that the older adult was and is unique and brings a lifetime of experiences and memories to the community. The valuing of the personhood of residents needs to be a primary concern of administrators and staff (Hirst et al., 2013). Getting to know the residents is elemental. Knowing a resident's name, and calling him by the title

[18] Boundaries, of course, must be respected; policies are in place and procedures followed so that the experience of all residents and family members, as well as staff members, is safe and positive.

he prefers, is essential; so is a supportive and respectful tone of voice (Hirst et al., 2013). Meaningful decision making for older adults in nursing homes, such as bath times and bedtimes, affirms personhood (Crandall, White, Schuldheis, & Talerico, 2007).

Gently Assess for Spiritual Distress

What is spiritual distress and how does it manifest itself? As has been affirmed in this chapter, the spirit is the essence of who a person is; it is the core of his being. Hence, spiritual distress is a deep, existential distress and it can be evidenced in many ways: by pain that cannot be controlled by medication (Floriani, 1999; Kuhl, 2003), insomnia, withdrawal, or isolation from spiritual support systems, conflict with family members and friends and/or support staff, anxiety, mistrust of family and physicians, breathlessness, depression, guilt, hopelessness, fear/dread, and feelings of failure in life (Hay, 1989; Heyse-Moore, 1996). For this desperate state, the founder of the modern hospice movement, Dame Cicely Saunders, coined the term "total pain" (Mount, 1993, p. 28).

Some of the above criteria could be deemed psychosocial. The distinction between psychosocial pain and that which is classified as spiritual is often a matter of degree. A high level of this type of discomfort is deemed to be spiritual pain. *Why me, God? Where will this illness lead? What is the meaning to my suffering?* These questions are asked by those who define themselves as being spiritual and/or religious and those who do not, and they evidence spiritual distress (Coates, 1995; Downing, 2003). Queries and symptoms such as these are evidence that the spirit, the essence of self, has been threatened; a person has become "estranged" from who he really is (Heyse-Moore, 1996, p. 308).

Egan and Prud'homme Brisson (2006) examined outreach nurses' perceptions of the spiritual needs of older adults who were housebound. These nurses discussed the difficulties faced by older adults who were unable to get out and about, including emotional and spiritual distress. They described that some of their older clients experienced anger, guilt (and desired forgiveness), feelings of abandonment, and fear. The nurses stressed the need for spiritual needs to be addressed cautiously, and only after trust had been established with older adults. Usually, they wait for older adults to suggest their desire to discuss spiritual distress. The nurses expressed concern that they do not enforce their beliefs upon their elderly clients, and neither do they want to make older adults feel like they have to discuss spiritual issues. Possible ways of broaching spiritual issues included offering help with completing advanced directives or asking older adults if they would like a referral to clergy (Egan & Prud'homme Brisson, 2006). Within a healthcare facility, nurses can and do informally assess for spiritual distress. A referral to a chaplain typically follows.

Address Meaning and Purpose in Life

For human beings, meaning in life is absolutely essential to quality of life. Not only is having meaning in life linked to better physical health (Krause, 2004, 2009) and mental health (Fry, 2000; Reker, 1997), and believed to counterbalance stressors in some older adults (Krause, 2007), it is also associated with lower death rates (Krause, 2009). As individuals age, meaning in life may evolve and change to incorporate life's experiences (Moore, Metcalf, & Schow, 2006). Sadly, for some older adults, their sense of meaning and purpose dwindles as they get older, stop working, and face the deaths of family members, spouses, and friends. The work of professionals involves, in part, helping aging adults review their lives and come to a sense of *integrity*, rather than *despair*.

Meaning and purpose in life in can be addressed by professionals in a number of ways. First, professionals can ask older clients directly, "What gives you meaning and purpose in life?" and "What gave you meaning in life in the past?" The purpose of this is to assess whether the older individual feels a sense of meaning and purpose now. If so, the professional can tap into this by asking follow-up questions about how often older adults engage in meaning-making activities and if there are any hindrances or barriers to these activities. For example, an older adult who loves to read but is having trouble seeing pages can be informed of where to access large-print books, as well as books on tape. Or, a senior who finds church services essential to his spirituality and sense of meaning in life can be encouraged to contact a nearby church to ask if a parishioner would be willing to transport him to church, if he is no longer able to drive. If an older adult states that she has no meaning or purpose in life, the professional can inquire about what gave her meaning in the past. The professional can then explore with the older client about possible ways to re-establish that sense of meaning. Unfortunately, as mentioned in the previous example of Wilma, if older adults have not engaged in some struggle and development of meaning earlier on in their lives, they may experience greater problems in wrestling with meaning in advancing age.[19] Some formal ways of re-establishing meaning—alluded to a number of times in this chapter—are listed below.

Engage in Life Review and Reminiscence

Older adults often engage in reminiscing and reviewing their lives (Butler, 1963). However, as a means of helping older adults address issues of meaning and purpose in life, professionals may embark upon a structured process of life review with their aging clients. The purpose of life review is to help older adults to reflect

[19] Moore et al. (2006) eloquently addressed the role of growing through adversity and what this brings to the older adult in her last days. Coming through adversity early in life was positively correlated with being able to handle the challenges of old age.

upon their past lives, accept the past and successfully integrate the past with the present. Older adults can be asked questions about who they are as individuals and how they have lived their lives (Lewis, 2001). Life review is noted to help older adults with symptoms of depression (Chippendale & Bear-Lehman, 2012; Korte, Bohlmeijer, Cappeliez, Smit, & Westerhof, 2012) and to improve self-esteem and confidence (Chiang, Lu, Chu, Chang, & Chou, 2008).

Life review may involve a very structured group program, such as the Life Review Group Program developed by Butler (1963) and Haight (1988). This program involves topical discussions over an eight-week period, including discussions on childhood, adolescence, the participant's family and job, the participant's friends, the most significant thing the participant has accomplished in life, a summary of the life review and an integration of life events (Chiang et al., 2008).

Life review may also occur in a more informal manner, whereby nurses, chaplains, or other professionals can ask older adults questions that lead them to reflect upon the events of their lives. They may be asked to describe an obstacle in their life and how they overcame this obstacle, as well as the skills they utilized to tackle the problem (Jenko, Gonzalez, & Seymour, 2007). They can be asked about what they have achieved in their lives and what they most enjoyed. Nurses, chaplains, and other professionals can inquire about what older adults would like to leave with their family and how they wish to be remembered by others (Jenko et al., 2007).

Reminiscence

Reminiscence therapy is similar to life review; however, some believe that it is a less active process than life review (Haight, 1988). The purpose of reminiscence therapy is to assist older adults to resolve conflicts from the past (Bohlmeijer et al., 2005) and involves the process of thinking or telling others about their past lives (Cappeliez, O'Rourke, & Chaudhury, 2005). Reminiscence therapy can take various forms. For example, on some hospital units, a recreational therapist will conduct a reminiscence group once a week which older adults can attend. The therapist may show a particular item from the past, such as an old-fashioned chamber pot, which becomes a springboard upon which older adults can reflect upon their pasts and share stories with each other. For older adults with dementia, reminiscence can be particularly meaningful, because they can still remember and talk knowledgeably about events, circumstances, and objects of the past. Thus, it can also bolster a sense of mastery and competence.

Like life review, there are variations in how reminiscence therapy can be conducted. For example, one kind of reminiscence therapy is entitled "Searching for the Meaning in Life" (Bohlmeijer et al., 2005). This form of creative reminiscence does not rely as heavily upon orally reviewing life, and hence, may be effective for those who prefer nonverbal forms of self- expression. Also, this form of reminiscence relies upon metaphors and creative ways of representing life; this taps into creativity and self-expression. This form of reminiscence involves 12 sessions that

focus on topics such as friendships and houses in which older participants have lived (Bohlmeijer et al., 2005).

Another form of reminiscence therapy, spiritual reminiscence, involves telling life stories with importance placed upon meaning and the underlying assumption that individuals have a spiritual dimension (MacKinlay & Trevitt, 2010). Older adults are guided to talk about what gives them meaning in life and what has brought joy, sadness, or other feelings. Within this form of spiritual reminiscence, six themes are discussed: ultimate meaning, adults' responses to meaning, self-sufficiency/vulnerability, provisional life meanings/final meaning, relationship/isolation, and hope/despair. This approach is viewed as being an effective way to engage older adults with dementia (MacKinlay & Trevitt, 2010).

Reminiscence therapy can also be undertaken in a directed, yet solitary fashion. Older adults can be asked to write about their lives. This may be particularly effective for older adults within continuing care facilities, where staff may have limited time to talk with residents (Elford et al., 2005). In one study, five older adults living in a continuing care facility were asked to participate. Each week (for a total of four weeks), they were given a booklet and asked to write about various topics including childhood, neighborhood, workdays, and holidays. The booklets would then be typed up and could be offered as an archive for older individuals to share with family members. The researchers concluded that older adults enjoyed the writing, found that the activity was cathartic, and provided the participants a purpose; however, they also noted that when using reminiscence writing as an intervention, there can be issues of confidentiality, as well as questions regarding whether this activity is suitable for the older adult (Elford et al., 2005).

A caution is in order. While reminiscence therapy is believed to be effective in helping older adults in alleviating symptoms of depression and in achieving a sense of meaning, it may not be helpful in all circumstances (Cappeliez et al., 2005). For instance, reminiscence focused on the loss of significant individuals, especially for older adults who have the tendency to ruminate, may actually cause psychological distress. Also, reminiscence for the purpose of relieving boredom may not be effective (Cappeliez et al., 2005).

Recommend Activities that Foster Meaning

Activities can foster meaning for people, including older adults. Activities that tie into enjoyment and even spiritual qualities enhance meaning. For instance, some older adults enjoy horticulture. They may view gardening as a spiritual experience where they feel close to the earth or God; for them, gardening is a healing and nurturing experience (Heliker et al., 2001). Not only does gardening connect older adults to the earth and to their spiritual dimension, it may also bring back pleasant memories of the past, when perhaps a parent taught them how to garden. When taking part in a gardening program with others, loneliness may be ameliorated and life satisfaction increased (Tse, 2010).

Other activities that are known to cultivate meaning include taking educational courses and volunteering (as discussed in Chapter 3). Taking educational courses may address and in some ways, rectify, regrets from the past, where older adults wished they had pursued interests in art or writing, or where they may deal with their disappointment at not having attended university. As will be addressed in Chapter 8, volunteer work can be extremely therapeutic and meaningful for older adults. Volunteer work with vulnerable individuals (such as with troubled youth) may bring richness; here, the wisdom acquired through the years can be shared and make a great difference. If an aging person is no longer able to perform strenuous activities, he may find great meaning in assisting in an organization representing a cause that he values. Many older adults are not able to do overseas work, but they assist in sending out correspondence or checking items donated for organizations that provide relief for the suffering in other parts of the world. Not only does volunteer work provide the opportunity to make a vital contribution to those in need and increase social contact with others who share a common passion, it also offers structure to everyday life.

Instilling Hope

As mentioned in Chapter 2, it can be very difficult to move some older adults toward hope, especially if they have lost the aspects of their lives that give them hope, such as family members, friends, work, and health. What is hope? Hope has been defined as:

> a multidimensional dynamic of life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally significant. (Dufault & Martocchio, 1985, p. 380)

Hope changes as people age. Individuals may hope for great wealth when they are younger, or hope for a rewarding career in a particular field, but as they age, they realize that they will probably never see these dreams come to fruition. As such, older adults will then need to refine and redefine what they hope for.

Within the literature, hope has often been examined in relation to young or middle-aged adults with chronic illness, hope in those who have been diagnosed with cancer, and hope in and for individuals who are dying. However, there is a growing body of literature examining hope in older adults. We applaud the recognition that hope may be different for aging adults than for younger adults. For example, hope in younger and middle-aged adults often pertains to goals and sought after achievements (Herth & Cutcliffe, 2002). *What* older adults hope for is most likely different than their younger counterparts, as energy levels, health, and work opportunities often change as they age. Also, what relatively healthy older adults hope for may be very different for individuals where death is imminent. For individuals who are dying, hope may be placed in achieving a peaceful

death or making amends with family members. While aging adults who are not actively dying may wish for the same hopes, a peaceful death is still in the future. They need to find hope in the present and sustain hope for the future prior to death. And for some, this is not easy.

Assessing hope in older adults involves asking them directly, "What gives you hope?" and "What causes you to lose hope?" Nurses and other professionals can assess for factors that promote hope in aging adults. Herth (1993) examined hope in older adults residing in the community and those who lived within institutional settings. For younger–old adults who were healthy and still living within their homes, they hoped for continued health, ability to travel, and comfort. The hopes of older residents (over 80 years of age) within institutional settings varied from those who still lived independently. These very aged individuals placed their hopes upon family members or upon life after death (Herth, 1993).

Dunne (2001) used the construct of "faith, hope, and love"[20] for encapsulating the needs of the dying, as well as sources of meaning for them. We suggest that this construct can apply to older adults who are not dying, as well. Regarding hope, Dunne (2001) spoke of "images and raw experiences" that give people hope (p. 26). Practically speaking, this involves experiences of beauty, of nature, and of relationship. From a spiritual perspective, these things connect people with transcendence, with *life*. For those in their homes, as well as institutionalized older adults, this may involve regular visits from significant people in their lives; it may mean sitting outside, enjoying the sun and breeze; it may mean a glass of wine to the individual who really enjoys that. Meaning is squeezed out of life, wherever it is!

MBR's mother enjoyed her backyard. She always looked forward to—indeed eagerly hoped for—the spring and summer. In her more youthful days, her yard was groomed exquisitely; "It looks just like a park!" visitors to our home would exclaim. Later on, she was not able to continue the yard care, but she anticipated the spring and summer times, and then enjoyed the time spent outside, with the sun and the breeze. "It's good for my bones!" she would happily say. But it was also very good for her soul. Hope is both a need and a source of meaning.

The motto of Dame Cicely Saunders was "live until you die"; this is the philosophy of palliative care. Hence, people's sources of meaning are met, in some form, as best can be possible. This is hope in the short term: hope for a visit by a staff member or loved one, anticipated time outside in a restful garden, music being played in the common room across the hall, the contemplative exercise of watching the birds at the feeder outside of one's window—these things both engender hope and bring meaning.

---

[20] Dunne (2001) mentioned that typically these three terms are used religiously (i.e., as a quotation from the New Testament, 1 Corinthians 13th chapter). He stated that this can be broadened to mean the following: *faith* means the commitments that the older adult has fulfilled in his or her life. *Hope* is explained above. And *love* means (possibly) love for God, and, certainly, love for others.

Professionals should also be aware of factors that dampen hope. For example, in Herth's (1993) study, older adults listed the following factors that impede hope: others, significant fatigue, uncontrollable pain and suffering, and impaired cognition. Some of these factors may not be able to be mitigated; however, nurses and other professionals may be able to intervene in relation to teaching about fatigue levels, as well as assessing and treating pain. If older adults are better able to manage fatigue and pain, they may experience greater hope and enjoyment in life.

In working with aging individuals to instill hope, it is vital that the object of hope is realistic. It probably is not reasonable for an older adult, who has never exercised, to hope to run a full marathon. However, if hope is tailored to the senior's fitness level, and thus involves increasing exercise to a level that is manageable (and approved by the individual's physician), then this goal can provide hope and purpose and also be attainable.

Examine and Attend to the Internal Dialogue of Older Adults

> I've developed a new philosophy . . . I'm only going to dread one day at a time
> (Charles Schulz, *Brainy Quotes,* 2013).

Charlie Brown's statement is both humorous and heartbreaking. It brings us humor, because we can relate, on some level, to the stresses that would cause us to dread some things in life (and Charlie Brown was honest enough to admit it). It is also heartbreaking, because there are people who truly do dread each day. And sometimes these people do not openly express such dread; rather, they live with an internal conversation that is fearful and punishing. It robs them of joy and meaning in life. The elderly are not exempt from this; and with the losses and stresses of growing old, they may be particularly vulnerable.

One way in which older adults can attend to a sense of meaning in life relates to monitoring their internal dialogue. Internal dialogue refers to how individuals talk to themselves about various situations. In one study researchers interviewed 12 older residents living in Swedish nursing homes about their views on dignity (Dwyer et al., 2008). Based upon their initial findings, the researchers then interviewed in-depth three of the 12 women. Dwyer and colleagues (2008) discovered that the inner dialogue of the older individuals helped create meaning in their situations, despite physical disabilities. The researchers' description of inner dialogue was more than just cognitive reframing, or cognitive appraisal. It involved recognizing personal strengths and drawing upon meaning from the past in the present. For instance, one woman would spend much time in her room looking at pictures of her family; this focus did not involve morbid rumination of how things were better in the past. Rather, the older woman pondered, with pride, her roles as wife, mother, and grandmother in the past and how she

still felt valued and prized by her family now, even if she did not see her family often (Dwyer et al., 2008).

Another woman who was blind at the time of the interview, revealed inner dialogue that reflected her ability to accept both the good and the bad in life. She used the metaphor of a fighter to describe how she had faced into difficulties in the past and the present. She stressed how her sharp cognitive abilities provide her meaning and allowed her to compensate for the loss of eyesight. She took great pride in keeping on top of social issues and readily engaged others in conversations about women's rights and class disparities (Dwyer et al., 2008). Both of these women demonstrated an ability to bring meaning, derived from relationships, passions, or strengths, from the past into the present, despite significant physical deficits. Although these women were not coached or counseled by professionals about how to manage their internal lives in such a fashion, this could be an avenue for some professionals to explore.

Address Issues of Forgiveness

Nurses, chaplains, and other professionals should be attune to the possibility that older adults desire forgiveness. When older adults feel a need for forgiveness, this can impact their quality of life, as well as their sense of meaning and purpose. Aging individuals may look back over their lives and feel a need for forgiveness from God, from others, or from themselves. Of the three possible sources for forgiveness—God, others, or the self—forgiveness of the self may be the most difficult to achieve (Enright, 1996).

Why is forgiveness important? Generally speaking, issues surrounding forgiveness—the ability to forgive others and feel forgiven—are associated with better physical and mental health (Ingersoll-Dayton, Torges, & Krause, 2010; Lawler et al., 2005; Toussaint, Williams, Musick, & Everson-Rose, 2008). Also, the act of forgiveness is associated with meaning in life. For example, in a study examining the relationship between forgiveness, meaning in life, and stressful events, Hantman and Cohen (2010) administered questionnaires to 225 Israeli older adults. Some of the research participants had lived through the mass execution of Jewish individuals during the World War II Holocaust, and all had experienced the strife of Israel with surrounding countries. When given the questionnaires to test forgiveness and meaning in life, the older participants were asked to think about a time they were hurt and to categorize this as being within the family or outside the family (Hantman & Cohen, 2010). The researchers found that family members were more likely to be forgiven than those outside the family and that older adults may be more willing to forgive those who are still alive, rather than those who have passed away. Notably, the researchers concluded that meaning in life is associated with forgiveness. That is, those who perceived their lives to be filled with meaning and purpose were more apt to forgive others. While Hantman and Cohen (2010) cautioned that the construct of meaning was operationalized

from an instrumental perspective (that is, from a standpoint of meaningful activities and hobbies that enhance quality of life), rather than examining meaning from an existential point of view (Hantman & Cohen, 2010), the findings are still relevant. A sense of meaning in life may lead to a greater willingness of older adults to forgive others; similarly, being able to forgive the self and others may also enhance meaning in life.

For many professionals (except, perhaps chaplains), the idea of assessing whether older individuals have a need for forgiveness seems foreign, and even intrusive. After all, not all aging individuals experience pressing spiritual needs or distress (Milligan, 2011). While most professionals will not routinely assess this area, they can listen carefully to the stories of older adults as they talk about the present and reflect on the past. Similarly, when engaging older adults in reminiscence therapy or life review, particularly if the purpose is to tap into the meaning older adults ascribe to their lives, issues of regrets about previous relationships, as well as the desire for forgiveness, may emerge (Gunther, 2008).

When engaged in life review or reminiscence therapy, older adults might spontaneously recall incidents of the past. As they talk through an incident, they might have a moment when they see the occurrence in a different light. In that moment, they may think or say, "Now I know why (a person) did that to me . . . . Now I understand." Especially if years have passed since an offense and through the years they experienced similar situations that may have contributed to their understanding of the behavior of someone who hurt them, they may now respond with empathy and understanding and discover that the anger is gone. This construct is termed "deferred empathy" (Gunther, 2008) and may assist older adults to move toward forgiveness.

We do not mean to imply that forgiveness is easy or natural for older adults. The act of attaining or granting forgiveness is extremely complex, and older adults can agonize over this. Regrets about how they treated others, how they were hurt by others, or questions about whether God can forgive them can result in great anguish and torment of the soul. We also recognize that some hold misunderstandings about what the act of forgiveness entails. While forgiveness involves a letting go of the right to think, feel, and behave negatively towards someone, it does not necessarily involve trust. For example, a person can forgive a former partner who acted violently toward her, but she does not necessarily need to enter into a relationship again with this person. The ex-partner may not be trustworthy and hence, it would be unwise to make herself vulnerable to this individual (Enright, 1996).

Forgiveness issues are very personal and there is always the potential that older adults—vulnerable individuals—may be wounded by well-meaning professionals who believe they know "what is best" for the elderly person. Ministry of presence, as elucidated earlier in the chapter, is absolutely vital. Humility, empathy, vulnerability —these qualities make the nurse or other professional *safe* in her questions and in her presence. The understanding that another's journey is "holy ground" is

important; for that ground that is sacred, the caring healthcare professional must "take off his or her shoes."[21] (This is, of course, intended in a metaphorical sense).

In recognition that issues of forgiveness can pierce right through to the soul of some older adults, we recommend that professionals refer their aging clients to chaplains or clergy when they appear particularly distressed spiritually. Clergy who are trained to deal with issues of forgiveness are often more adept at guiding their clients through the process of forgiveness. If older clients are deeply troubled by the need for forgiveness, but do not want to speak with clergy, nurses can refer them to professionals with advanced training in spiritual counseling (Milligan, 2011).

EXISTENTIAL WORK FOR PROFESSIONALS

Why is it important for nurses and other professionals to do their own existential work? Or in rephrasing the question, why would we suggest that professionals examine their beliefs about life, the world, the meaning of their existence, and so on?

From a professional perspective, having done one's own existential work prepares one to work with others experiencing the challenge of life transitions. A nurse will be alert to the existential issues of life, able to empathize with his patients, and be better equipped to ask questions of aging adults to help them process and come to terms with their lives.

Although important from a personal perspective, doing one's own existential work is very necessary in working in human services. In the context of this text, professionals who do not do their own existential work may avoid working with older adults. They may feel that the issues of older adults "hit too close to home." In our experience, we have worked with colleagues in gerontology and palliative care who seem to enjoy their work, but at a certain time, move on to other specialties. This can be in part related to the desire to make a change, to learn new knowledge and different skills. However, colleagues have also told us that they decided upon another focus in healthcare because working with aging and death and dying triggered issues in them.

To some degree, the calling of working with suffering others "forces" existential work. It taxes the nurse, the social worker, the chaplain, significantly. A recent study in Great Britain showed that 10 percent of the nurses surveyed missed more than six days due to illness in a three month period; and 20 percent admitted coming to work when they were too ill to perform the job.[22] One recent American

---

[21] This metaphor is drawn from the biblical story of when Yahweh told Moses, at the burning bush, to take off his shoes, as "this is holy ground" (Exodus 3: 4–6).

[22] The original study was commissioned by the British Department of Health, and surveyed National Health Services workers. For the study itself, see Van Stolk, Hassan, Austin, Celia, Disley, et al. (2009). For the response from the National Health Services, to deal with these issues, see Nash (2011).

study (Letvak, Ruhm, & McCoy, 2012) indicated that registered nurses suffered from depression at about twice the regular rate of the population.[23] In both cases, the researchers stressed that these conditions affected the nurses themselves, the quality of care delivered, as well as their patients. It was recognized that the work itself led to physical and mental illness in nurses.

Strategies

Earlier on in this chapter Viktor Frankl (1986) was quoted as saying human beings exist in the somatic (body), the mental (psychological), and the spiritual. The lifelong development of personhood, it would follow, would focus on those three areas.

As all aspects of being human are interrelated, the following strategies touch upon the physical, the psychological, and the spiritual. As they relate to personhood (the spirit) it could be argued that they all are spiritual. Because we are all different, and express our spirituality in different ways, we suggest that the reader "pick and choose" that which resonates with their person.

Kalina (2007) counseled the following exercises: First, she recommended prayer. To pray (in whichever way one is accustomed) connects the healthcare professional with the Transcendent. It is one way to set down the burdens of the work and step away. It is another way to integrate the experiences of work and of life into one's soul.

Inspirational writings can be uplifting. The scriptures from one's faith can be a source of strength. So can popular books that appeal to the "faith, hope, and love" needs and sources of meaning in all of us.

Live graciously and in forgiveness. The qualities that we admire so greatly in those patients we worked with—quiet strength, perseverance, ability to overcome adversity, forgiveness—were worked out in the trenches of life. The "muscles" that work for the aged—the muscles of the soul—have been developed over a lifetime and need to be exercised over the long haul to work effectively as one approaches the end of life.[24]

As healthcare providers, we are grateful for those who are grateful for our services. Gratitude is an exercise of the soul. Meister Eckhart said, "If the only prayer you said was 'thank you', that would be enough" (Good Reads, 2013). Those who are grateful "embrace life" and find meaning in the "little things" (Moore et al., 2006, pp. 296–297). Fill your life with the things for which you are grateful; harness those things that bring you joy! For some, that means running outside on a

---

[23] Letvak, Ruhm, and McCoy (2012) conducted a study of 1171 North Carolina hospital nurses. They found that 18 percent of nurses within this study suffered from depression and compared this with the American national rate of 9.0 percent. For more information on this study, see Letvak et al. (2012).

[24] For a more complete discussion of these spiritual exercises, see Kalina (2007), pp. 62–69.

crisp January morning; for others, it is sitting with a cup of coffee, reading a good book, on that same winter's day. In this way, meaning and joy are intentionally incorporated into each day.

Moore and colleagues (2006) suggested that individuals who have developed a philosophy of life that integrates adversity and challenge into the warp and woof of life do better in older adulthood. As with the other spiritual practices, this outlook involves work over the long term.

A nurse can develop such a philosophy by drawing off of the experiences of the older adults she works with. Religious faith typically has such a philosophy built into it; so do many spiritual maxims. Susan, still working in her early senior years, was doing much existential work, born largely, out of crisis: A dear friend had dropped dead at work. This woman was the same age as Susan and had died "for no apparent reason." Susan did not consider herself religious; from my working with her, I experienced her as a very spiritual person—one who sought to extract meaning out of every experience in life. In her 60s, Susan adopted the maxim "everything happens for a reason" and, in her grief and spiritual work, had this saying tattooed in large print down the underside of her forearm.[25] Although she did not know the reason of her precious friend's death, this proverb helped to anchor her.

For the experiences that an individual has particular difficulty with, it is recommended that he conducts his own search. Finding meaning is truly a search, as Frankl's (2006) book title suggested. As has been mentioned earlier, working with people will tug at particular issues within each of us, based upon our experiences. When those tugs occur, it is wise for an individual explore his reactions. For some, this is a natural exercise; for others, it is not.

Processing existential issues may be particularly difficult for the professional for whom meaning in life is in flux. For example, the nurse who was raised with a religious faith, but set that faith aside, may be particularly impacted by the spiritual/religious crisis of a patient. She may wonder how to view this event in the light of her current philosophical shift. Speaking with a counselor, a chaplain, or spiritual advisor may be helpful. While we recognize that spiritual development is a process that occurs over a lifetime, and also appreciate that individuals change in their understandings of the world as they experience challenges, it is essential that professionals working in health and human services have a paradigm through which to process both the joys and sorrows of their personal and professional lives.

Doing one's own spiritual and existential work is all about the development of personhood over the lifespan. Attention to such matters will help professionals remain effective in the personal lives and professional practice over the long term.

---

[25] The authors of this book do not recommend a "permanent" action like getting a tattoo when one is in the throes of grief!

SUMMARY

"To ride the truth of the soul can be a fearsome journey . . ." said Claire Nahmad (1994, p. 19). It can, indeed—for older adults and for those who work with them. But this journey is also awesome—for journeys fraught with challenge can also be very meaningful. In this chapter we looked at the concept of personhood and considered the existential issues of adults as they age. We addressed interventions within the family and the healthcare system that can help maintain and even further develop personhood in the latter years. And, we encouraged healthcare providers to do their own existential work. A few ethical issues, which will be dealt with more fully in Chapters 6 and 8, have been alluded to here. If we have "rattled the bars of the cage" (Fulghum) for you, the reader, just a bit, then we have succeeded.

Critical Thinking Exercise

- What aspects of assessing for existential issues are most difficult for you?
- How do you address your own existential issues?
- What impact do you think aging will have upon your existential issues?

REFERENCES

Ainsworth, M. D. (1967). *Infancy in Uganda.* Baltimore: Johns Hopkins.

Ainsworth, M. D., & Bowlby, J. (1991). An ethological approach to personality development. *American Psychologist, 46*(4), 331–341. doi: 10.1037/0003-066x.46.4.333

Allport, G. W., & Ross, J. M. (1967). Personal religious orientation and prejudice. *Journal of Personality and Social Psychology, 5*(4), 432–443.

American Association of Suicidology. (2009). Suicide risk sheet. Retrieved February 18, 2013, from www.suicidology.org/c/.../get_file?folderId=232&name=DLFE-242.pdf

Anandarajah, G., & Hight, E. (2001). Spirituality and medical practice: Using the HOPE questions as a practical tool for spiritual assessment. *American Family Physician, 63*(1), 81–88.

The Barna Group. (2009). New statistics on church attendance and avoidance. Retrieved February 10, 2013, from www.barna.org/barna-update/article/18-congregations/45-new-statistics-on-church-attendance-and-avoidance

Benner Carson, V., & Koenig, H. G. (2004). *Spiritual caregiving: Healthcare as a ministry.* Philadelphia: Templeton Foundation Press.

Bibby, R. (2012). Religion and spirituality in Canada: Religion and spirituality remain pervasive: Latest national survey findings. Retrieved February 28, 2013, from www.reginaldbibby.com

Blue, K. (1998). *Healing spiritual abuse.* Downer's Grove, IL: Intervarsity Press.

Bohlmeijer, E., Valenkamp, M., Westerhof, G., Smit, F., & Cuijpers, P. (2005). Creative reminiscence as an early intervention for depression: Results of a pilot project. *Aging & Mental Health, 9*(4), 302–304. doi: 10.1080/13607860500089567

Bowlby, J. (1953). *Child care and the growth of love.* London: Penguin Books.

Bowlby, J. (1999) [1982]. *Attachment and loss. Vol. II* (2nd ed.). New York: Basic Books.

Brainy Quotes. (2013). Retrieved March 10, 2013 from www.brainyquote.com/quotes/authors/c/charles_m_schulz.html

Buber, M. (1958). *I and thou.* (Translated by Ronald Gregor Smith). New York: Charles Scribner's Sons.

Butler, R. N. (1963). The life review: An interpretation of reminiscence in the aged. *Psychiatry, 26,* 65–76.

Butler, R. N. (1969). Ageism: Another form of bigotry. *The Gerontologist, 9*(4), 243–246.

Byock, I. (1997). *Dying well: Peace and possibilities at the end of life.* New York: Riverhead Books.

Caldwell, J. M., & Caldwell, D. (2010). Reading Luke for community formation against ageism. *Journal of Religion, Spirituality & Aging, 22*(3), 211–219. doi: 10.1080/15528031003613359

Cappeliez, P., O'Rourke, N., & Chaudhury, H. (2005). Functions of reminiscence and mental health in later life. *Aging & Mental Health, 9*(4), 295–301. doi: 10.1080/13607860500131427

Chiang, K-J., Lu, R-B., Chu, H., Chang, Y-C., & Chou, K-R. (2008). Evaluation of the effect of a life review group program on self-esteem and life satisfaction in the elderly. *International Journal of Geriatric Psychiatry, 23*(1), 7–10. doi: 10.1002/gps.1824

Chippendale, T., & Bear-Lehman, J. (2012). Effect of life review writing on depressive symptoms in older adults: A randomized control trial. *American Journal of Occupational Therapy, 66*(4), 438–446.

Cicirelli, V. G. (2001). Personal meanings of death in older adults and young adults in relation to their fears of death. *Death Studies, 25*(8), 663–683.

Coates, S. (1995). Spiritual components in spiritual care. *European Journal of Palliative Care, 2*(1), 37–39.

Coila, B. (2011). *The effect of human contact on newborn babies.* Retrieved November 25, 2012, from www.livestrong.com/article/72120-effect-human-contact-newborn- babies/#ixzz2D9wp5WMD

Corner, L., & Bond, J. (2004). Being at risk of dementia: Fears and anxieties of older adults. *Journal of Aging Studies, 18*(2), 143–155. doi: 10.1016/j.jaging.2004.01.007

Cram, R.H. (2003). *Bullying: A spiritual crisis.* St. Louis, Missouri: Chalice Press.

Crandall, L. G., White, D. L., Schuldheis, S., & Talerico, K.A. (2007). Initiating person-centred care practices in long-term care facilities. *Journal of Gerontological Nursing, 33*(11), 47–56.

Dark-Freudeman, A., West, R. L., & Viverito, K. M. (2006). Future selves and aging: Older adults' memory fears. *Educational Gerontology, 32*(2), 85–109. doi: 10.1080/03601270500388125

Dennis, H., & Thomas, K. (2007). Ageism in the workplace. *Generations, 31*(1), 84–89.

Dobbs, D., Emmett, C. P., Hammarth, A., & Daaleman, T. P. (2012). Religiosity and death attitudes and engagement of advance care planning among chronically ill older adults. *Research on Aging, 34*(2), 113–130. doi: 10.1177/0164027511423259

Downing, M. (2003). *Transitions in dying and bereavement: A psychosocial guide for hospice and palliative care.* Winnipeg: Health Professions Press.

Dufault, K., & Martocchio, B. C. (1985). Symposium on compassionate care and the dying experience. Hope: its spheres and dimensions. *Nursing Clinics of North America, 20*(2), 379–391.

Dunne, T. (2001). Spiritual care at the end of life. *Hastings Center Magazine, 31*(2), 22–26.

Dwyer, L-L., Nordenfelt, L., & Ternestedt, B-M. (2008). Three nursing home residents speak about meaning at the end of life. *Nursing Ethics, 15*(1), 97–109. doi: 10.1177/0969733007083938

Egan, M., & Prud'homme Brisson, D. (2006). Outreach nurses' perceptions of the spiritual needs of their homebound older clients. *Journal of Religion, Disability & Health, 9*(4), 71–85. http://dx.doi.org/10.1300/J095v09n04_05

Elford, H., Wilson, F., McKee, K. J., Chung, M. C., Bolton, G., et al. (2005). Psychosocial benefits of solitary reminiscence writing: An exploratory study. *Aging & Mental Health, 9*(4), 305–314. doi: 10.1080/13607860500131492

Enright, R. D. (1996). Counseling within the forgiveness triad: On forgiving, receiving forgiveness, and self-forgiveness. *Counseling & Values, 40,* 107ff.

Erikson, E. H., Erikson, J. M., & Kivnick, H. (1986). *Vital involvement in old age.* New York: Norton.

Erikson, E. H. (1982). *The life cycle completed: A review.* New York: Norton.

Floriani, C. M. (1999). The spiritual side of pain. *American Journal of Nursing, 99*(5), 24PP–24RR.

Frankl, V. E. (1986). *The doctor and the soul* (2nd ed.). New York: Vintage.

Frankl, V. E. (2006). *Man's search for meaning.* Boston: Beacon Press.

Free OnLine Dictionary. (2012). Retrieved November 20, 2012, from www.thefreedictionary.com

Fry, P. S. (2000). Religious involvement, spirituality and personal meaning for life: Existential predictors of psychological wellbeing in community-residing and institutional care elders. *Aging & Mental Health, 4*(4), 375–387. doi: 10.1080/713649965

Goffman, E. (1961). *Asylums: Essays on the social situation of mental patients and other inmates.* New York: Anchor.

Good Reads. (2013). Retrieved March 01, 2013, from www.goodread.com/author/quotes/73092.Meister.Eckhart.

Gress, L., & Bahr, R. (1984). *The aging person: A holistic perspective.* St. Louis, MO: Mosby.

Gunther, M. (2008). Deferred empathy: A construct with implications for the mental health of older adults. *Issues in Mental Health Nursing, 29*(9), 1029–1040. doi: 10.1080/01612840802274974

Haight, B. K. (1988). The therapeutic role of a structured life review process in homebound elderly subjects. *Journal of Gerontology, 43*(2), 40–44.

Hall, P., McCarney, P., Hamilton, P. D., Robertson, C., & Yates-Fraser, J. (1996). Anne's garden: A journey of the human spirit. *Humane Health Care International, 12*(1), 24–26.

Hamilton, D. G. (1998). Believing in patients' beliefs: Physician attunement to the spiritual dimension as a positive factor in patient healing and health. *The American Journal of Hospice and Palliative Care, 15*(5), 276–279.

Hantman, S., & Cohen, O. (2010). Forgiveness in late life. *Journal of Gerontological Social Work, 53*(7), 613–630. doi: 10.1080/01634372.2010.509751

Hawley, J. (1993). *Reawakening the spirit in work: The power of Dharmic management.* San Francisco: Barrett Koehler Publishers.

Hay, M.W. (1989). Principles in building spiritual assessment tools. *American Journal of Hospice & Palliative Care, 6*(5), 25–31. doi: 10.1177/104990918900600514

Heliker, D., Chadwick, A., & O'Connell, T. (2001). The meaning of gardening and the effects on perceived well being of a gardening project on diverse populations of elders. *Activities, Adaptation & Aging, 24*(3), 35–56. http://dx.doi.org/10.1300/J016v24n03_03

Hemfelt, R., Minirth, F., & Meier, P. (1991). *We are driven: The compulsive behaviors America applauds.* Nashville: Thomas Nelson.

Herth, K. (1993). Hope in older adults in community and institutional settings. *Issues in Mental Health Nursing, 14*(2), 139–156.

Herth, K. A., & Cutcliffe, J. R. (2002). The concept of hope in nursing: Hope and gerontological nursing. *British Journal of Nursing, 11*(17), 1148–1156.

Heyse-Moore, L. H. (1996). On spiritual pain in the dying. *Mortality, 1*(3), 297–315. doi: 10.1080/13576279609696250

Hinck, S. M. (2007). The meaning of time in the oldest-old age. *Holistic Nursing Practice, 21*(1), 35–41.

Hirst, S. P., Lane, A. M., & Reed, M. B. (2013). Personhood in nursing homes: Results of an ethnographic study. *Indian Journal of Gerontological Studies, 27*(1), 69–87.

Hood, R. W., Spilka, B., Hunsberger, B., & Gorusch, R. (2003). *The psychology of religion: An empirical approach* (3rd ed.) New York: Guilford Press.

Hughes, D., & Peake, T. (2002). Investigating the value of spiritual well-being and psychosocial development in mitigating senior adulthood depression. *Activities, Adaptation & Aging, 26*(3), 15–35.

Hunter, E. G. (2007–2008). Beyond death: Inheriting the past and giving to the future, transmitting the legacy of one's self. *OMEGA, 56*(4), 313–329. doi: 10.2190/OM.56.4.a

Ingersoll-Dayton, B., Torges, C., & Krause, N. (2010). Unforgiveness, rumination, and depressive symptoms among older adults. *Aging & Mental Health, 14*(4), 439–449. doi: 10.1080/13607860903483136

Jenko, M., Gonzalez, L., & Seymour, M. J. (2007). Life review with the terminally ill. *Journal of Hospice & Palliative Nursing, 9*(3), 159–167.

Kalina, K. (2007). *Midwife for souls: Spiritual care for the dying* (Rev. ed.). Boston: Pauline Books & Media.

Kind, V. (2010). *The caregiver's path to compassionate decision-making: Making choices for those who can't.* Austin, Texas: Greenleaf Book Group Press.

King, M. L., Jr. (1962). Towards freedom. Speech given at Dartmouth College, Hanover, NH. Retrieved November 22, 2012, from www.dartmouth.edu/~towardsfreedom/transcript.html

Koenig, H. G. (2001). Spiritual assessment in medical practice. *American Family Physician, 63*(1), 30–31.

Korte, J., Bohlmeijer, E. T., Cappelicz, P., Smit, F., & Westerhof, G. J. (2012). Life review therapy for older adults with moderate depressive symptomatology: A pragmatic randomized control trial. *Psychological Medicine, 42*(6), 1163–1173. doi: 10.1017/S0033291711002042

Krause, N. (2004). Stressors in highly valued roles, meaning in life, and the physical health status of older adults. *Journal of Gerontology: Social Sciences, 59*(5), S287–S297. doi: 10.1093/geronb/59.5.S287

Krause, N. (2007). Evaluating the stress-buffering function of meaning in life among older people. *Journal of Aging and Health, 19*(5), 792–812. doi: 10.1177/0898264307304390

Krause, N. (2009). Meaning in life and mortality. *Journal of Gerontology: Social Sciences, 64B* (4), 517–527. doi: 10.1093/geronb/gbp047

Kuhl, D. (2003). *What dying people want: Practical wisdom for the end of life.* Toronto, ON: Anchor Canada.

la Cour, P. (2008). Existential and religious issues when admitted to hospital in a secular society: Patterns of change. *Mental Health, Religion and Culture, 11*(8), 769–782. doi: 10.1080/13674670802024107

Lawler, K., Younger, J., Piferi, R., Jobe, R., Edmondson, K., & Jones, W.H. (2005). The unique effects of forgiveness on health: An exploration of pathways. *Journal of Behavioral Medicine, 28*(2), 157–167. doi: 10.1007/s10865-005-3665-2

Letvak S., Ruhm, C. J., & McCoy, T. (2012). Depression in hospital-employed nurses. *Clinical Nurse Specialist, 26*(3), 177–182. doi: 10.1097/NUR0b013e3182503ef0

Lewis, M. M. (2001). Spirituality, counseling, and elderly: An introduction to the spiritual life review. *Journal of Adult Development, 8*(4), 231–240.

Ley, D. (1992). Spiritual care in hospice. In G. R. Cox and R.J. Fundis (Eds.), *Spiritual, ethical and pastoral aspects of death and bereavement* (pp. 207–215). Amityville, NY: Baywood Publishing.

MacKinley, E., & Trevitt, C. (2010). Living in aged care: Using spiritual reminiscence to enhance meaning in life for those with dementia. *International Journal of Mental Health Nursing, 19*(6), 394–401. doi: 10.1111/j.1447-0349.2010.00684.x

MacMillan, K., Peden, J., Hopkinson, J., & Hycha, D. (2000). *A caregiver's guide: A handbook about end of life care.* Edmonton: The Palliative Care Association of Alberta.

May, G. G. (1982). *Care of mind, care of spirit: A psychiatrist explores spiritual direction.* San Francisco, CA: Harper.

McKernan, M. (2005). Exploring the spiritual dimension of social work. *Critical Social Work, 6* (2). Retrieved March 08, 2013, from www.uwindsor.ca/criticalsocialwork/2005-volume-6-no-2

McSherry, C. B. (2011). The inner life at the end of life. *Journal of Hospice & Palliative Nursing, 13*(2), 112–120. doi: 10.1097/NJH.0b013e318207af49

Merriam-Webster Online Thesaurus. Retrieved November 28, 2012, from http://www.merriam-webster.com/dictionary/thesaurus.

Milligan, S. (2011). Addressing the spiritual care needs of people near the end of life. *Nursing Standard, 26*(4), 47–56.

Moore, S.L. (1997). A phenomenological study of meaning in life in suicidal older adults. *Archives of Psychiatric Nursing, 11*(1), 29–36.

Moore, S. L., Metcalf, B., & Schow, E. (2006). The quest for meaning in aging. *Geriatric Nursing, 27*(5), 293–299.

Mount, B. (1993). Beyond psychosocial and physical needs. *The American Journal of Hospice and Palliative Care, 10*(1), 28–37. doi:10.1177/104990919301000109

Munsey, B. (1980). *Moral development, moral education, and Kohlberg: Basic issues in philosophy, psychology, religion, and education.* Birmingham, AL: Religious Education Press.

Nahmad, C. (1994). *Garden spells.* London: Pavillion Books.

Nash, S. (2011). Health and wellbeing part 1: Helping ourselves and others. *Nursing Times, 107* (22), 19–20.

Newport, F. (2011). More than 9 in 10 Americans continue to believe in God. Retrieved February 4, 2013, from www.gallup.com/poll/147887/americans-continue-believe-god.aspx.

Nietzsche, F. (1911). *Twilight of the idols* (translated by A. M. Ludovici). New York: Macmillan.

Poor, B., & Poirrier, G. P. (2001). *End of life nursing care.* Sudbury, MA: Jones and Bartlett.

Power, J. (2006). Religious and spiritual care. *Nursing Older People, 18* (7), 24–27.

Purcell, B. (2008). *Spiritual terrorism: Spiritual abuse from the womb to the tomb.* Bloomington, IN: AuthorHouse.

Reyna, C., Goodwin, E. J., & Ferrari, J. R. (2007). Older adult stereotypes among care providers in residential care facilities. *Journal of Gerontological Nursing, 33*(2), 50–55.

Reker, G.T. (1997). Personal meaning, optimism, and choice: Existential predictors of depression in community and institutional elderly. *The Gerontologist, 37*(6), 709–716. doi: 10.1093/geront/37.6.709

Religious Tolerance. (1999–2007). How many North Americans attend religious services (and how many lie about going)? Retrieved February 04, 2013, from www.religioustolerance.org/rel_rate.htm.

Ryan, P. Y. (2005). Approaching death: A phenomenologic study of five older adults with advanced cancer. *Oncology Nursing Forum, 32*(6), 1101–1108. doi: 10.1188/05.ONF.1101-1108

Speck, P. (1998). Spiritual issues in palliative care. In D. Doyle, G. W. Hanks and N. MacDonald (Eds.), *Oxford textbook of palliative medicine* (2nd ed.;pp. 805–814). Oxford, UK: Oxford University Press.

Statistics Canada. (2009). Suicide and suicide rates, by sex and age group. Retrieved November 28, 2012, from www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/hlth66e-eng.htm.

Stoneking, C. B. (2003). Modernity: The social construction of aging. In S. Hauerwas, C.B. Stoneking, K. G. Meador, and D. Cloutier (Eds.), *Growing old in Christ* (pp. 63–89). Grand Rapids, MI: Eerdmans.

Sulmasy, D. (2006). Spiritual issues in the care of dying patients: "It's okay between me and God." *Journal of the American Medical Association, 296*(11), 1385–1392.

Sutterly, L. (2001). Guilt, shame and religious and spiritual pain. *Holistic Nurse Practice, 15*(2), 30–39.

Thomas, C. L., & Cohen, H. L. (2006). Understanding spiritual meaning making with older adults. *Journal of Theory Construction & Testing, 10*(2), 65–70.

Thompson O'Maille, T., & Kasayka, R. E. (2005). Touching the spirit at the end of life. *Alzheimer's Care Quarterly, 6*(1), 62–70.

Timmer, E., Westerhof, G. J., & Dittmann-Kohli, F. (2005). "When looking back on my past I regret . . .": Retrospective regret in the second half of life. *Death Studies, 29*(7), 625–644. doi: 10.1080/07481180591004660

Toussaint, L. L., Williams, D. R., Musick, M. A., & Everson-Rose, S. A. (2008). The association of forgiveness and 12-month prevalence of major depressive episode: Gender differences in a probability sample of U.S. adults. *Mental Health, Religion & Culture, 11*(5), 485–500. doi: 10.1080/13674670701564989

Tse, M. M. (2010). Therapeutic effects of an indoor gardening programme for older people living in nursing homes. *Journal of Clinical Nursing, 19*(7-8), 949–958. doi: 10.1111/j.1365-2702.2009.02803.x

Turesky, D. G., & Schultz, J. M. (2010). Spirituality among older adults: An exploration of the developmental context, impact on mental and physical health, and integration into counseling. *Journal of Religion, Spirituality & Aging, 22*(3), 162–179. doi: 10.1080/15528030903437406

VandeCreek, L., & Burton, L. (2001). Professional chaplaincy: Its role and importance in healthcare. *The Journal of Pastoral Care, 55*(1), 81-97.

Van Stolk, C., Hassan, E., Austin, C., Celia, C., Disley, E., Hunt, P., Marjanovic, S., et al. (2009). *The NHS workforce health and wellbeing review.* London: Department of Health.

Walsh, F. (1999). *Spiritual resources in family therapy.* New York: The Guilford Press.

Walsh, F. (2009). Religion, spirituality and the family: Multi-faith perspectives. In F. Walsh (Ed.), *Spiritual resources in family therapy* (2nd ed.; pp. 3–30). New York: The Guilford Press.

Weingarten, K. (1999). Stretching to meet what's given: Opportunities for a spiritual practice. In F. Walsh (Ed.), *Spiritual resources in family therapy* (pp. 240–255). New York: The Guilford Press.

Worthington, E. L. (1989). Religious faith across the lifespan: Implications for counseling and research. *Counseling Psychologist, 17*(4), 555–612. doi: 10.1177/0011000089174001

Wright, L. M. (2005). *Spirituality, suffering and illness: Ideas for healing.* Philadelphia: F. A. Davis.

Chapter 6

DEATH: THE FINAL TRANSITION

The boundaries which divide Life from Death are at best shadowy and vague. Who shall say where the one ends, and where the other begins.
(Edgar Allan Poe, American writer)
There is no Death;
What seems so is transition.
(Anonymous, quoted in Ley & van Bommel, 1994, p. 42)

Death is the final transition that older adults face. This transition is imbued with mystery; what the dying process will look like and what will happen afterwards are not known for certain. These mysteries result in the shadows and vagueness described by American writer Poe. For some aging individuals, death is a welcomed transition out of this world into the next. Others fear death greatly and move into this transition with considerable trepidation. Coming face to face with death not only entails the physical act of dying, but also involves a psychological and spiritual response. And facing one's mortality can result in existential issues, as discussed in Chapter 5. From many spiritual perspectives—and what is increasingly being understood within the discipline of palliative care—is that physical death is not "the end," but rather a transition.

Within this chapter, we examine myths and issues that surround the dying and death of aging adults, both for the aging individuals themselves, as well as for their family members. As we look at these issues, we weave into these discussions what the work of nurses and other professionals involves in assisting dying older adults, as well as their family members. Finally, we raise ethical issues in relation to dying, older individuals.

We suggest that Chapters 5 and 6 be read in tandem, as many of the concepts appear in both. As well, examples from Chapter 5 will be referred to in Chapter 6, further examining these examples using concepts from the latter chapter. Of significant difference, Chapter 6 will focus upon the *vulnerability* of the dying older

adult, with care and interventions tailored specifically to uphold dignity and personhood in this circumstance.

Before we delve into the content of the chapter, a foundational concept needs to be explicated. In dealing with dying of any individual across the lifespan, the terms *palliative care* or *hospice* come up. Canadian Virtual Hospice (2011) defined palliative care as:

> a type of health care for patients and families facing life-threatening illness. (It) helps patients to achieve the best possible quality of life right up until the end of life. Palliative care is also called end-of-life, or comfort care.

Further, palliative care focuses on the concerns of the patient: physical symptoms and the emotional and spiritual concerns of the patient and family. Its goal is to maintain and uphold dignity; it seeks to honor the religious and cultural practices of the patients; and after the patient passes, the family receives bereavement support (Canadian Virtual Hospice, 2011).

This definition of *palliative care* also contains the concept of *hospice* within it; hospice care being understood to focus on end-of-life, with a time frame attached to it. A number of sources differentiate between the two concepts, stating that palliative care focuses on the reduction of physical symptoms (such as pain, nausea or constipation), which can occur at any time during a serious illness, while hospice care encompasses this and the psychosocial and spiritual supports, as well as reflecting that these are provided at the very end of life (for example, Buchanan, Choi, Wang, & Ju, 2004). However, the terms *hospice*, *palliative care,* and *end-of-life care* tend to be used interchangeably in common usage, as the definition from Canadian Virtual Hospice suggests, and so will be here.

The definition from Canadian Virtual Hospice describes the breadth of hospice palliative care; however, it does not capture its heart. Here, Dorothy Ley provides us with that dimension:

> Palliative care is about living and the meaning of life. It's about loss and grief and joy. It's about caring and sharing. It's about tears and laughter. . . . They are very powerful words when acted upon. . . . Palliative care is about life, not death. (Ley & van Bommel, 1994, p. 30)

MYTHS ABOUT DYING IN ADVANCING YEARS

There are myths that surround death and dying in older individuals. These myths are taken up in everyday conversation about the final transition in life and

impact how individuals view and respond to death in the aged. In the following discussion, we attempt to debunk these myths.

Dying and Death Are Not as Difficult for Older Adults as They Are for Younger Individuals

Death and dying are difficult for many people, irrespective of age. It is true that some older adults want to die, perhaps due to significant illness or pain as well as having lost close friends and family members. Others, however, do not. They may not feel ready, still enjoying life. Others may fear the unknown; the mysteries surrounding dying, as well as what will happen after death, may still trouble and even haunt some older adults, despite having had many years to wrestle with such concerns (Sourkes, 1987). Family members and healthcare professionals may unwittingly assume that the dying process is easier for their older patients (Sidell, Samson Katz, & Komaromy, 2000) and thus fail to provide the level of attention to psychological and spiritual issues that they might for younger patients.

I (MBR) had a number of delightful interactions with a terminally ill gentleman. He was well into his 90s and was now bedridden. "I just don't understand it," he said in reference to being confined to bed. "Just a year ago I was golfing." I responded with a comment about his age and having done so well for so long. "Yes, I know that," he replied, "but I just don't understand it!" As I reflected upon this particular interaction, it became clear to me that his "lack of understanding" was really an existential statement about still feeling young inside and, hence, the surprise at being physically limited. This realization shifted the focus of the conversations from that which was more corporeal (issues of the body) to that which was more spiritual (issues of the heart).

The same grandmother of my spouse (Brian), who was referred to in Chapter 5, said on numerous occasions to my husband, "On the inside, I'm not old; I'm still the same me I've always been." A lovely statement of personhood! A very active woman, she had once enjoyed swimming in the Georgian Bay. Visiting at "the cottage" (she was now in her 90s and a resident in a nursing home), she said to my husband on a sweltering August day, "What I wouldn't give to feel the coolness of the bay!" Brian took her hand and walked her down to the water; she took her shoes off and being supported by her grandson, dipped her hands and feet in, enjoying the sensation of cold water on her warm skin. Unexpectedly, to my husband as well as his siblings on the shore, she plunged in for a brief swim! She spent the next couple of hours in borrowed clothes in the cottage, as her own clothes were being dried; but this experience of swimming was, she said, totally worth it!

In both of these examples, there were no significant existential issues and no fear in getting very old and facing into death; there was simply incredulity in both of these very elderly people; they could not quite believe they were at the end of their lives. For older adults who have lived life fully, in their spirits they may still

be young ("young at heart"); and so being very old, with its limitations, may seem like a surprise or even an offense.

Chapter 5 provided a number of examples of older adults with existential issues surrounding age and dying. These issues can be profound. Older adults can and do find peace in dealing with these concerns, and they seem to become uniquely sensitive to spiritual matters as they age (Meraviglia, Sutter, & Gaskamp, 2008). One man said that his palliative experience caused him "to come alive spiritually." That growth came as a result of his spiritual pain in dying, and his willingness to reach out for and receive help. He died peacefully.

But not all older adults leave this life placidly. Dylan Thomas' famous poem "Do Not Go Gentle into that Good Night" contains the following lines:

> Do not go gentle into that good night.
> Old age should burn and rave at close of day;
> Rage, rage against the dying of the light.
> (Thomas, 1953, p. 122)

Although the night is "good"—perhaps Thomas is inferring an afterlife—one is encouraged to fight death. And many people do. It would seem that we are "wired" for life, and a person does not simply turn off the "switch for living" as she would turn off a light. That same strength of spirit that kept this woman going through difficulties in life can keep the dying older adult alive—sometimes longer than she herself would wish! Even when an individual has done her existential work, the goodbyes have been said, and practical affairs are in order, it can still take some time for the passage to happen. This can be very distressing to family members. But discussion with them generally reveals that their loved one was a strong, independent person who tended to live life on his or her own terms. "Each person dies in his or her own way" (Halifax, 2009, p. 65).

Older Adults Experience Less Pain

Perhaps because aging individuals do not often complain to healthcare professionals about pain, or because some conditions preclude the voicing of pain to others (e.g., aphasia related to strokes or dementia), it is sometimes assumed that older adults experience less pain in dying than their younger counterparts. This is not true; older adults can experience just as much pain as younger individuals in the dying process. Sheehan and Schirm (2003) spoke of an attitude within healthcare that pain is just a part of growing old. Healthcare professionals may respond less vigorously to complaints. Also, many elderly people hold the same opinion, and so may not voice their discomfort; they also may be concerned about worrying their adult children, or that voicing persistent pain may precipitate a change in living arrangements (from home to a continuing care facility, for example), thereby resulting in a loss of independence (Sheehan & Schirm, 2003).

Sheehan and Schirm (2003) recommended a more comprehensive approach to assessing pain in an older adult who is dying. They suggested such pain assessments as the Minimum Data Set (MDS) Pain-assessment Scale that involves direct questions from the assessor (the nurse, generally), as well as trained observation. Using this pain assessment scale, Won and colleagues (2004) assessed the older adults in nursing homes in 10 American states for persistent pain. They concluded that pain was identified in 49 percent of the residents; the residents were age 83 years on average, with most of these older adults being female.

Although this study was not specifically palliative in nature, many elderly people die in nursing homes. Sheehan and Schirm (2003) reported that currently about 25 percent of deaths of older adults occur in nursing homes in the United States. Given that the lengths of hospital stays are decreasing, it is estimated that by 2020, about half of the deaths of older adults in the US will occur in nursing homes (Last Acts, 2002).

There are unique challenges when a person is unable to express her pain accurately, due to dementia or other physiological conditions. There are a number of assessment tools that professionals can use to determine pain levels, such as the Numeric Rating Scale (NRS), the Verbal Descriptor Scale (VDS),[1] the Faces Pain Scale—Revised (FPS-R), Pain Assessment in Advanced Dementia (PAINAD) and the Pain Assessment Checklist for Senior Adults with Limited Ability to Communicate (PACSLAC).[2]

Ersek and Polomano (2011) recommended the following in assessing pain in older adults, including those who are dying. First, older adults *deserve* effective pain assessment and control. Sometimes, the most difficult person to convince of this fact is the dying person himself! (One dying man in a palliative setting continually refused pain medications. He used the "tough guy" approach, but as his cancer pain increased, he became increasingly agitated in his mood and behaviors. As staff got to know him, it became apparent that he felt he did not deserve good pain management. Dealing with issues of shame psychosocially and spiritually aided him in receiving the analgesics that he so obviously needed. The soul work also may have lessened some of his physical pain).

Second, counseled Ersek and Palomano (2011), what the patient *says* about her pain should take precedence over other indicators. Pain thresholds are different from person to person; pain is subjective. Individuals who have experienced chronic pain may be more sensitive to it—in their living and in their dying. Pain assessment tools, including observation for physiological and behavioral indicators of pain, must only replace the patient's verbal report if the dying individual is not able to communicate herself.

---

[1] The Iowa Pain Thermometer is a more recent adaptation of the VDS and is considered to be an effective scale for rating pain in the young and old cognitively impaired population. See Herr, Spratt, Garand, and Li (2007).

[2] For information on all of these tools, see www.geriatricpain.org.

A number of the pain assessment tools mentioned previously recommend the family's knowledge of their dying adult as a resource for assessing pain. We would like to stress that here. Healthcare providers can be limited in pain assessment, particularly if the older adult is cognitively impaired or unable to communicate, due to lack of experience with and historical knowledge of that individual. For instance, hospital stays can be short, and nurses may not care for a patient more than once or twice. The family who has been caregiving for their loved one has the inside track.

In one example of this guideline, a delightful very elderly woman was in a residential hospice. In her late 90s, she presented with humor and spunk. Her dementia did not seem really pronounced on first glance; she sat in her chair with her newspaper daily. (Over time the extent of the dementia became clearer; she did not really read and forgot whether she had seen the paper that day). To questions of pain she would respond, "Oh, no!" She came from a very professional family; her father had been a doctor, her husband had been a doctor, and an adult daughter and grandson were doctors also! It was her daughter who initially tipped the nurses off that her mom would routinely say, "no" to questions of pain. This loving daughter encouraged staff to look deeper than the verbal response. They knew her better than anyone![3]

The Death of Older Adults Should Not Be Too Hard on Adult Family Members

It is commonly assumed that the death of aging relatives, while sad, should not be too upsetting for adult family. After all, it is reasoned, death is to be expected in older adults and they have lived their lives. It is not unusual for adult children to be asked the age of a parent when it is known that the parent is dying or has passed away. If the grieving adult children admit that the parent is over 80 years of age, the response is often something like, "Well, she had a long life," or "At least his suffering is over." While these comments are well intended, they often speak more about the discomfort of those who offer the comments, than the actual impact of the death of a parent upon the adult child (ren).

Adult children can sometimes express surprise in their own responses to a parent's (impending) death. They may express disbelief. One man was speaking about the imminent death of his elderly father. He expressed disbelief that his father's life was ending. "I'm a science kind of guy, and it should be possible for people to live well into their hundreds," he said. When the healthcare provider sought to touch upon the emotional aspects of his impending loss, he rebuffed her: "It's just wrong that he should die; there should be still lots of years left." He was

[3] Of course, caution is in order here. Sometimes family members, in their anxiety, are not accurate in their assessment of their loved one's pain levels. However, they can give healthcare providers clues about what to look for.

not comfortable in dealing with the existential issues of death and his emotional response. Rather, he chose to speak about the impending death "scientifically" as a way to vent his distress.

And sometimes adult children are surprised (and ashamed) of the depth of their emotions in response to an elderly parent's death. "I should be handling this better," is sometimes expressed with tears. This may reflect an acceptance of the societal myth that the death of an older adult—specifically a parent—should not be too hard on adult family members. To this, McDaniel and Clark stated, "No human being can know how he or she will feel when a parent dies" (2009, p. 45).

Healthcare professionals are not immune to buying into this myth. They may assume that family members will be able to accept the passing more easily; after all, their loved one "was old!" I (MBR) remember being called in on a sunny Saturday afternoon to provide support for the family of a woman who was well into her 90s and had passed. My own thoughts, as I shifted from gardener (I was pruning shrubs) to chaplain, was "Oh, this shouldn't be too difficult," as the nurse who paged me had let me know that the deceased woman was very elderly. I arrived unprepared for the level of grief I found in the room. An adult granddaughter was distraught; her grandma had raised her and was closer to her than anyone else in her life. And an older sister (who was nearing 100 years of age) cried, as her wheelchair was pushed into the room, "Why wasn't it me?! I'm older. Now there is no one left but me!" It was truly humbling for me—at that time I was a relatively new palliative care chaplain. I believe that I brought the requisite clinical skills to the situation, but my ability to provide the ministry of presence was not there. I was caught off guard, unprepared to tread on this very sacred ground with my shoes off!

When the Relationship is Close

Even if the death of an aging parent is expected, it still can result in a significant grief reaction in family members. One factor in grief is the depth of the relationship; the closer the connection, the greater the grief (Rando, 1984). The assumption that family is prepared for the death of an older loved one, simply because their loved one is older, is fallacious. Preparation is vital and support is invaluable.

In one instance, a very elderly man came into the hospital for palliative care. His daughter, who had worked as an aide in a nursing home for decades, could not accept that her father was dying. (This was a surprise to a number of staff members, who assumed that her professional experience would provide some preparation for the challenges of her personal life; but witnessing others' deaths did not prepare her to come to grips with her own father's imminent passing). As the trust relationship was established and deepened, she revealed that she did not believe in an afterlife and could not bear to "lose" her dad. Cremation was the plan, so it was suggested to her that she purchase a locket, in which she could keep a few of

her father's cremains. Wearing this locket on a chain would keep her dad "close to her heart." This seemed to resonate with this adult daughter and she did just that. In that act she could carry some of her father with her in her daily life and derive comfort from his presence.

When the Relationship is Conflicted

As will be discussed in Chapter 7, traumatic or conflicted issues of the past may be dredged up through the process of caring for the dying parent; this, too, makes the death of a parent difficult. Being present to the dying parent is painful, not simply because of the imminent death; it is also painful because of past wounds/experiences that the contact brings up.

Here, the adult children experience anticipatory grief as well as conflicted grief. They know the death is coming, and they experience the anticipated loss. The grief is conflicted, because while this individual was a parent that they were connected with (and have likely loved), the complicating factors (abuse in the past, neglect or indifference, unresolved conflicts, or other serious issues) make the situation even more painful. Adult children often feel the need to speak of past experiences to health professionals and need to be heard. Even if they have had counseling to deal with the past, they are now experiencing those issues in another way. This parent who once abused or neglected them is now vulnerable, and they are, perhaps, in a position of "power" for the first time in their lives (the adult children are now the ones possessing the health and youth). There is a notable shift in the dynamics of the relationship. (However, it should be noted that although dying older adults are vulnerable, some still wield power over their children on their deathbed).

It is essential that healthcare professionals provide a safe place for these adult children to work through their grief *as it is,* rather than what the nurse, doctor, social worker, or chaplain feels it should be. Old experiences are reprocessed in the new reality (the impending death of the parent). Here it is very helpful to have an interprofessional approach, with a referral to a social worker or chaplain, to provide that place for the grief work (regarding both anticipatory and conflicted grief) to happen.

It is often a time when some significant internal growth can happen in the adult children. In one case, two adult daughters, of their own accord, confronted their dying father regarding abuse from the past. While this was initially frightening, it turned out to be empowering for them. Although they felt that the apology for the past abuse was "weak," they saw their father through new eyes. He was no longer the terrifying figure who abused them; he was now vulnerable and, in some ways, pitiful. The tasks of the social worker and chaplain in this situation were to listen, to validate, to help the adult children sort through the complex strands of their grief, as well as to provide them with the support they needed to do what *they* felt they needed to do. It is vital to point out that, as professionals, we cannot tell

people who have been victimized what they should do or how they should feel, in such situations. We can help them sift through and bring some understanding to their conflicted emotions, but they must make their own choices, as they bear the consequences of them.

Existentially Speaking

Not only do adult children grieve the loss of an aging parent and recognize that their life histories, up to this point in time, have been ensconced within their parents' lives, but the death of one, and particularly both parents, signal that they themselves are entering a later phase of their own lives. Adult children may talk about the stark realization that they will die next, barring some unfortunate twist of fate that younger family members die before them. The growing recognition that they are aging and that death is not as far away as once thought can be unsettling and unnerving for some individuals. Existential questions, such as "Have I done what I've wanted to do with my in life?" may be triggered (Milligan, 2011). And, a very real sense of alonenesss may be experienced; these adult children may exclaim, "I'm an orphan now!" (McDaniel & Clark, 2009).

Whatever individuals' lives have entailed, their past history and a significant part of who they are has been intertwined with the lives of their parents. As so aptly stated by Maya Angelou, "I've learned that regardless of your relationship with your parents, you'll miss them when they're gone from your life" (Good Reads, 2013). We recognize that not all readers will agree with this statement; nevertheless, it is poignant. Parents have played a significant role in their children's lives; for acquaintances or professionals to assume that the loss is not significant because the parent was older, is doing a disservice to grieving adult children or family members.

In order for nurses and other professionals to appropriately and effectively assist older adults and their family members through the final transition of life, it is important that they are apprised of the issues experienced in dying. Dying is challenging for aged adults as well as for their adult children (and grandchildren), and age does not prevent pain in the dying process. Dying is also a formidable process for those who work with them. "Live to the point of tears," said Albert Camus (Thinkexist.com, 2013); in working with the dying, all involved experience life to this degree—to the point of tears.

ISSUES RELATED TO DYING FOR OLDER ADULTS

There are physical issues related to dying, as well as spiritual ones. Many of the issues related to dying are the same as the existential issues explicated in Chapter 5. However, the existential issues are often magnified in dying, as there is finality in the experience, as well as a limited time frame in which to deal with them. The

need to deal with the existential issues of dying is central to personhood; one's sense of mortality may have been avoided over the course of the lifespan, but when dying, an individual has little choice. Palgi and Abramovitch (1984) stated, "Death awareness is a natural sequel to self-awareness—an intrinsic attribute of humankind" (p. 385).

Next within this chapter, we will look at "the" major physical (and psychological) concern that older adults have in dying: pain. We also will look at the existential issues in the light of impending death: loss of control, aloneness, meaning in life and in death, and relationship with self and others. Additionally, we explore a common term in palliative care: a *good death*. Is this possible? What is a good death? We will also look at the impact of dementia upon the dying process.

Pain

Earlier in the chapter we discussed the prevalence of pain in the elderly. We also looked at their reticence to speak of it and sometimes healthcare providers' reluctance to treat it assertively. It is now possible with palliative medications to effectively deal with pain.

As was mentioned in Chapter 5, some believe that pain can *always* able to be managed. Byock (1997), for example, believes this is possible and looks toward the day when this will be a reality. Dealing with pain effectively is a distinguishing strength of hospice and palliative care. And pain in end-of-life care can be complex; families caring for loved ones at home, staff on acute care units within hospitals, and nursing home staff often do not feel equipped to handle it.

When a terminally ill older adult experiences pain, she likely already has a number of co-existing medical conditions; she may also have allergies and sensitivities to certain standard pain medications (such as codeine). The number of medications she is taking can be dizzying (to her and her healthcare providers!). Compounding the difficulties, these pharmaceuticals may be interacting with each other. Herbal remedies, unknown to her family doctor, may also be a part of her health repertoire, as well as over-the-counter medications, and these may be interacting with the prescribed medications. Other factors, such as being bedridden, may be contributing to her pain. As well, she may have a number of complex psychosocial and spiritual burdens that contribute to her overall malaise.

So in a palliative setting, professional caregivers are educated and experienced in dealing with the whole person. A medication review will take place; some medications may be removed from her list; others, specific to palliative care, may be added. A patient's goals of care will be delineated. Pain control is generally a part of a patient's goals. In a palliative situation, health professionals will not worry about opioid addiction as they would in other situations (Sheehan & Schirm, 2003). This type of specialized medical and nursing care will be provided around the clock. Studies show that pain management is better for those in hospice programs

than for those who are not (Buchanan et al., 2004; Last Acts, 2002; Miller, Mor, Wu, Gonzalo, & Lapane, 2002[4]).

In the palliative care construct, psychosocial and spiritual supports will also be put into place, using social work, chaplains, and volunteers. Family members will also be supported. In this type of setting, pain is generally managed very well. Quality of life is maintained and even enhanced. Patients and family members work together and grow in the process.

However, does this mean that pain is nonexistent? For a variety of reasons, involving the patient, the setting, the circumstances of the pain, and the expertise of the staff in the healthcare setting, truly, it does not (Buchanan et al., 2004). A terminally ill man may come into a palliative setting with pain issues that take some time to sort through. Or a medication may come to the end of its effectiveness. Or, new pain may develop as cancer spreads. It is erroneous to assume that because there *are* effective pain medications available that a person will *never* experience pain. This is stated bluntly here because sometimes patients and their families come into a palliative care setting with this idea firmly entrenched; then, if pain is experienced, they feel let down and sometimes become angry at the healthcare providers.

And not everyone receives the benefits of palliative care. Within Canada and the United States, the nature of and the benefits of palliative care, either through home care services, hospice care within a nursing home, or within residential hospices, are being increasingly understood. It would be ideal if everyone *who wanted to* experience this care could. However, healthcare realities at this time do not make this possible; sometimes, there are not open beds within a hospice facility and so older adults cannot be transferred. Unfortunately, then, effective pain control does not always occur.

It also happens sometimes that a person will pass away quickly from a catastrophic event, such as a pulmonary embolism, unrelated to his terminal condition.[5] Medication can help to ease the suffering if an embolus occurs. However, the event may happen so quickly that nursing staff are not able to get that medication to the individual to ameliorate the suffering. In this case, the individual may pass in distress, and this is very distressing to family members! Some of the challenges of this will be discussed further on in this chapter.

---

[4] The last two articles in this list involved comparing those *within* nursing homes who receive hospice care (coming in to the continuing care facility) and those who do not. Future trends in Canada and the United States will be discussed further in Chapter 8.

[5] In palliative care, the focus is on quality of life, rather than on prolonging life. So a dying person who is bedridden may develop a blood clot from lying down all the time; this is not directly related to the condition that is making him terminally ill. In a palliative setting, a patient often does not want medications such as blood thinners, as his focus is not on the prolonging of life, but rather on the quality of the remaining days. Due to blood stasis in the deep veins, a clot may develop and travel to his lungs (a pulmonary embolism) and death may result sooner than anticipated.

Occasionally, a terminally ill person will ask to "be put out of (my) misery." Or, a family member will say, "If this were our dog, we'd have had her put down!" These expressions of distress can involve physical pain and often existential pain, as well. From a palliative care perspective, the physical pain is generally resolved through adjusting medications and/or dosages. However, the cries are more than physical; they are existential, revealing a sense of suffering without meaning (Frankl, 2006). From psychosocial and spiritual perspectives, social workers, chaplains, and nurses come alongside these suffering individuals and their family members (who are suffering too [Georgesen & Dungan, 1996]) to provide support and assist with meaning. Many important things, such as relationship restoration and the blessing of family members, happen in a person's final weeks or days. And the healing impact of relationship restoration or blessings from the dying person to family members cannot be emphasized enough; such end-of-life work is enormously helpful for family members in their grieving when the older adult passes away.

One woman came into a palliative care setting "just done." She had had enough, she stated, and hoped that the end came sooner, rather than later. Through the care of the interprofessional staff, and the support of her family, she gained a new lease on life. Her days were meaningful and her interactions rich. "I hope God gives me many more days!" she stated as I (MBR) was offered cake at a little party in her room. The value of this time for her and for her family cannot be overstated: Bonds were deepened, the things that needed to be said were, she prepared herself emotionally and spiritually for her own passing and the family became better prepared to handle her death after demise.

To complete this section on pain, there is in some of the literature a distinction between "pain" and "suffering" (Halifax, 2009). An individual can be in *pain*, but not be *suffering*. Physical pain is distinguished from the existential messages about the pain (the suffering) that overtake us—as Halifax said, the "story" surrounding the pain. She quoted the Buddha:

> When touched by . . . pain, the ordinary, uninstructed person sorrows, . . . becomes distraught. So he feels two pains, physical and mental, just as if he was shot with an arrow, and, right afterward, was shot with another one, so that he felt the pain of two arrows. (Halifax, 2009, p, 72)

Halifax's point is poignant. She was not minimizing physical pain, but rather encouraging those experiencing it not to interpret it as we so often do in North America—as something that is an aberration! Dr. Paul Brand, a Christian surgeon who worked for decades in India on the hands and feet of those ravaged by leprosy, echoed the same concerns about western society. Brand (Yancey &

Brand, 1997) stated that we need to "master pain, before it masters us." How an individual views her physical pain is a key factor in how she deals with it and experiences life.

Need to Have Control in the Dying Process

For many dying individuals, including older adults, maintaining meaningful control of their lives, in their dying, is vital. Decision making is foundational in personhood (Hirst, Lane, & Reed, 2013), and hence is essential in an older adult's experience of the dying process.

Sourkes (1987) enumerated the losses of control that a dying individual faces: over his body, disease and pain, emotional boundaries, and life itself. For many, loss of control over bodily functions is deeply distressing. When needing incontinence products, they may exclaim, "I started life this way, and now I guess I'll be finishing it this way too!" This is not only an expression of concern regarding the need to address incontinence, but is an existential expression of sorrow. Other existential statements concerning loss of other forms of control—and perhaps, diminishment of the person one once knew—could be: "I didn't used to look this way, you know," and "It seems like I cry so easily right now!"

Besides the loss of control that terminally ill people face because of disease and/or effects of medication, Sourkes (1987) and others (see Goffman, 1961) spoke of the loss of control (and hence personhood) in institutionalized settings, such as a hospital. An example comes to mind. When I (AML) was a fairly new graduate nurse, I worked on a medical/oncology unit. I cared for a man dying of stomach cancer. The man was in hospital receiving a particular form of nutrition through intravenous tubing (called TPN or total parenteral nutrition). This fluid was very thick, sugary, and sticky (if some landed on the floor). This man was very particular about needing his square pad placed near his pillow, with his spit basin placed in a specific position, as well as his square box of tissues arranged just right. Being young and not knowledgeable about his need for control in his dying process, I was sloppy about how I arranged his basin and tissues, as well as in spilling TPN fluid when changing the intravenous bag. He would become very annoyed as a small amount would land on the floor. By the end of four 12 shifts, I was frustrated and frazzled by his attempts to control his environment. Being much older now, and also being aware of the importance for human beings to have some semblance of control in their lives, particularly in the dying process, I truly regret not being more attentive to his need for control. I also recognize, however, that my inability to give him more control was also related to the environment—a busy hospital unit. Even if I had been more knowledgeable and aware of the significance of facilitating control on his part, the busyness of the unit would preclude my attempts, at least to some degree, to allow him more control. As is being highlighted in this chapter, palliative care seeks to restore that sense

of personhood, of dignity, and of control by providing the environment within which individuals can make meaningful decisions surrounding their own bodies, their care, and their lives.

Sourkes (1987) spoke of the need for a dying person to have emotional flexibility—letting go of control and taking it back—in order to negotiate the path of dying. This resonates with us. The elderly adult, in the interest of total control, who will not allow others within her space tends not to benefit from the very activities that could enhance her personhood: visits from significant others, the massage of a nurse, and meaningful conversations with professionals. If she retains no control (the other extreme), her room may be overrun with visitors, or she may not make her wishes known. Healthy control is the balance, and, in terminal illness, this balance is not easily achieved.

The threads of loss of control are many and are often interwoven. For instance, the dynamic between the individual and his medications and the wishes of the family and the dying older adult with respect to those medications, can be complicated. For instance, a family may strongly desire their loved one to be "more awake," hence discouraging the older gentleman from taking medications that could alleviate pain (but might also lead to drowsiness). Sometimes the dying older adult wishes to be more alert, but his family struggles emotionally with his pain.

Besides the effects of the particular medications upon the patient, the power structure within the family may be revealed and challenged. A healthy sense of personhood in the dying adult is so vital. If he has capacity, his wishes, in consultation with medical staff (and in accordance with the law), are followed. However, sometimes the elderly dying individual does not have a sufficient sense of self to insist upon what he desires; this is generally a part of a lifelong pattern of giving in to the wishes of others. Hence, whatever control he had in life is further jeopardized in his dying process.

Aloneness

The older adult who is dying may feel very alone. This may involve a lack of visitors to her nursing home room or to her social isolation from being confined to her home. But there is different "aloneness" that some people who are dying feel keenly: This is an existential aloneness. Caregivers can only journey so far with their loved ones and their patients. In conversation with these individuals, they sometimes remind this chaplain (MBR) that while they appreciate the company, they "cross over" on their own. How true this is.

Sourkes (1987) used the term "the deepening shade" to describe the impact of a terminal illness upon the psyche, and he spoke of the aloneness that dying people feel. As already discussed, they fear a loss of control; they also fear the loss of identity and the loss of relationships (the separation from loved ones at death). Briefly stated, the loss of identity involves losing the person as she once was. This

can involve physical changes, due to disease and medication. One woman said of her elderly mother, before cancer literally ate her face away, "I wished you had known her as she was; she was beautiful!" Interestingly, however, in this dying woman's gracious response to her disease, her willingness to accept new people into her life and her resilience, I (MBR) found her to be very beautiful!

Loss of identity can also entail the cessation of activities (such as work or defining hobbies) that an individual once performed. The very elderly have more time to deal with those losses, so this loss may not be as pronounced. For men, however, their sense of personhood is often attached to what they have *done,* thus in their dying they look back longingly at the past with their instrumental role in this world. And they feel alone in their current reality. With a greater proportion of women now in the workforce than during the 1960s and 1970s, we suggest that this loss of identity may become more pronounced for aging women in the coming decades.

In the deepening shade, an older adult may fear the loss of relationship—she may fear losing her loved ones—certainly in the short term and perhaps in the long haul. For those who do not believe in an afterlife, the impending loss of relationship may propel them to do some rethinking and research on this topic. One gentleman, who had been raised within a major faith tradition but set it aside during his lifetime, picked up threads of it again in his dying. Of prime importance to him was being able to see his loved ones again in the afterlife. For him, the exact parameters of the afterlife were not defined; it was enough to know (for him) that there *is* one (he appreciated some stories about deathbed phenomena/near death experiences), and he wanted to prepare himself for that. Always a man of great integrity, he said, "You don't think it's duplicitous of me to now, in my dying, come back to faith, do you?" Of course, I (MBR) responded that it was part of his integrity that he reconnected to that which had previously been meaningful to him.

Existential aloneness and its "solution" was expressed so well by family therapist Kathy Weingarten (1999), who herself has faced into death more than once. In the following, she spoke of the need for connection, and then the reality that at some point in her dying, she will not have it. She wondered how she will fare.

> For me, connection remains the answer. I value connection, although I know that I will not always have it. Stretching to face the inevitability of my death, not just once but recurringly, forced a relationship to aloneness. Tending to this relationship is part of my spiritual practice. (p. 249)

The dying older adult may actually have an advantage over his younger terminally ill counterpart in that he has had years to tend to this aloneness through introspection, prayer, and solitude. But not all adults have worked with their existential

aloneness. Wilma, discussed in Chapter 5, could only bear her aloneness in the reassuring presence of others. In her dying, she needed the physical and psychological presence of others to bring her security.

Integration of Life Experiences

The need for integration of life experiences has been discussed at length in Chapter 5. In dying, the need is greater for many, and the time frame in which to complete the work is more compact. Older dying adults may do this work through asking adult children to write down for them their family history. Others will compose their own obituary, having their children act as scribes. Some will plan their own funerals, calling in people to ask of them special requests. Tara, a teacher for many years, asked a number of individuals to represent her at her funeral service. One old family friend was asked to speak of Tara when she was a girl and discuss her life into her growing up years. Another was asked to speak of Tara's work professionally; yet another of Tara in her later years. In this way, she integrated life experiences within her soul by reflecting back on her life, "commissioning" other to tell her story, and setting the scene for her life history to be viewed at her funeral. The eulogies and the video tribute honored this well-deserving woman.

There is, today, a tendency to forego a formal service to remember one's life. This may be, in part, a reflection of the secularization of North America (particularly Canada); it also may reflect our discomfort with death (Rando, 1984). We would like to suggest that the ritual of having some kind of formal remembrance is very important. The ritual need not be religious. And it gives the dying elderly person a chance to reflect upon her life by being involved in the planning; it also provides those who grieve the opportunity to *celebrate* her. The work of integration is hers, but it also belongs to her loved ones.

Sometimes family members say of a dying relative, "Jim does not want a formal service." On the surface, this would seem noble to honor the loved one's request. However, not having a formal remembrance can impact the grieving process for family members, as will be discussed later in the chapter. Perhaps it also reveals an inability of the dying older adult to come to *integrity* (as discussed in Chapter 5), being trapped in *despair* (Erikson, 1982; Thomas & Cohen, 2006). A frank discussion with the dying older adult and his family members can often result in a compromise, balancing the dying person's desire and the grieving family's needs. Sometimes, the reason behind not wanting a service or ritual can open up a valuable opportunity to speak of unresolved aspects of a dying person's life and can lead to some further integration.

For instance, in one case an elderly gentleman in a hospice said that he did not want a service after his passing. "I don't think that anything good will be said of me!" In this situation, there had been profound family issues; there was some restitution and reconnection in the latter part of his life, but he feared that he would

be remembered for "the bad years." His family felt the need to have some kind of formal remembrance. This issue was, at the request of the family, addressed by the chaplain; the dying man spoke of his fears but also his willingness to speak with his children about their desire. The two adult children approached their father with their hope: to have a small private family gathering in the hospice's chapel, led by the chaplain that this gentleman had come to trust. Some details were discussed, and this older adult added his suggestions. A quiet candlelighting service was held for his immediate family (about 10 present); several of his favorite poems and prayers were read. His two adult children gave tributes, acknowledging the struggle but also the victories of this man and his family. And, at his insistence, the family went out for a nice supper at a favorite restaurant afterwards, at his expense. The service and the dinner served to bring some measure of closure and hope in this man's passing.

Meaning in Life and Death

Chapter 5 spoke about the need for meaning in life, in every stage, and the challenges for older adults as transitions lead to significant changes in their lives. These changes can lead to great wrestling with how to attain meaning and purpose (Erikson, Erikson, & Kivnick, 1986; Walsh, 2009).

The terminally ill older adult may approach this transition with a sense of immediacy, needing to make each moment count (Hantman & Cohen, 2010). This is seen often in legacy work, in celebrating, in a big way, last experiences (such as having the house decorated from top to bottom to celebrate Christmas, one last time). Within palliative settings, terminally ill persons may have the birthdays celebrated early. Anticipated weddings within the family may be expedited, so that Grandma can be there. This reveals the urgent need to find meaning in what time is left in life.

These older adults sometimes seek to attach meaning to their deaths. One significant way is organ donation. Depending upon the diagnosis, and the age of the older adult, her eyes and perhaps other organs may be harvested to bring "life" to others. Sometimes older individuals desire to donate their bodies to science that others may learn from them.[6] Monetary donations from the terminally ill person while still alive and then again in the will are other ways that people seek to bring meaning to their passings. It cannot be overstated here that in the case of donation of organs or funds, strict ethical practices and procedures must be adhered to. The dying older adult is very vulnerable, and he can be exploited by others. Healthcare

[6] It is vital that an individual and their family are informed in their donating. From time to time individuals think that donating their body to science may lead to the cure for a disease, when, in fact, the donated body is used for students learning to do dissections. Social workers in hospitals and palliative settings can walk individuals and families through the process, ensuring this understanding and consent.

in the western world has firm codes of conduct for healthcare workers and the institutions themselves in this area.

For some older adults, final days and death are deemed to be meaningless; the experience is one of despair, rather than integrity (Erikson, 1982; Thomas & Cohen, 2006). Hence, a dying older adult in this position may emotionally and spiritually withdraw (Georgesen & Dungan, 2005), not wishing to connect with others, self and/or God. This is a profound form of existential distress. Presence, if the patient is willing, can be a gentle intervention; in this, nothing is asked of the dying older adult, but spiritual care may be felt by the empathic, humble caregiver, whether that individual is a family member or professional.

This condition can be temporary, with the palliative interprofessional approach ameliorating suffering, bringing about opportunity for further quality of life and opportunities for integrity (Erikson, 1982; Thomas & Cohen, 2006). Georgesen and Dungan (2005) told of a dying gentleman who had withdrawn in such an experience of existential despair. Medication for his depression, the work of a nurse clinician, spiritual counseling and the rites of his faith all contributed to his "return" to his family and his God. One last goal remained; this was a trip to see a family member out of state. Although the trip was not completed (he could only make it part way due to physical deterioration), the family member they had planned to see was able to meet them part way. As a family they returned home, within several hours, the patient passed, having completed his final desire.

Forgiveness at the End of Life

The meaning and need for forgiveness has been discussed in Chapter 5. The struggles of forgiving, and the benefits thereof, were discussed. Forgiveness is often a theme in religion. The Dalai Lama said, "All major religious traditions carry basically the same message that is love, compassion and forgiveness; the important thing is they should be part of our daily lives" (Brainy Quotes, 2013). In addition, however, forgiveness is at times larger than a few individuals, encompassing sociological and political concerns, as illustrated by the lives and work of people like Mahatma Gandhi and Nelson Mandela. South African Bishop Desmond Tutu, speaking politically as well as theologically, said, "Without forgiveness, there is no future" (Brainy Quotes, 2013). And forgiveness is deeply personal issue. A hospital psychiatrist, in seeking to encourage an estranged elderly parent into reuniting with his adult children, was verbally ousted out of the room with "Don't you *dare* talk to me about forgiveness!"

The discussion here in Chapter 6 about forgiveness will focus, gently, on the topic of the meaning of forgiveness for vulnerable people—those elderly adults who are dying. The need to forgive and be forgiven seems almost to be universal; it is inextricably tied to love. Thomas Fuller said, "He that cannot forgive others breaks the bridge over which he must pass himself; for every man has need to be

forgiven" (Brainy Quotes, 2013). Dying people, especially the elderly who have experienced so much of life, seem to know this instinctively. They also know, having been through the difficulties of life, that forgiveness is not always easily achieved.

General Principles on Forgiveness

As nurses and professionals, we must be very gentle in our approach to those in our care, those in need of forgiveness from God, others, or self. From this foundation of care, we offer the following suggestions.

Forgiveness is a key component to meaning in life, as personal relationships are intrinsic to a meaningful life (De Vogler & Ebersole, 1981; Hantman & Cohen, 2010). As discussed in Chapter 5, a key component of spiritual distress is disconnection from self, others and God (Heyse-Moore, 1996). These disconnections lead to profound pain; forgiveness, extended and received, brings completion to relationship (Byock, 1997). The healthcare provider can feel confident in this understanding. Sometimes patients with the greatest bravado are actually masking great pain, the suffering coming through disconnection. Within Chapter 5 we suggested that nurses and other healthcare professionals be open about speaking about such issues. In the context of a dying older adult sharing life experiences that have involved ruptured relationships, or if the dying individual demonstrates spiritual distress, it is appropriate for the professional caregiver, with a ministry of presence and valuing the patient, to gently raise the issue and to do so with a quiet confidence.

Providing the opportunity for the patient to speak, it is vital that the nurse listens much more than she speaks. This is often difficult for nurses, as they often feel that they need to give answers. However, this listening validates personhood (Hirst et al., 2013); it also allows the professional to discern deeper meaning, the themes of the patient's life, which she can draw out as pertinent.

Unconditional love both affirms personhood by demonstrating to the suffering individual that he is known for who he is and that he is loved (Satterly, 2001). Being accepted by others allows an individual to believe that he is accepted by God. This sense of being accepted and loved by others, translating (eventually) to a sense of being loved by self, others, and/or God (wherever the need lies), takes time. Initially, conversations surrounding deeper issues may not occur. It takes great courage for the older adult to expose her soul. By dignifying the dying older individual with sensitive care, the nurse or professional may demonstrate that unconditional love. Over time, as trust develops the older adult may open up. Interesting, nurses sometimes report that individuals with complex issues of disconnection often begin to open up to their caregivers during the night, in the dark, as a nurse is tending to them! In this way, perhaps, the dying older adult feels less exposed; the darkness of the night provides him with some protection to raise painful issues. Ultimately, the goal is that the dying individual can experience

unconditional love that strengthens him to forgive others, to forgive himself, and to perhaps receive forgiveness from God, if this is his need.[7]

It is in this safety of acceptance that dying individuals can pursue the reconnections that they feel they need. Upon their request, nurses may help facilitate this through connecting the dying older adult with family members or by sending a referral to the social worker or chaplain.

The dying individual often knows what he needs. I (MBR) was called in after hours to be with an individual in great spiritual distress. I asked him what he needed. "I need to reckon with the Savior," he replied. We sat together and I prayed with him. I was deeply moved by the pouring forth of his soul to reconnect with his God—the literal calling out in his weak voice, occurring upon the "amen" of my prayer. He sought and received the forgiveness he needed. This experience, for both of us, was holy ground.

Cautions

The stories of the lives of dying older adults are deeply layered and truly filled with mystery. Nurses, social workers, chaplains, and other healthcare professionals enter into their stories in the last chapter (sometimes on the last page of the final chapter). We do not understand all the whys and hows of their lives; and we cannot begin to know exactly what they need. (Ryan [2005], as well as Field and Cassel [1997], reported on how often healthcare providers make assumptions about what patients need, without really understanding). So as caregivers, we must enter their stories with care, with respect and with humility.

Myrla Seibold (2001) wrote a beautiful article about forgiveness from a Christian perspective. She cautioned against a quick-forgiveness approach toward those who have experienced deep wounding, stating that well-meaning people can re-victimize those who have known deep hurt. She encouraged narrative work—the telling of people's stories—and stated clearly that recounting one's experiences in life is not evidence of unforgiveness. And, akin to Satterly (2001), she spoke of forgiveness ultimately flowing out of love—love that is replenished in the life of the hurt individual by *safe* others. From that position of safety, the violated individual can do the forgiveness work he or she needs to do.

---

[7] The ability to give and receive unconditional love is rooted in our experience as children; conditional love and acceptance from family members (parents) and from God (through unforgiving religious teaching) negatively impacts our ability to give and receive unconditional love and acceptance ourselves (Satterly, 2001), and the ability to be simply ourselves in relationship is not established in our formative years (Ainsworth & Bowlby, 1991; Bowlby, 1999). According to our experience, major personality and family issues are generally not resolved in the weeks before a person's death. However, significant steps can be taken that can bring peace to the dying individual and her family. And if this individual never is able to complete all of that work, at least she has *received* that type of love in her dying. This is akin to the work of Mother Teresa of Calcutta, who gave the dying unconditional love and care as an antidote to individuals' suffering, knowing that there would never be any tangible payoff.

Although not written for dying older adults, the principles of Seibold's article apply. The role of the professional caregiver, in the life of a dying individual, is to be a source of that unconditional love to assist in providing the environment that the older adult needs. The caregiver must resist being invested in a result, or else she risks meeting her needs, rather than the patient's need.

Restoration of Relationship?

There is much confusion regarding what forgiveness means; many assume that it involves the restoration of relationship, no matter what has occurred in the past. However, a number of authors who addressed the need for forgiveness clarify that forgiveness does not necessarily mean the restoration of relationship. Smedes (1997) emphasized that a person can forgive without there being a restoration of relationship; the restoration of relationship takes two people and sometimes one of the parties is not interested. In the case of terminally ill older adults, there can be a great sense of urgency to repair broken relationships, but their families are not always interested. Here, Smedes' principle can be helpful. From a palliative perspective, the older adult can do his forgiveness work in preparation for death (asking for or extending forgiveness), and perhaps leave a letter for the adult child to receive later.

Enright (1996) cautioned that it may not always be safe to restore relationship. In situations where there has been significant violation, the offended individual may not feel emotionally safe to re-engage. The urgency of a parent's imminent passing and the common misunderstanding that forgiveness means restoration of relationship—imposed by others—can cause great psychological and emotional distress. An individual's wishes and boundaries must be respected by healthcare professionals.

I (AML) recall a situation of an elderly father in hospital. In earlier days, he had been abusive toward his children. His sensitive daughters could not visit. But they did what they could. They baked cookies, brought clothes and cigarettes, and left them at the nursing station in the hospital, to be given to their father. This was, in my mind, noble.

This caution regarding the restoration of relationship also applies to family members of the dying older adult. Adult children who have not been in relationship for years can be "thrown together" in a parent's dying. This causes enormous stress on all. A dying person may say, "I just want my children let the past go and to get along." A very human desire! Family members will often set aside differences for the sake of the situation at hand. But this does not mean that relationship can or should continue after the parent's death, especially if the relationship has involved violation.

The emphases of Enright (1996) and Smedes (1997) are that the requesting and extending of forgiveness is a deeply personal action; one can do their own soul work apart from the readiness of the other within the relationship. Forgiveness can, but not necessarily does, mean the restoration of relationship!

The "Good Death"

There is much in the literature of death about what constitutes a "good death" (Ryan, 2005). This goal is expressed in a number of ways: the "peaceful death" (Callahan, 1993), the "appropriate death" (Weisman, 1988), the "happy death" (Corless, 1994), and "dying well" (Byock, 1997). The literature reveals a discrepancy between what healthcare providers consider to be a good death and what patients perceive. Healthcare providers have tended to view pain and symptom management as key in deciding whether a death is good. Patients described a good death as "sudden death" or "dying in one's sleep" (Ryan, 2005; Vig, Davenport, & Pearlman, 2002). One commonality between healthcare providers and patients is that a "good death" is one in which pain is controlled (Vig et al., 2002).

This discrepancy of opinion does not surprise me (MBR). The dying and their family members often query: "What would be better? A death that takes time or something quick and easy?" This question is generally existential, as it takes courage for the dying older adult and family members to face into death. (The value of the palliative experience will be discussed in the grief section, as well as the ethical issues section later in this chapter).

The literature increasingly reflects the need for those dying to be met in *their* places of need (Ryan, 2005). And based upon studies of patients on dialysis, with HIV or in nursing homes, Singer, Martin, and Kelner (1999) identified five key domains for end-of-life care, from *patients'* perspectives: pain and symptom management, the avoidance of inappropriate prolongation of life, patients achieving a sense of control, relieving the burden of care on the loved ones, and the bolstering and deepening of relationships with loved ones. This, in a nutshell, is the thrust of hospice/palliative care. And, more than just the focus of palliative work, the provision of this type of care is an ethical obligation (Singer et al., 1999).

What is striking within a clinical context is that the dying and their families can feel much pressure to experience a good death. Could this reflect the North American compulsion to "succeed"? I (MBR) have been present at many, many passings. The dying express concerns that they will not display sufficient courage. Family members, in a typical grief response and perhaps societal pressure, query whether they have done a "good enough job" in supporting their loved one. Again, this pressure —almost moral in nature—to succeed is present even in death! An older woman had struggled tremendously with faith and with fear in her dying; she agonized through the entire process. At her funeral, the celebrant stated numerous times that "she died well." In this context, the focus was that she died in faith. Whether she did was not the issue; the fact that the minister felt the need to stress this repeatedly to members of the congregation revealed the pressure that is applied to people to die a certain way. Placing this type of weight upon a dying individual and her family members is not helpful.

Roshi Joan Halifax (2009) takes a very practical approach to dying. She told of an individual who died with great struggle, and she wrestled with whether this was a good death. Here is her conclusion:

> The concept of a good death can put unbearable pressure upon the dying and their caregivers.... Our expectations of how someone should die can give rise to subtle or direct coerciveness. And no one wants to be judged for how well she dies! (Halifax, 2009, p. 65)

Part of my (MBR) work with grieving individuals is to help them work through this pressure of having performed adequately during their loved one's illness and dying. One woman came into the palliative setting in the last stages of a chronic condition. She was expected to be with us for a time. In the course of events, she passed within a couple of hours after her arrival with what appeared to be a pulmonary embolism. Her dying was very quick and she was anxious. Her daughter, who had wanted to make sure that everything was "perfect" for her mom, was devastated. As I came into the room moments after her mother's passing, the adult daughter collapsed into my arms. "Why did it have to happen this way?" was her cry. No doubt, there is much mystery and we live in "the richness of not knowing" (Halifax, 2009, p. 65). I responded to her that we often come into this world crying, and sometimes we leave that way too. Being birthed into this life is a transition that comes with stress; being birthed into the next life sometimes involves stress also.

For this palliative chaplain (MBR), the primary factor in determining whether a death is good is the presence of love. If the dying individual and his family *know* that they are loved, and diligent efforts are made to cover off on the other factors (described by Singer et al., 1999), the death has been good. "The salvation of man is in love and through love" (Frankl, 2006, p. 37).

ISSUES FOR FAMILY MEMBERS

Even though family members of an aging adult are not personally dying, they typically experience significant grief and grapple with a number of issues related to the impending death of the older adult, whether this person is a spouse, parent, or other relative. The experience of personally standing by someone who is loved and is dying can impact a person to his core—to the depths of his spirit. It impacts his identity; it changes his world forever. For the family, this process is about detaching from their loved one as they currently experience her, just as the dying individual is letting go of them. It is also about developing a new relationship to the deceased.

Anticipating the Death of an Elderly Spouse

The death of a spouse is one of the most profound losses of a person's life (Anderson & Dimond, 1995; Hamilton, 2005a). As people are living longer, many older adults will experience the death of a partner of many years. Having lived so long, and experienced so many things, older adults often have coping mechanisms that help them deal with loss; however, the sheer number and magnitude of the losses can compromise their ability to handle impending loss (Gibson, 2009). The soon-to-be surviving spouse may refer to the day the terminal diagnosis came as when life, as he had known it, was changed forever (Duke, 1998; Hamilton, 2005a). The bonds that have been formed and strengthened throughout the years are many; the thought of separation can be unbearable. How the older adult left behind copes—in the time of anticipating this loss and after the spouse's death—may be dependent upon a person's personality and how he has coped with challenges in the past (Buckman, 1998).

Decision Making Regarding End-of-Life Care

It is not uncommon for family members to hold opposing views on end-of-life decisions for the dying individual. One family member may be adamant that treatment must be continued regardless of the diagnosis, prognosis or response to treatment; another family member may argue just as vehemently that care should be just supportive with no extenuating measures. And ironically, the aging, dying older adult may be lying comatose on the hospital bed between these two family members who are engaged in the verbal tussle.

Family members' decision making may be complicated when an older adult has not made her wishes known or prepared a living will (Clabots, 2012). The older, dying adult may assume that she can let the family know "when time comes," but then suffers a stroke or becomes comatose, and it becomes too late for wishes to be spoken out loud. While in some developed countries, individuals and/or family members designate the level of care (e.g., no invasive treatment) they wish the aging and/or dying adult to receive when entering continuing care facilities (such as nursing homes) or palliative care facilities, this may not occur within hospitals. Then, when a major event occurs, such as a massive cardiac event or a stroke, families may be paralyzed in their decision making on behalf of their hospitalized elder.

Decision making regarding end-of-life care can be straightforward for some families and less smooth for others. When older adults have prepared a living will and have designated a family member to make decisions on their behalf, the process may be clearer. Although family members may not necessarily agree with the stated wishes, they at least know that their spouse, parent, or relative made the decision when of sound mind. This may relieve family members of great angst

and guilt at a time of great vulnerability and turmoil: when their family member is dying.

Nurses and other professionals need to broach the conversation of end-of-life care decisions on behalf of their aging and ailing patients. However, studies have revealed that nurses and physicians may be reluctant to talk to aging adults about end-of-life wishes (Boyle, Miller, & Forbes-Thompson, 2005; Kahana, Dan, Kahana, & Kercher, 2004). As the focus of care within acute care hospitals is often to sustain life, such conversations may be seen as giving up hope (Clabots, 2012). Also, nurses and other professionals may be uncomfortable with end-of-life discussions, as these may raise their own existential issues. Therefore, professionals need to consider their own beliefs, values, and fears about dying and death, as well as meaning and purpose in life (Clabots, 2012).

Supporting Older Adults in the Dying Process

Not only will some family members require support in their grieving and concerns about a dying older adult, but they may also *require support to support the dying, aged individual.* The need for support may be related to other reasons besides a tumultuous relationship with the dying parent (as has been discussed already within this book). For example, a family member of a dying elderly person may have significant mental illness and may be experiencing an exacerbation of her symptoms due to the stress of grieving. Or, an adult child with an intellectual disability may not know how to express his grief regarding the impending death of his parent, or, on some level, may not understand what death entails. A spouse with dementia who is visiting her dying husband will need much support in her own process.[8]

Dealing with Caregiving Exhaustion

Standing *with* an aging family member who is dying is exhausting in every way: physically, mentally, and spiritually. Just the anticipation of the dying of a family member results in profound weariness; however, other factors exacerbate this fatigue. For example, an adult daughter may have spent months being up frequently during the night to assist her terminally ill mother and hence is sleep deprived; when Mom is hospitalized, she may spend nights sitting in the hospital

[8] There is some literature on helping those with dementia cope with the (impending) deaths of loved ones. For example, Miller Lewis and Trzinski (2006) stated that those with dementia have the same grief needs as others, and so need help in their grieving. With impaired cognition, they may "forget" that their spouse has passed, and so may experience acute reactions repeatedly. For this situation, Miller Lewis and Trzinski (2006) recommended *spaced retrieval* and *group buddies* as approaches to helping the cognitively impaired with their grieving. In these approaches, the bereaved person with dementia retains cognition that there has been a death, and, over time, that the person who died was their spouse. In this way, the bereaved does not experience the loss repeatedly in an acute fashion, every time the passing of their spouse is mentioned.

chair, straining her back to hold her mother's hand. The walks that were a part of her routine may be given up; her practice of yoga set aside. In the understandable preoccupation of caring for the needs of her mother, she may have neglected to eat and drink adequately, losing or gaining weight. Without adequate sleep, nutrition, and hydration, she finds herself to be prone to colds (due to stress on the immune system), headaches, and backaches, and the "well" of her spirit may be dry.

Healthcare providers often encourage self-care for caregivers. "Oh, don't worry about me. I'll take care of myself after this is all over" is a common reply from family members. However, when the caregiving goes on for longer than expected, caregivers can find themselves exhausted and ill. They themselves can suffer with depression.

Bioethicist Viki Kind (2010) discussed the notion of care-grieving. The stresses of caregiving, combined with anticipatory grieving—for either the death that will occur or the loss of the older adult one once knew—as well as perhaps the loss of the job or social relationships that one limited or gave up to provide care, can leave family members exhausted, burned out, and depressed. Walker and Pomeroy (1996) sought to distinguish between clinical depression and anticipatory grieving in their research regarding the caregivers of those with dementia. Whether the caregiver is depressed or engaged in anticipatory grieving, the sense of being overcome by circumstances bigger than self is very real; one's own personhood can feel threatened. Kind (2010) stated "Care-grieving can become so overwhelming that it creates in us a desperation and a need to survive. It's not that we wish our loved one was gone, we just wish our pain was gone" (p. 106).

There are many factors in the dying process that are outside of the caregivers' control. This sense of being out of control (and exhausted) is associated with the "burden" of caregiving (Walter & Pomeroy, 1996). Having said that, elderly people who have provided care for their dying spouses derive great comfort, during the bereavement process, from having done so (Chan & Chan, 2011; Duke, 1998; Hamilton, 2005b).

Grieving the Death of the Older Adult

Grieving is intensely demanding work. Even when the death is expected due to the age and illness of a spouse or parent, the amount of grief can overwhelm some family members. "Death creates chaos. It creates a total upheaval in the entire family structure," stated Kagawa-Singer (1998, p. 1752). The following is a brief discussion of the types of grief as they impact the passing of an older adult. Because this text is geared toward the transitions of older adults, and the impacts upon family members, the discussion about some of the forms of grief will be limited to those that impact and have relevance to the grieving family.[9]

[9] For a detailed discussion of the various forms of grief, see Rando (1984).

Some of the types of grief and their application

Anticipatory grief has been touched upon a number of times in this text. The term was coined by Lindemann in 1944, in his seminal work on acute grief. He wrote of wives of soldiers at war (World War II) who so anticipated the deaths of their husbands at war that if they returned, the wives had already successfully detached emotionally from them (Siegel & Weinstein, 1983). Since then the term has been used extensively in the field of grief to describe a form of grieving that begins before a person actually dies. Family members and the dying adult experience this as they begin to come to grips with the reality that death is coming. Often, the loss comes in stages: a loss of health due to disease; a loss of body image due to the impact of treatment; a loss of capacity; and eventually, the actual loss of the loved one. Hence, the boundaries between life (as it was once experienced) and death are shadowy and vague (Good Reads, 2013), as quoted from Poe at the beginning of this chapter.

This means that in the dying process, the dying older adult and the loved ones suffer a number of losses, as is typical of grief, but the process is elongated. The existential question raised by many dying people, as well as their loved ones, was raised earlier: "What would be better: a death that takes time or something quick and easy?" Ryan (2005) cited that patients sometimes desire the latter. The existential concerns discussed in Chapters 5 and 6 figure in heavily here. "I'm not sure that I'm up to this," an elderly gentleman said, about his dying process.

Within practice, it is generally assumed that knowledge ahead of time that a loved one is going to die leads to better grief resolution. However, from a grief research perspective, the evidence is not conclusive. According to Parkes (1975), a family having time to prepare for a passing leads to better grief outcomes; Golsworthy and Coyle (1999), in their study examining older adults who had lost a spouse, concurred. Maddison and Walker (1976) and Gerber, Rusalem, Hannon, Banin, and Arkin (1975) did not find that knowing of the death ahead of time aided in the bereavement process. Some of the conflicting evidence appears to be tied to the lack of clarity in defining anticipatory grief. Siegel and Weinstein (1983) spoke of the need to have the empirical foundations of the concept of anticipatory grief firmly established; they noted that the concept is too ambiguous to be clearly tested. Costello (1999) noted that this topic is under-researched.

It is this clinician's experience (MBR) that preparation for a death *is* helpful, *if* the family has received support through the process. Adult children have stated that the palliative experience, with the support provided, both before and after their parent's death, was far superior to their experience when compared to the death of another parent that was sudden and unexpected; in one situation the family (with five adult children) commented on how helpful this experience was for their teenage children, to learn about death and to develop coping skills, as well. But here, too, the concept of anticipatory grief is not specifically isolated; my generalization is made with another factor involved, and that is of palliative care.

A lengthy illness and then passing of a loved one, without the supports of hospice and palliative care, may simply wear a family down, without leading to better grief resolution. Research shows that the hospice palliative experience, which includes support in anticipatory grief , provides the dying individual and the family a better experience (Teno, Gozalo, Lee, Kuo, Spence, et al., 2011; von Gunten, 2012).

Normal grief is the process of emotional detachment that occurs after a death. It is an intense process, involving physical symptoms (chest pain and tightness, tightness in the throat, sleep disturbances, appetite disturbances, dry mouth, sensitivity to noise), emotional symptoms (fear, crying, emotional numbness, anger, guilt, depression), psychological symptoms (trouble with concentration and decision making) and spiritual symptoms (existential angst) (Rando, 1984). It is helpful for the reader to note that these symptoms are "normal." Meaningful attachment to people (as spoken of in Chapter 5) leads to a strenuous time when that relationship, as it was experienced, is altered through death. That being said, physical symptoms in the bereaved, such as chest pain and tightness, need to be checked out medically to rule out serious health problems. And the depression of grief can lead to suicide; nurses and other healthcare professionals need to be aware of this fact and prepared, in their work with grieving people, to assess for suicide risk. In order to move through this "normal" phase of detaching, individuals need to be able to attach meaning to the death; meaninglessness in death is associated with anger and an indefinite grieving period (Chan & Chan, 2011).

When an elderly person has lost her spouse of many years, the process of grief will be especially arduous; also, the length of the bereavement period may be especially long (Golsworthy & Coyle, 1999). Older grieving adults have higher morbidity rates (Elwert & Christakis, 2008); they experience a higher level of mental health issues after the death of a partner (Ott, Lueger, Kelber, & Prigerson, 2007). Men, in particular, are even more susceptible to the impact of losing a spouse (Fitzpatrick, 1998). Their adaptive capacities in their later years may be stretched beyond their limit with the number of challenges they are facing (Gibson, 2009). Given the length of many marriages of the elderly (50-plus years), the shared identity and life histories, many older adult never really emotionally detach. Here, I (MBR) like the term of J. William Worden, that of "emotionally relocating" the loved one who has passed. The loved one does not cease to exist in the life of the one who remains on earth; in this way, the personhood of the deceased is not nullified.

As such, one of the "tasks" of grieving (Worden, 2009)[10] is to emotionally relocate the deceased person; this is so some form of relationship with the deceased

[10] There are a number of grief models: Elisabeth Kubler-Ross' (1969) Five Stages of Grief is probably the most famous. We like Worden's model—the "Tasks of Grieving" because it seems less passive. Those in grief apply themselves to "tasks," rather than moving passively through stages. It should be noted, though, that grief is far too complex a process to distill down to a set of stages or tasks; this is being increasingly recognized in the literature (see Hamilton, 2005b, and Copp, 1998).

remains. The carrying out of this task is evidenced in many ways. For some, their loved one resides in a cemetery. The surviving spouse may go, on special occasions, to "speak" with her deceased husband. An adult daughter, earlier in this chapter, kept some cremains of her father in a locket that she wore close to her heart. Literally and figuratively, her dad stayed in (or upon) her heart!

Another woman, herself now in a palliative setting, kissed her husband's photograph and said, "He's always with me." The nature of the relationship changed (he was no longer physically present), but she still felt his influence and his presence in her life. She also expressed that tender connection through looking at, and periodically kissing, his picture.

Golsworthy and Coyle (1999) addressed the place of religious and spiritual beliefs in aiding the surviving spouse to form the new relationship with the deceased loved one, in essence, to emotionally relocate the departed; the loved one may be always in his or her heart ("I always feel her with me") or in heaven ("we'll be together again"). They found that having spiritual/religious beliefs assists the older adult in the grief process, because older individuals are able to make some meaning of the passing and also able to place this loved one in the next life. Religious involvement is also associated with the support of a faith community.

Conflicted grief occurs when the relationship with the deceased has been ambivalent. It is characterized by the exaggeration of one aspect of normal grief, with the suppression of other aspects. Rando (1984) spoke of guilt and anger being two common elements in conflicted grief. For example, in situations where there has been a very dependent relationship, grief can be very difficult. An adult son may feel much anger toward his elderly mother, the anger coming from his own dependence upon her, and her "leaving" him in death, after "all he's done for her!" He may not feel able to express this, and so outwardly emphasizes to others only the positive things. But internally, there is guilt over his internal relief that the relationship is done, fear of what the future holds (he has not reached his developmental milestones and only knows a life of dependence upon her), as well as sadness for the loss of his mother. In essence, the conflicted grief results in a tangled mass of emotions that the son is unable to understand.

For the health professional, an acknowledgment that both the positive feelings (love, affection) and the "negative" ones (anger, hurt) are present and normal, in this context, is vital. It is important that the bereaved adult child grieve the loss of that which was good and that which was not. (It is common for these adult children to grieve the loss of the type of parent they never had). Many hospice programs in the community have bereavement follow up; in situations where the grief is conflicted, these services are even more important. Researchers have found, however, that even within hospice settings, the majority of people do not access these bereavement services (Cherlin et al., 2007; Holland, Futterman, Thompson, Moran, & Gallagher-Thompson, 2013).

We would be remiss if we did not spend some time discussing grief in situations of ambiguous loss. The term *ambiguous loss* (Boss, 1993) was explained in Chapter 3. For those experiencing ambiguous loss, where their loved one is still physically present, but emotionally or psychologically absent (with dementia or brain injury), the grief can be confusing. The loved ones—spouses, adult children, caregivers—feel the loss keenly (Riggans, 1992), but may not recognize that it is grief they are experiencing, because the loved one is still physically present (Gibson, 2009). As well, there are not the rituals in our society to mark this type of loss (such as a funeral), and others may not recognize it and provide support (Kind, 2010).

Gibson (2009) noted that when older adults are experiencing this ambiguous loss caused by dementia in their partner, they are also experiencing a number of other challenges: the passings of friends, difficulties with their own health, and the deaths of siblings. Hence, the resources for coping are limited. On top of this, the social network that used to provide help, such as neighbors and relatives, is often no longer there (Gibson, 2009) because of the length of the illness (as discussed in Chapter 2).

The strain on the older adult without dementia, as well as on adult family members, is enormous. Feelings of anger and guilt will often be present, as they wish that "this were all over." The need for adequate provision of appropriate nursing home placements cannot be overemphasized. By the time families reach a palliative setting (if they do), they often need reassurance that their expressions of frustration have come from exhaustion, not lack of love. They also need to be reassured of the personhood of their loved one.

It is no wonder that when a loved one does pass, there are a myriad of feelings: relief that one no longer needs to give care, guilt that one has felt this way, as well as sadness for the passing of one he loved. I (MBR) remember so clearly a gentleman that was admitted into hospice with end stage Alzheimer's disease. His two sons showed me many pictures on their computer of the man he used to be. The gentleman in the bed—no longer eating or drinking, eyes open but not making contact —was not the person they had known. They had a great need to tell story after story of who he was and what he did when he was well: "So that you will know that he wasn't always like this!" They needed to be reassured that their feelings of loss as well as relief were normal and "okay."

For all people, including the elderly and their adult children, meaning is a significant issue in life and in death. The loss of a partner and the loss of a parent represent the loss of meaning. And so, the bereaved must be able to accommodate the massive loss of her spouse into her life, to "make sense" of it (Holland et al., 2013). There are many deaths that are difficult to make sense of. The elderly parent who loses an adult child and the very old woman murdered for change in her purse are two examples. Here, the grief is difficult, and coming to acceptance is impeded by the fact that it goes against everything we believe should happen. Chan and Chan (2011) used the term "timely" in relation to a death that is more easily made sense

of and accepted. They suggested that the death that is "untimely"—where it is unexpected, hastened by medical error, or where there are people older than the deceased still alive—make acceptance more difficult. They added that just because a person is aged does not necessarily mean that the death is "timely."

How does one make sense of death, and hence be able to move beyond a loss. For the elderly, research is showing more and more that some sort of relationship with the deceased continues (Golsworthy & Coyle, 1999; Ho, Chan, Ma, & Field, 2013). This sense of relationship can be sustaining. Health professionals can help bereaved individuals tap into coping mechanisms from the past; that which brought meaning in the past can be utilized to bring meaning into the present and for the future (Chan & Chan, 2011). As mentioned, religious faith and spirituality that "relocate" the deceased can aid bereaved people (Golsworthy & Coyle, 1999). Sometimes, forms of meaning can be made through transcendence. "My loved one died of cancer, but perhaps research on her body can lead to the cure for someone else." Chan and Chan (2011) spoke of the importance of volunteer work, which brings an "other-centeredness" to the bereaved person, and which may help a spouse in accepting the death of her husband.

Funeral Services

As was mentioned earlier in the chapter, many people are opting out of having funeral/memorial services for a departed loved one.[11] Obituaries regularly mention phrases such as "according to John's wishes, there will be no funeral service." This, on first glance, appears respectful of the person who has died. But the question must be asked, for whom is the service for? Gire (2002) noted that a funeral service is a *rite of passage* for both the dying person and the living. As a palliative chaplain, I (MBR) repeatedly observe how terminally ill people utilize the funeral service as an opportunity to impart "one last message" or to celebrate the life they have lived, in anticipation of the life they are now entering.

However, primarily, the service (in which ever form it takes) is for the living. Researchers have noted a number of purposes of the memorial (Birchenall & Streight, 1993; Gire, 2002; Palgi, & Abramovitch, 1984; Rando, 1984). First, the funeral provides a context in which everyone formally recognizes that "the death has really happened." Second, the function of the funeral is to realign relationships among the living. The bereaved wife is now a widow, in need of care and support in a way that she previously has not needed; the community comes together to provide that care for her in her new context, in the service itself and afterwards. Third, it provides the rituals within which the bereaved can "send off" the deceased person into his new life. These rituals can continue after the funeral; for example,

[11] Technically, a funeral is a service where the deceased is present in body—in the casket. A memorial service may include an urn, but there is no body. More and more, people are entitling their services, in whatever format they are held, as "Celebrations of Life."

prayers for the "repose of the soul" may continue for a period of time after a passing. And finally, funeral services may provide a place for the bereaved to deal with their guilt and grief. One astute minister, in the funeral of the unexpected passing of a congregant, stated, "I meant to get together with this gentleman. I did not, and feel guilty. You may feel guilty too. In our presence here, we are 'getting together' with him and honoring him. We need to forgive ourselves for where we feel we have been lacking in relationship to him." In this way, he gave the mourners permission to admit to themselves their guilt, to forgive themselves, to honor the deceased and to grieve in a healthy manner. Funerals can provide the context for individuals to act out their grief—through mourning—in a place of support (Gire, 2002; Martinson, 1998).

As has been expressed a number of times in this text, the western world is uncomfortable with death and expressions of grief. I (MBR) have officiated at many funerals (in whatever form they have taken). Grown men, weeping over their loved ones, have sometimes expressed, "I shouldn't be crying like this!" In one service, the sons-in-law of the deceased elderly woman—burly, strong men—wore sunglasses to cover their swollen eyes and wept like babies. They loved her! While their weeping may not be common in North America, in many societies, overt weeping (and even wailing) is both typical and helpful (to release grief).

I have also officiated at memorial services/celebrations of life that occurred a lengthy time after the passing. In one circumstance, the elderly man had passed three years earlier. His nieces said, "We need to have this service; we can't just can move on!" A woman, whose mother-in-law had just passed, said it best: "This day cannot be just like any other; we have to remember and celebrate her!"

As has been mentioned, the form of the ritual is not nearly as important as the *meaning* that the chosen ritual holds to the person who has passed and to his or her loved ones. Gatherings can take many forms; but the gathering needs to fulfill the needs of the mourning community to recognize the loss, to realign the relationships among the bereaved, and to provide a place to deal with grief needs, such as mourning.

Tending to Issues Related to Will, Estate, Finances

Ideally, work related to establishing wills and keeping financial matters current should be ongoing and, therefore, minimize the responsibilities of a grieving spouse or adult children after the death of an older individual. However, even when the aging adult has tended to matters of finances, will, and the estate, there still is work involved for the executor of the estate. Adult children may fight over items in the will or dividing up of the estate. Fighting about these matters may begin even before the aging adult has died.

In situations that are complex, and where difficulties are expected, some elderly people are opting to have an independent third party (such as a representative

from a bank) look after matters of the estate. This can be costly but may ameliorate difficulties among adult children. As legal issues are beyond the scope of this text, we encourage readers to access texts addressing legal matters in relation to older adults.

ETHICAL ISSUES

Ethical issues, where there are competing values in difficult decision making, make the process of resolution strenuous. Those who deal with these issues—in whatever field—wrestle significantly with dilemmas.

This is not a text on ethics, so the discussion will be limited. But briefly, in the area of biomedical ethics, there are four foundational concepts[12] to guide decision making: autonomy, beneficence, nonmaleficence. and distributive justice.[13] These foundational principles form the base for ethical decision making. While the meaning of each of the concepts appears to be straightforward, there are situations in life where the relationship between foundational principles is strained. It is in these circumstances, where there is conflict between these guiding values, where the ethical dilemmas arise. For example, an older man may have suffered with kidney disease for many years. For the last ten years, he has had to have dialysis three times a week. Recently, he received a cancer diagnosis. He does not want to receive treatment for the cancer, and he feels like he is just "done" with dialysis. His desire to refuse forms of medical treatment that will prolong his life (chemotherapy and dialysis) come into conflict with his family and their values; they believe he has the obligation to receive the treatment that is available. His assertion of autonomy and their understanding of beneficence (doing what is good) come into conflict.

In such situations, decision making models such as the Latimer Ethical Decision Making Model and the Kuhl Ethical Grid can be helpful (see Downing & Wainwright, 2006; and Kuhl & Wilensky, 1999). As discussed in Chapter 5, a fully developed person learns from a young age and in ever-deepening ways throughout his life, that he matters, and so do others! The needs of the individual are balanced with the needs of others (Kissane & Kelly, 2000).

---

[12] The foundational concepts of ethical decision making are also values and principles. So the terms will be used interchangeably, where appropriate.

[13] Autonomy refers to an individual having the right to his or her own values and beliefs and, when possible, decision making. Hence, regarding older adults, living wills are vital. Second, there is beneficence; this mean to do good. Third, nonmaleficence refers to "doing no harm." This is central to all healthcare! And finally, there is distributive justice, which means that there is to be fairness among people. This four-principle model, with the discussion of scope of each in relationship to the others, was first postulated by Beauchamp and Childress in text form in 1985. Since then, their text *Principles of Biomedical Ethics* has become a classic in biomedical ethics; there have been a number of editions of this text, with some significant revisions. The reference list provides information for the most recent edition (2012).

The following two issues, as they arise in end-of-life, are ethical issues because the foundational values of autonomy, beneficence, nonmaleficence, and distributive justice—or the *interpretation* of these values—come into conflict. So much could be said about suicide and euthanasia from legal and religious perspectives; entire books have been written on the subjects! This text is not a legal text, nor is it a religious one, however. So the following topics will be covered primarily from a grief and loss as well as palliative care perspective.

Suicide

It has been discussed in other chapters within this text that suicide in older adults is a major issue. But it is not something we are comfortable speaking about. So I (MBR) was surprised, when guest lecturing about grief in a university class, when a delightful older adult broached the subject in front of his many, and much younger, classmates. This gentleman shared openly that his wife had died and that when he felt that he was "done," he would spare his family and society the burden of caring for him and simply end his life. "What do you think about that?" he questioned me in front of the large class. I acknowledged the loss of his wife and the difficulties that elderly people have with grief and finding (new) meaning. As the issue of suicide is emotionally charged and value-laden, I paused before responding.

Gathering my thoughts, I explained to the class that each individual has a right to her own life (autonomy), but that there are always more people involved than simply an individual (family and friends). From a grief perspective, death always leaves "guilt" (some of it justified; some of it not). However, suicide leaves a mountain of guilt and regret that is not easily reckoned with or resolved. Bereaved family members struggle to make sense of the death and often feel that they are at least in part responsible for it. ("If only I had taken her out for breakfast that day . . . " "I never should have moved across the country to take this job!") The grief that follows a suicide is very complex; it is traumatic (Rando, 1984; Swarte, van der Lee, van der Bom, van den Bout, & Heintz, 2003).

In the western world we are strongly oriented toward the youth and the individual. While this affords certain "advantages" in terms of self-actualization, the lifelong development of personhood, through all of its transitions, may actually be hampered, because we attempt to cope with transitions on our own. And when we reach our final years, we may feel that we have little to contribute to, or receive from, our families. It could be said that suicide in the elderly is a symptom of this isolation and disconnect with others.

One healthcare professional declared to me (MBR) that if he received a terminal diagnosis, he would end his life immediately. "No one should have to go through that," he said. But when a valued member of his family passed away from suicide, he struggled tremendously. At this point, the perspective changed, as he was one left behind; what was once "logical" to him was no longer so.

Physician-assisted Suicide and Euthanasia

There is much in the news regarding physician-assisted suicide and euthanasia today. Physician-assisted suicide is when a doctor intentionally provides, at patient request, the drugs needed for that patient to kill herself; euthanasia is the doctor's intentional killing of a patient by drugs, as a response to the patient's intentional and competent (with capacity) request (Frileux, Lelievre, Munoz Sastre, Mullet & Sorum, 2003; Materstvedt et al., 2003).[14] Both of these actions have been legalized in certain regions in the western world. The reasons why a patient may request such a procedure are complex; often, they reveal the physical, psychological, and spiritual suffering (such as pain, feelings of aloneness, spiritual distress) that palliative care seeks to address (Ley & van Bommel, 1994; Materstvedt et al., 2003). In general, physician-assisted suicide is viewed more kindly than euthanasia, because of the patient's intention of dying (by asking the physician, sometimes repeatedly, for the medications to terminate her own life) and her action to carry out the desire on her own (Frileux et al., 2003).

Within western regions that practice physician-assisted suicide and euthanasia, there is great concern about what constitutes "consent." In The Netherlands, for example, euthanasia can be carried out without a patient's current consent, because he had mentioned previously to his physician that he feared suffering (Materstvedt et al., 2003); sometimes *there is no patient consent* at all, hence the terms nonvoluntary and involuntary euthanasia[15] (Hendin, Rutenfrans, & Zylicz, 1997). Hendin (1998) spoke of a physician who carried out the euthanasia of a nun, who was suffering terribly, but whose religious convictions did not condone her asking for it; hence, her convictions were violated.[16]

Dorothy Ley (Ley & van Bommel, 1994) separated euthanasia from the popular phrase: "dying with dignity":

> The current fashion to equate dying with dignity with euthanasia reflects the mistaken belief that death whose moment is chosen is somehow more dignified than one not chosen (p. 67).

---

[14] Euthanasia must not be confused with palliative sedation. In palliative sedation, the patient is within days or hours of death, the symptoms being uncontrolled without some sedation (mild or heavier). In this circumstance, the guidelines for the procedure are clear, consultation among palliative physicians must occur, and the intent is to control symptoms, not to end life (Materstvedt et al., 2003).

[15] Nonvoluntary euthanasia refers to euthanasia where the patient is not able to consent. Involuntary euthanasia is euthanasia against the patient's will. (See Materstvedt et al., 2003).

[16] The literature reveals that within The Netherlands, the boundaries of what is considered acceptable in euthanasia continue to widen; doctors who oppose the practice receive professional pressure and ostracism; and when instances of euthanasia are carried out that are outside of the boundaries of the law, they are not prosecuted (Fenigsen, 2012; Hendin, 1998; Hendin, Rutenfrans, & Zylicz, 1997; Kissane & Kelly, 2000; Materstvedt et al., 2003).

Ley (Ley & van Bommel, 1994) alluded to a western ideal that equates dignity with health, looking good, and control over all bodily functions. She suggested that we revisit this concept and understand that dignity is not something that can be taken away by bodily changes. Kissane and Kelly (2000) noted that the loss of continence is often more distressing for family members than it is for the patient themselves. Fenigsen (2012) said, "We are told that to be assisted by medical technology entails loss of dignity, as if the dignity of honest, caring, courageous people, our parents and spouses, could somehow be drained out of them through medical devices" (p. 73).

Ley (Ley & van Bommel, 1994) continued to caution that the "right to die" easily gets converted into a "duty to die" (p. 67). This conviction was echoed by a number of researchers into the Dutch medical system, which practices euthanasia (see Fenigsen, 2012; Hendin et al., 1997; Materstvedt et al, 2003). Ley (Ley & van Bommel, 1994) also mentioned that vulnerable populations are most at risk for this pressure: the elderly, the poor, the handicapped.

Regarding older adults, Kissane and Kelly (2000) stated that "the practice of euthanasia and physician-assisted suicide is clearly related to age" (p. 330), and they cautioned against using the ethical principle *autonomy* as the predominant standard for making decisions regarding end-of-life, as this autonomous choice may be unachievable in the context of advanced age or severe illness. And it is worth noting that one never acts in isolation; autonomous actions always impact others. (The interdependence of individuals in the experience of transition [Hutchison, 2008] was discussed in Chapter 1). A study carried out by Segers (1988) observed that vulnerable peoples (particularly the elderly) are less likely to agree with euthanasia, as they fear the procedure may be carried out on them against their will.[17]

Loss of dignity is something that involves the negating of personhood. A thrust of this text has been to affirm the personhood of older adults, in all of their transitions. And effective palliative care both maintains and even develops personhood at the end-of-life. Research shows that when issues such as total pain are dealt with, patients who had been thinking about euthanasia no longer wish to die in that way (Materstvedt et al., 2003; Segers, 1988; Teno et al., 2011; von Gunten, 2012).

From a grief perspective, as has been touched upon, grieving is made much more difficult for the bereaved when a death does not make sense (Holland et al., 2013) and is not seen to be timely (Chan & Chan, 2011). Confusion over consent, premature ending of life, the violation of convictions (whether the patient's or her family members) all lead to pronounced and prolonged grief. When family members are called upon to help plan the death (physician-assisted suicide or

[17] Dr. J. Segers (1988), in a Dutch study, found that 66 percent of older adults living independently, and 95 percent of older adults living in care facilities opposed government support of euthanasia, and they expressed fear of involuntary euthanasia.

euthanasia), they often experience a conflict of values—wanting to honor their loved one's wishes, but struggling because to honor their loved one's wishes may lead to violating their values (Starks et al., 2007). Starks and colleagues (2007) spoke of the family of a "Mrs. Bowen," who were involved in hastening her death, at her request. Two and a half years after Mrs. Bowen's death, a daughter said this:

> The impact of this is so huge . . . . I've become socially isolated, exhausted . . . . It's been three years since I've had a life . . . . I'm not sleeping well . . . Sometimes I'll wake up around 4 (a.m.) thinking, "Did I kill her?" (p. 117)

Swarte and colleagues (2003) stated that the grief from suicide is worse than that from euthanasia, because in the latter situation, family members have the chance to say goodbye.

Chapters 5 and 6 in this text have illustrated the personal growth and relational work that can occur in the context of end-of-life, particularly when there is effective palliative care. It is this clinician's experience (MBR) that when the medical expertise and the social and spiritual supports are in place, dying older adults may experience profound meaning in their last days, and families are aided greatly in their journeys of grief, as well as their own development of personhood. Suicide, physician-assisted suicide, and euthanasia precludes dying individuals and their families the opportunity for profound growth and meaning, and those left behind face very complex journeys of grief. Chapter 8 will include a brief section on the need for palliative care to be available to everyone who needs it.

SUMMARY

Within this chapter, we have examined some myths that surround the dying and death of aging adults. We also addressed issues related to dying in older adults, both for the aging individuals themselves, as well as for their family members; healthcare interventions were woven into the discussion. And finally we looked at ethical issues surrounding death and dying. To quote "Jesse," a dying individual who participated in a study conducted by Patricia Ryan (2005), "Dying is no easy thing; there's a lot to it" (p. 1106)

Critical Thinking Exercise

- What has been your experience with death up to this point in time?
- What concerns do you have in assisting a dying older adult, as well as his family members?
- How do you mentally and spiritually process death?

REFERENCES

Ainsworth, M. D. S., & Bowlby, J. (1991). An ethological approach to personality development. *American Psychologist, 46*, 331–341.

Anderson, K., & Dimond, M. F. (1995). The experience of bereavement in older adults. *Journal of Advanced Nursing, 22*(2), 308–315.

Beauchamp, T. L, & Childress, J. F. (2012). *Principles of biomedical ethics* (7th ed.). New York: Oxford University Press.

Birchenall, J. M., & Streight, M. E. (1993). *Care of the older adult* (3rd ed.). Philadelphia: Lippincott.

Boss, P. (1999). *Ambiguous loss: Learning to live with unresolved grief.* Cambridge, MA: Harvard University Press.

Bowlby, J. (1999). Attachment. *Attachment and loss, Vol. I* (2nd ed.). New York: Basic Books.

Boyle, D. K., Miller, P. A., & Forbes-Thompson, S. A. (2005). Communication and end-of-life care in the intensive care unit: Patient, family, and clinician outcomes. *Critical Care Nursing Quarterly, 28*(4), 302–316.

Brainy Quotes. (2013). Retrieved March 06, 2013, from wwwbrainyquote.com/quotes/topics/topic_death5.html .

Buchanan, R. J., Choi, M., Wang, S., & Ju, H. (2004). End-of-life care in nursing homes: Residents in hospice compared to other end-stage residents. *Journal of Palliative Medicine, 7*(2), 221–232. doi: 10.1089/109662104773709341

Buckman, R. (1998). Communication in palliative care: A practical guide. In D. Doyle, G. W. C. Hanks, and N. MacDonald (Eds.), *Oxford textbook of palliative medicine* (2nd ed.; pp. 141–158). Oxford, UK: Oxford University Press.

Byock, I. (1997). *Dying well: Peace and possibilities at the end of life.* New York: Riverhead Books.

Callahan, D. (1993). Pursuing a peaceful death. *Hastings Center Report, 23*(4), 33–38.

Canadian Virtual Hospice. (2011). What is palliative care? Canadian Virtual Hospice. Retrieved February 14, 2013, from www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/What+Is+Palliative+Care_/What+Is+Palliative+Care_.aspx

Chan, W. C. H., & Chan, C. L. W. (2011). Acceptance of spousal death: The factor of time in bereaved older adults' search for meaning. *Death Studies, 35,* 147–162. doi: 10.1080/07481187.2010.535387

Cherlin, E. J., Barry, C. L., Prigerson, H. G., Schulman-Green, D., Johnson-Hurzeler, R., Stanislav, K., & Bradley, E. H. (2007). Bereavement services for family caregivers: How often used, why, and why not. *Journal of Palliative Medicine, 10*(1), 148–158. doi: 10.1089/jpm.2006.0108

Clabots, S. (2012). Strategies to help initiate and maintain end-of-life discussion with patients and family members. *MEDSURG Nursing, 21*(4), 197–203.

Copp, G. (1998). A review of current theories of death and dying. *Journal of Advanced Nursing, 28*(2), 382–390. doi: 10.1046/j.1365-2648.1998.00794.x

Corless, I.B. (1994). Dying well: Symptom control within hospice care. *Annual Review of Nursing Research, 12,* 125–146.

Costello, J. (1999). Anticipatory grief: Coping with the impending loss of a partner. *International Journal of Palliative Nursing, 5*(5), 223-231.

De Vogler, K. L., & Ebersole, P. (1981). Adults' meaning in life. *Psychological Reports, 49,* 87–90.

Downing, G. M., & Wainwright, W. (2006). *Medical care of the dying.* Victoria, BC: Victoria Hospice Society.

Duke, S. (1998). An exploration of anticipatory grief: The lived experience of people during their spouse's terminal illness and in bereavement. *Journal of Advanced Nursing, 28*(4), 829–839.

Elwert, F., & Christakis, N. A. (2008). The effect of widowhood on mortality by the causes of death of both spouses. *American Journal of Public Health, 98*(11), 2092–2098. doi: 10.2105/AJPH.2007.114348

Enright, R. D. (1996). Counseling within the forgiveness triad: On forgiving, receiving forgiveness, and self-forgiveness. *Counseling & Values, 40,* 107ff.

Erikson, E. H. (1982). *The life cycle completed: A review.* New York: Norton.

Erikson, E. H., Erikson, J. M., & Kivnick, H. (1986). *Vital involvement in old age.* New York: Norton.

Ersek, M., & Polomano, R.A. (2011). Nursing management of pain. In S. L. Lewis, S. R. Dirksen, M. M. Heitkemper, L. Bucher, and I. M. Camera (Eds.), *Medical-surgical nursing: Assessment and management of clinical problems* (8th ed.; pp. 127–152). Philadelphia: Elsevier.

Fenigsen, R. (2012). Other people's lives: Reflections on medicine, ethics and euthanasia. *Issues in Law and Medicine, 28*(1), 73–87.

Field, M. J., & Cassel, C. K. (Eds.) (1997). *Approaching death: Improving care at the end of life.* Washington, DC: National Press Academy.

Fitzpatrick, T. (1998). Bereavement events among elderly men: The effects of stress and health. *Journal of Applied Gerontology,17*(2), 204–228. doi: 10.1177/073346489801700209

Frankl, V.E. (2006). *Man's search for meaning.* Boston: Beacon Press.

Frileux, S., Lelievre, C., Munoz Sastre, M. T., Mullet, M., & Sorum, P. C. (2003). When is physician-assisted suicide or euthanasia acceptable? *Journal of Medical Ethics, 29*(6), 330–336. doi: 10.1136/jme.29.6.330

Geriatric Pain.org (2012). Retrieved February 14, 2013, from www.geriatricpain.org

Georgesen, J., & Dungan, J. (1996). Managing spiritual distress in patients with advanced cancer pain. *Cancer Nursing,19* (5), 376–383.

Gerber, I., Rusalem, R., Hannon, N., Banin, D., & Arkin, A. (1975). Anticipatory grief and aged widows and widowers. *Journal of Gerontology, 30*(2), 225–229. doi: 10.1093/geronj/30.2.225

Gibson, J. (2009). Living with loss. *Mental Health Practice, 12*(5), 22–24.

Gire, J. T. (2002). How death imitates life: Cultural influences on conceptions of death and dying. In W. J. Lonner, D. L. Dinnel, S. A. Hayes, and D. N. Sattler (Eds.),

Online readings in psychology and culture (Unit 14, Chapter 2). Bellingham, WA: Center for Cross-Cultural Research, Western Washington University. Accessible @ www.wwu.edu/culture/gire.htm.

Goffman, E. (1961). *Asylums: Essays on the social situation of mental patients and* other inmates. New York: Anchor.

Golsworthy, R., & Coyle, A. (1999). Spiritual beliefs and the search for meaning among older adults following partner loss. *Mortality, 4*(1), 21–37.

Good Reads. (2013). Retrieved March 05, 2013, from www.goodreads.com.

Halifax, J. (2009). *Being with dying: Cultivating compassion and fearlessness in the presence of death.* Boston: Shambhala Publications.

Hamilton, N. (2005a). Grief and bereavement: Anticipating the loss of a spouse. *Nursing and Residential Care, 7*(4), 167–169.

Hamilton, N. (2005b). Grief and bereavement: Coping with the loss of a spouse. *Nursing and Residential Care, 7*(5), 214–216.

Hantman, S., & Cohen, O. (2010). Forgiveness in late life. *Journal of Gerontological Social Work, 53*(7), 613–630. doi: 10.1080/01634372.2010.509751

Hendin, H. (1998). *Seduced by death: Doctors, patients, and the Dutch cure.* New York: Norton.

Hendin, H., Rutenfrans, C., & Zylicz, Z. (1997). Lessons from the Dutch. *Journal of the American Medical Association, 277*(21), np. Retrieved March 20, 2013, from www.life.org.nz/euthanasia/abouteuthanasia/history-euthanasia10/Default.htm.

Herr, K., Spratt, K., Garand, L., & Li, L. (2007). Evaluation of the Iowa Pain Thermometer and other selected pain intensity scales in younger and older adult cohorts using controlled clinical pain: A preliminary study. *Pain Medicine, 8*(7), 585–600. doi: 10.1111/j.1526-4637.2007.00316.x

Heyse-Moore, L. H. (1996). On spiritual pain in the dying. *Mortality, 1*(3), 297–315.

Hirst, S. P., Lane, A. M., & Reed, M. B. (2013). Personhood in nursing homes: Results of an ethnographic study. *Indian Journal of Gerontological Studies, 27*(1), 69–87.

Ho, S. M., Chan, I. S., Ma, E. P., & Field, N. P. (2013). Continuing bonds, attachment style, and adjustment in the conjugal bereavement among Hong Kong Chinese. *Death Studies, 37*(3), 248–268. doi: 10.1080/07481187.2011.634086

Holland, J. M., Futterman, A., Thompson, L. W., Moran, C., & Gallagher-Thompson, D. (2013). Difficulties accepting the loss of a spouse: A precursor for intensified grieving among widowed older adults. *Death Studies, 37*(2), 126–144. doi:10/1080/07481187.2011.617489

Hutchison, E. (2008). *Dimensions of human behavior: The changing life course.* Thousand Oaks, CA: Sage.

Kagawa-Singer, M. (1998). The cultural context of death rituals and mourning practices. *Oncology Nursing Forum, 25*(10), 1752–1756.

Kahana, B., Dan, A., Kahana, E., & Kercher, K. (2004). The personal and social context of planning for end-of-life care. *Journal of the American Geriatrics Society, 52*(7), 1163–1167. doi: 10.1111/j.1532-5415.2004.52316.x

Kind, V. (2010). *The caregiver's path to compassionate decision-making: Making choices for those who can't.* Austin, TX: Greenleaf Book Group.

Kissane, D. W., & Kelly, B. J. (2000). Demoralisation, depression and desire for death: Problems with the Dutch guidelines for euthanasia of the mentally ill. *Australian and New Zealand Journal of Psychiatry, 34*(2), 325–333.

Kubler-Ross, E. (1969). *On death and dying.* London: Tavistock Publications.

Kuhl, D. R., & Wilensky, P. (1999). Decision making at the end of life: A model using an ethical grid and principles of group process. *Journal of Palliative Medicine, 2*(1), 75–86.

Last Acts. (2002). Means to a better end: A report on dying in America today. Washington, DC. Retrieved February 26, 2013, from www.lastacts.org/files/misc/meansfull.pdf

Ley, D., & van Bommel, H. (1994). *The heart of hospice.* Toronto: NC Press Limited.

Lindemann, E. (1944). Symptomatology and management of acute grief. *American Journal of Psychiatry, 101,* 141–148.

Maddison, D., & Walker, W. L. (1967). Factors affecting the outcome of conjugal bereavement. *British Journal of Psychiatry, 113,* 1057–1067.

Martinson, I. M. (1998). Funeral rituals in Taiwan and Korea. *Oncology Nursing Forum, 25*(10), 1756–1760.

Materstvedt, L. J., Clark, D., Ellershaw, J., Forde, R., Boeck Gravgaard, A. M., Muller-Busch, H. C., Porta i Sales, J., & Rapin, C.H. (2003). Euthanasia and physician-assisted suicide: A view from an EAPC ethics task force. *Palliative Medicine, 17*(2), 97–101. Doi: 10.1191/0269616303pm673oa

McDaniel, J. G., & Clark, P. G. (2009). The new adult orphan: Issues and considerations for health care professionals. *Journal of Gerontological Nursing, 35*(12), 44–49.

Meriviglia, M., Sutter, R., & Gaskamp, C. D. (2008). Providing spiritual care to terminally ill older adults. *Journal of Gerontological Nursing, 34*(7), 8–14.

Miller, S. C., Mor, V., Wu, N., Gonzalo, P., & Lapane, K. (2002). "Does receipt of hospice care in nursing homes improve the management of pain at the end of life?" *Journal of the American Geriatrics Society, 50*(3), 507–515.

Miller Lewis, M., & Trzinski, A. L. (2006). Counseling older adults with dementia who are dealing with death: Innovative interventions for practitioners. *Death Studies, 30*(8), 777–787. doi: 10.1080/07481180600853199

Milligan, S. (2011). Addressing the spiritual care needs of people near the end of life. *Nursing Standard, 26*(4), 47–56.

Ott, C. H., Lueger, R. J., Kelber, S. T., & Prigerson, H. G. (2007). Spousal bereavement in older adults: Common, resilient, and chronic grief with defining characteristics. *Journal of Nervous & Mental Disease, 195*(4), 332–341. doi: 10.1097/01.nmd.0000243890.93992.1e

Palgi, P., & Abramovitch, H. (1984). Death: A cross-cultural perspective. *Annual Review of Anthropology, 13,* 385–417.

Parkes, C.M. (1975). Determinants of outcome following bereavement. *Omega, 6,* 303–323.

Rando, T. A. (1984). *Grief, dying and death: Clinical interventions for caregivers.* Champaign, IL: Research Press.

Riggans, L. (1992). Living with loss. *Nursing Times, 88*(27), 34–35.

Ryan, P. Y. (2005). Approaching death: A phenomenologic study of five older adults with advanced cancer. *Oncology Nursing Forum, 32*(6), 1101–1108. doi: 10.1188/05.ONF.1101-1108

Satterly, L. (2001). Guilt, shame and religious and spiritual pain. *Holistic Nursing Practice, 15*(2), 30–39.

Segers, J. H. (1988). Persons on the subject of euthanasia. *Issues in Law & Medicine, 3,* 407–424.

Seibold, M. (2001). When the wounding runs deep: Encouragement for those on the road to forgiveness. In M. R. McMinn and T. R. Phillips (Eds.), *Care for the soul* (pp. 294–308). Downer's Grove, IL: InterVarsity.

Sheehan, D. K., & Schirm, V. (2003). End-of-life care of older adults: Debunking some common misconceptions about dying in old age. *American Journal of Nursing, 103*(11), 48–58.

Sidell, M., Samson Katz, J., & Komaromy, C. (2000). The case for palliative care in residential and nursing homes. In D. Dickenson, M. Johnson, and J. Samson Katz (Eds.), *Death, dying and bereavement* (2nd ed.) (pp. 107-121). London: Sage.

Siegel, K., & Weinstein, L. (1983). Anticipatory grief revisited. *Journal of Psychosocial Oncology, 1*(2), 61-73. doi: 10.1300/J077v01n02_04

Singer, P. A., Martin, D. K., & Kelner, M. (1999). Quality end-of-life care: Patients' perspectives. *Journal of the American Medical Association, 281*(2), 163–168.

Smedes, L. B. (1997). *The art of forgiving: When you need to forgive and don't know how.* New York: Ballantine Books.

Sourkes, B. (1987). Views of the deepening shade: Psychological aspects of life-threatening illness. *The American Journal of Hospice Care, 4*(3), 22–29.

Starks, H., Back, A. L., Pearlman, R. A., Koenig, B. A., Hsu, C., Gordon, J. R., & Bharucha, A. J. (2007). Family member involvement in hastened death. *Death Studies, 31*(2), 105–130. doi: 10.1080/07481180601100483

Swarte, N. B., van der Lee, M. L., van der Bom, J. G., van den Bout, J., Heintz, A. P. M. (2003). Effects of euthanasia on the bereaved family and friends: A cross sectional study. *British Medical Journal, 327* (7408), 189–192.

Teno, J. M., Gozalo, P. L., Lee, I. C., Kuo, S., Spence, C., Connor, S., & Casarett, D. J. (2011). Does hospice improve quality of care for persons dying of dementia? *Journal of the American Geriatrics Society, 59*(8), 1531–1536. doi: 10.1111/j.1532-5415.2011.03505.x

Thinkexist.com. (2013). Retrieved February 10, 2013, from www.thinkexist.com

Thomas, C. L., & Cohen, H. L. (2006). Understanding spiritual meaning making with older adults. *Journal of Theory Construction & Testing, 10* (2), 65–70.

Thomas, D. (1953). *Dylan Thomas selected poems: 1934–1952.* New York: New Directions.

Vig, E. K., Davenport, N. A., & Pearlman, R. A. (2002). Good deaths, bad deaths and preferences for the end of life: A qualitative study of geriatric outpatients. *Journal of the American Geriatrics Society, 50*(9), 1541–1548.

von Gunten, C. F. (2012). Evolution and effectiveness of palliative care. *American Journal of Geriatric Psychiatry, 20* (4), 291–297. doi: 10.1097/JGP.0b013e3182436219

Walker, R. J., & Pomeroy, E. C. (1996). Depression or grief? The experience of caregivers of people with dementia. *Health Social Work, 21*(4), 247–254.

Walsh, F. (2009). Religion, spirituality and the family: Multi-faith perspectives. In F. Walsh (Ed.) *Spiritual resources in family therapy* (2nd ed.; pp. 3–30). New York: The Guilford Press.

Weingarten, K. (1999). Stretching to meet what's given: Opportunities for a spiritual practice. In F. Walsh (Ed.), *Spiritual resources in family therapy* (pp. 240–255). New York: The Guilford Press.

Weisman, A. D. (1988). Appropriate death and the hospice program. *Hospice Journal, 4,* 65–77.

Won, A. B., Lapane, K. L. Vallow, S., Schein, J., Morris, J. H., & Lipsitz, L. A. (2004). Persistent nonmalignant pain and analgesic prescribing patterns in elderly nursing home residents. *Journal of American Geriatrics Society, 52*(6), 867–874.

Worden, J. W. (2009). *Grief counseling and grief theory: A handbook for the mental health practitioner* (4th ed.). New York: Springer.

Yancey, P., & Brand, P. (1997). *The gift of pain.* Grand Rapids, MI: Zondervan.

Chapter 7

THE FAMILY

Happy or unhappy, families are all mysterious. We have only to imagine how differently we would be described—and will be, after our deaths—by each of the family members who believe they know us.

Gloria Steinem (American feminist and writer)

Reflective Questions

- What are several potential challenges that families may face when assisting an older adult through a transition?
- What are three guiding principles that may help you as a professional in facilitating older adults and their family members in navigating a transition?
- How do societal definitions of family impact your understanding of family and how you practice as a professional working with older adults?

Regardless of whether we agree with the quote from Gloria Steinem, she raised some important aspects about families. Families are indeed mysterious, and defining their composition is not as easy as it may seem. They are made up of much more than physical bodies; they entail aspects that are not so visible, such as beliefs, patterns, alliances, and norms (Wright & Leahey, 2013). What regulates families, in terms of patterns, norms, roles, and beliefs can be a source of great comfort and stability, and can be, paradoxically, endlessly frustrating and befuddling. How members of a family relate to each other, understand and describe each other can change over time and can vary from context to context. And, after the death of a family member, our understandings, descriptions, and relationship to the departed family member can change markedly.

Despite the challenge of understanding families and work involved in unraveling family patterns and relationships, it is vital that older adults be considered within the context of their family. While an individual is always best understood within the context of the family (Wright & Leahey, 2013), this is particularly so

for older adults, especially when older adults are experiencing transitions. For a number of older adults, particularly as they reached more advanced ages of 80 years and above, the physical and cognitive problems that become more prevalent at that time in life make them more vulnerable and in greater need of support. They are less able to compensate for their disabilities and hence may need to rely upon others. Even if family members have been estranged, at this time of life, some adult children become involved. This means that it is imperative for nurses and professionals to assess and intervene not just with the older adult who is experiencing transitions, but also the family. It is not just the older adult who may be feeling traumatized, but family members as well.

Within this chapter, we begin with attempting to define "family." We briefly mention the idea of developmental tasks for aging families, then proceed to address some challenges nurses and other professionals might encounter when working with families in facilitating transitions for their older adults. We offer some specific ideas to address the difficulties professionals may face. Next, a case example is presented that reflects some of the challenges professionals face when working with families. Finally, we cover some guiding principles that can assist nurses and other professionals in working with older adult families experiencing transitions and, where applicable, apply the case example through this discussion.

DEFINITION OF THE FAMILY

Decades ago, it was generally accepted that the family was composed of individuals who were biologically related. Typically, a family was made up of a father, mother, and a number of children. Some families might also have an aging grandparent living within the home. Roles were rigidly and clearly defined with men as "breadwinners" and women as "homemakers." Today, roles have become more relaxed; women predominantly work outside the home, there are increased rates of divorce with single parent families, there is greater awareness and visibility of gay and lesbian families (Carter & McGoldrick, 2005), and correspondingly, the definition of family has stretched beyond the borders of biologically related individuals.

So what is the definition of a family? Certainly, the legal definitions vary from country to country and change over time. For instance, in 2005, the Statistics Canada definition of family was:

> [A] now-married couple, a common-law couple or a lone-parent with a child or youth who is under the age of 25. . . . Now-married couples and common-law couples may or may not have such children and youth living with them. (Statistics Canada, 2012)

In the 2011 Canadian Census, the definition of family became broader. This Census definition stated:

> A census family is composed of a married or common-law couple, with or without children, or of a lone parent living with at least one child in the same dwelling. Couples can be of the opposite sex or of the same sex. (Statistics Canada, 2012)

Thus, the Census definition of family has expanded to include gay and lesbian couples. Further, step-families and foster children were counted for the first time in the 2011 census (Statistics Canada, 2012). Thus, legal definitions are expanding to include the multiple forms of families present in Canada and other developed nations.

DEVELOPMENTAL TASKS OF AN AGING FAMILY

Wright and Leahey (2013) provided a lens through which to understand family processes: the family life cycle (originally discussed by Carter and McGoldrick, 1989). Within the family life cycle, families progress through various stages. As part of moving through the various stages in the growth and development of the family, Wright and Leahey (2013) discussed the idea of the completion of tasks for families at various developmental stages. For instance, one stage is entitled "Marriage: The Joining of Families" (p. 100). In this stage, two individuals marry and thus form their own family unit. The tasks at this developmental stage involve the establishment of an identity as a couple, as well making choices about having children (Wright & Leahey, 2013). These tasks, then, are part of the fabric and work of that stage of life and stage of the formation of the couple relationship.

The last stage of development in the family life cycle is "Families in Later Life" (Wright & Leahey, 2013, p. 108). This stage may begin with the commencement of retirement and extends until the death of both spouses. However, as noted by Wright and Leahey (2013), it is hard to know when this stage now begins. The suggested tasks for this phase (we quote verbatim) include:

- Maintaining own or couple functioning and interest in the face of physiological decline: exploration of new familial and social role options.
- Making room in the system for the wisdom and experience of seniors.
- Dealing with loss of spouse, siblings, and other peers and preparation for death (Wright & Leahey, 2013, pp. 109–110).

As will be evident from the forthcoming discussion in this chapter, the ability for older adults and their family members to address the tasks of aging families

may be compromised by transitions caused by illness (e.g., dementia, depression), relocation (e.g., to continuing care facility, such as a nursing home) or extremely troubling existential issues.

CHALLENGES IN WORKING WITH THE FAMILY

There are a number of challenges inherent in working with families of older adults who are undergoing transitions. The challenges may be related to family composition, past family experiences, and the challenges in transitions such as the placement process.

Defining the Family: Who Really is the Family?

Although there are legal definitions, or definitions used for statistical purposes within countries, there is little agreement among scholars or the public regarding what constitutes a family (Edwards & Graham, 2009). Broadly speaking, families can be conceptualized and categorized according to structure, psychosocial aspects, and transactional processes. The structural understandings of family emphasize biological and adoption ties, as well as the extended family. Psychosocial definitions focus on whether particular family tasks are performed. Thus, psychosocial definitions assume that there is at least one adult who is responsible for the nurturance and socialization of children. Finally, the third category focuses upon transactional processes. This understanding of family highlights families as sharing rituals, identity, loyalty, and belonging. Within this understanding, there is great variance in conceptions of the "family" (Edwards & Graham, 2009). One such example of a definition that privileges transactional processes is that of family therapists Lorraine Wright and Maureen Leahey. They suggested that the family is "who they say they are" (Wright & Leahey, 2013, p. 55).

While we agree with this definition, we also recognize that when dealing with transitions in older adults, healthcare and legal processes may demand greater tightness in the definition. For instance, healthcare professionals will generally seek input from biological family members, rather than from a neighbor or a friend. Even if a friend or neighbor has more contact and a closer relationship with an older adult, professionals will generally seek to involve family members in decision making, rather than a neighbor, in order to avoid legal issues if family members contest the decisions. As such, sometimes professionals in the community, as well as those in hospital or in nursing homes, need to spend some time navigating through "who is who" in the older adult's family, their connection, and who makes decisions. Older adults, as well as family members, need to be counseled regarding the importance of personal directives (for healthcare decisions

often involving end-of-life care), guardianship (for decisions regarding treatment and issues such as placement), and enduring power of attorney or trusteeship (for financial decisions).

What if Family Members are Not Involved?

Occasionally, within our clinical work with older adults, we have come across older adults where there seems to be no family involvement. In these situations, there may be family members, such as adult children, but for various reasons they have chosen not to be involved. Or, the older adults may be single (never married or divorced) with no children and no other family members, such as nieces, nephews, or cousins, have presented to the professionals involved. These situations pose difficulties, depending upon the setting in which the older adult is currently situated. For instance, a nurse or occupational therapist who visits an older adult in the home may be concerned about the safety of the older adult. If the therapist enters the home of an older woman and finds little food in the refrigerator and cupboards, many stairs and scatter rugs, papers and objects scattered across the floor (fall risk), he may ask if family members are concerned about safety. If the elderly woman tells him that she has no family, he might become even more concerned that there are no family members to provide ongoing support and monitoring. He may wonder if he needs to refer his older patient for a psychiatric consultation; and he may struggle, knowing that if this woman is deemed unsafe and mentally unable to care for herself at hospital, she might be removed to live in another setting.

If this same older woman is brought to hospital and placed on a geriatric or a mental health unit, she will be assessed for mental competency, and her abilities to care for herself independently within her own home. All staff—psychiatry, nursing, social work, occupational therapy and recreational therapy—will conduct assessments to ascertain the soundness of this woman's cognition, her ability to plan a meal, buy the groceries, and cook for herself. They will determine if she is able to take care of personal hygiene, dress, and complete other functions related to independent living (Lane, 2007). If they decide that their older patient is unable to care for herself independently, they may need to look at placement. However, there is a problem. If this woman truly has no family members, the social worker may need to contact the Office of the Public Guardian in order to have a guardianship order put in place (Office of the Public Guardian, 2012). However, if there are family members, but they are unwilling or reluctant to become involved, the situation becomes stickier. The Office of the Public Guardian may be reluctant to secure the guardianship order, if there are family members who are not unstable or deemed unfit to assume guardianship of this older woman. This means that this woman may spend longer on the hospital unit than she would like, as the professionals on the unit address issues with the Office of the Public Guardian.

What if the Older Adult has Different Views of What should Happen in the Transition?

It is not uncommon that an older adult disagrees with family members regarding what should happen in his care. He may think that despite his health problems, he can manage well enough in his home or apartment. He may remain within his home, but when a health crisis hits, he will often be brought to hospital by family members or ambulance. Once in hospital, healthcare professionals will work to stabilize his health and then may wonder if he is fit to return home. They may begin some mental status assessments, as well as physiotherapist and occupational therapist assessments, to determine his abilities to function alone within his home. When consulting family members, professionals may find that adult children are worried about the safety of their father and that they would like to see him move to an assisted living facility or be placed in a nursing home. When talking with the older patient, he may be adamant about his desire to remain in his home and his ability to manage.

The work of nurses and other professionals involves careful assessment of this older man's abilities to manage independently. The assessment of the occupational therapist, in terms of this man's ability to plan meals, shop for groceries, cook food, manage money, and call 911 in a crisis, becomes front and central in the decision making of the healthcare team (Lane, 2007). While they cannot force a move to an assisted living facility or a nursing home (unless the man is deemed incompetent, at which point a family member may become the legal guardian and decides that her father needs placement), but the healthcare team can make recommendations.[1]

When making recommendations, it is very important that the older patient, as well as family members, are present to hear the deliberations of the interprofessional team. If the healthcare team believes that their older patient is still competent to make decisions and still able to cope independently, they can help the older man and family with suggestions regarding additional supports in the home to enhance his safety and living. These suggestions can include mechanical devices such as a raised toilet seat, a railing by the toilet, and a bath stool for the shower. They can also suggest a homemaker for cleaning and a personal aide to assist with showering (depending upon the coverage of the province or state, or the personal finances of this man or family members). If the healthcare team agrees with family members that the older man is not mentally competent or able to function independently within the home, the general axiom of placement (as discussed in Chapter 4) is to suggest the *least restrictive environment* for the patient (Lane, 2007). Hence, in this situation, the team might recommend an assisted living

[1] We encourage professionals to access The Office of the Public Guardian in their province or state for information specific to their geographical region.

facility with additional supports if they determine that this man is still cognitively intact, but just needing additional supports.

What if There are no Family Members Available, or if Both Members of the Couple are Experiencing Cognitive Impairment?

It is not that uncommon to have both members of a couple experiencing some degree of dementia, particularly if they are both well into the 80s (the incidence of dementia climbs markedly by age 85 years) (Canadian Study of Health and Aging, 1994). It is, however, uncommon to have both members of a couple experiencing dementia in their early to mid 70s, where there are no children and no nearby relatives involved. In such a situation, healthcare professionals may need to take additional steps.

I (AML) remember one situation where both the husband and wife suffered from a dementia. Their caring doctor recognized that each member of this couple was experiencing significant memory loss. Out of concern regarding their living situation, she visited their home to find that the house was a mess, the couple had many dogs and cats, and the couple ate poorly, preferring to feed their animals their supply of vitamins and food. This physician contacted our unit psychiatrist to arrange a day where the couple could be admitted to our unit. She herself personally arranged for the husband and wife to be brought to the hospital and admitted to our unit. By making all the arrangements, she circumvented the normal multi-stepped process of being admitted to hospital. Once in hospital, the professionals in the healthcare team began their assessments, according to their disciplinary focus. This couple was situated together in the hospital room, prior to the practice of men and women sharing hospital rooms. The couple pushed their beds together to make a double bed, rather than two single beds. They could be seen walking the unit together, hand in hand, with the husband carrying his briefcase. They were obviously very attached to each other, both physically and emotionally. Every now and then, the husband might say to me, "Excuse me, we've had a very nice stay in this hotel, but can we pay our bill and leave now?"

This couple was eventually placed in an assisted living facility that had a locked unit for those with dementia. They were able to share a room together on this unit. However, they also had a paid companion who took them out on day trips. I remember one day running on a lovely pathway along the side of a large body of water within the city. There were benches strategically placed at various points on the path, so that individuals could enjoy the scenery, including the lovely blue water, the deciduous and coniferous trees and grass. The couple sat on the bench, gazing at the blue water in the distance, enjoying the gentle and soft wind blowing in their faces, and looking truly contented. Knowing that they would not recognize me, I stopped anyways to chat about the weather and the lovely view. The couple happily agreed about the beauty and the weather. As I took my

leave from them and commenced jogging again, I felt extremely glad that they appeared happy and at peace, and, that they remained together. This situation was one in which the husband and wife, while having no children, had a caring physician who took additional steps, probably outside her scope of responsibility. The couple also had significant monetary resources that could ensure their placement in a nice facility, as well as pay for extras, such as a companion to take them out on day trips. Unfortunately, not all situations where there are few or no family members resolve so well.

In situations where both members of the couple are experiencing cognitive impairment, and there appears to be no available family members to directly intervene, a member of a mental health team, a family doctor or a psychiatrist may need to get involved. The couple may have to be brought to hospital under the provincial mental health act (or state act, depending upon country) to be assessed. If at all possible, it is important to keep the couple together, both in hospital and in placement in the upcoming facility. This fosters the "couple functioning" (Wright & Leahey, 2013, p. 109), despite the cognitive impairment. While it is true that sometimes one member of the spousal couple wants to be placed on a different nursing home unit than the spouse, usually spouses that have been together for decades prefer to remain together. This may necessitate a longer wait within hospital. During the wait in hospital, the unit social worker can continue the search for some family members, be they nephews or nieces or cousins.

When Grandchildren are Caregiving

It is not unusual today to hear of grandparents raising grandchildren due to parents being unable to give care. The parents may have severe mental illness, be incarcerated, or frequently in other parts of the world, have HIV/AIDS, or have passed away from AIDS. It is far less common to hear of grandchildren providing care for their grandparents. However, there is a growing cohort of grandchildren between the ages of 18 to 30 who are providing significant care for aging grandparents of which we know little about[2] (Dellmann-Jenkins, Blankemeyer, & Pinkard, 2000; Ihara, Horio, & Tompkins, 2012; Levine et al., 2005). Within the literature, questions are raised about the impact of providing care to grandparents at this developmentally crucial time. During these years, individuals go to college or university to study, work on a career, marry, and have children (Dellmann-Jenkins et al., 2000).

Generally, there is little research on this cohort of individuals. Some research examines grandchildren's role when they are not primary caregivers; they may

[2] While there is also a small body of research on adolescents as caregivers for grandparents, these individuals are caregiving within their family structure and home. Therefore, they are not the primary caregivers, but rather, assist parents in caregiving (Hamill, 2012; Orel, Dupuy, & Wright, 2004). As such, this section will not address adolescents who assist in care.

be assisting parents, but do not carry the share of the load. They may provide instrumental care such as shopping, transportation, and housework (Levine et al., 2005), but are less likely to provide more personal care. The research suggests that when grandchildren are not the primary caregivers, the negative impact is relatively small. Grandchildren caregivers reported some emotional stress, less time for family and friends and less time for hobbies (Levine et al., 2005). However, when grandchildren are the primary caregivers, they may suffer greater stress and impact upon mental health. In the study by Dellmann-Jenkins and colleagues (2000), young adult children and grandchildren who were the primary caregiver reported struggles with their spouses or dating relationships, challenges in managing careers and caregiving duties, and mental health issues, such as depression. The most commonly stated need among the young caregivers was emotional support from individuals in the same age group. Unfortunately, despite the need for emotional support, few caregivers accessed formal support systems, such as support groups (Dellmann-Jenkins et al., 2000).

An interesting subset within this category is the group of English-speaking young adults who become essentially responsible for their relatively recently immigrated extended families. In such situations, these grandchildren may provide vital service to their non-English speaking grandparents in their dying. While the adult children are present, language barriers make the necessary conversations between healthcare staff and the patient very difficult; hospitals and hospices may frequently access these English-speaking grandchildren for assistance in communication. The role these grandchildren fulfill is more than simply translation, however. It can also be bridging two traditions: North American mores (in which they are immersed) and the traditions of their grandparents/parents. These grandchildren may find themselves caught between cultural norms and unwittingly in a double bind. Not uncommon in palliative care settings with recently immigrated Asian families is the reluctance to speak to the terminally ill family member about her impending death. Family may state to the terminally ill individual that she is coming to a very nice hospital to get better. While this is a cultural practice, it does not fit with the North American practice of being open with a dying person about her looming death. Palliative care staff can feel a conflict in not being able to speak of the dying person's impending death; grandchildren, accustomed to North American norms, may also feel conflicted about keeping this information about their grandparent's health a secret. In one situation, a grandfather's impending death was not revealed to the patient himself or to members outside of the immediate family. In the elderly gentleman's dying, the family used computer technology to connect relatives in Asia to what was happening in the hospital room, so that they would understand that their relative was truly dying. The adult grandchildren felt truly conflicted and may well have violated their parents' wishes; but they felt they had to let extended family know of the situation before Grandfather passed.

Nurses and other professionals assessing and intervening with families where grandchildren are caregivers need to assess how much care grandchildren are providing for the older adult, the impact of caregiving upon their lives in terms of their ability to work, date, and lead normal lives, as well as upon their emotional/mental health. Professionals need to ask grandchildren caregivers what kinds of support they need in providing care: Are there formal supports that can be accessed to relieve them of some of their duties? Are there supports, such as counseling or support groups, that might provide a venue for venting the stress of caregiving, receiving emotional support, as well as helpful care giving information? Further, are there family members that could be involved to lessen the load? Grandchildren caregivers should be reassured that committed caregivers *do* access formalized supports and share the work load (Piercy, 2007). This may be particularly significant for those from other cultures (Benner Carson & Koenig, 2004); in these situations, accessing professional help can sometimes be seen as a disgrace or a failure. Professionals should also commend them (Wright & Leahey, 2013) for their resilience and acknowledge that their role gives a sense of purpose and meaning to their lives (Piercy, 2007). With the growing numbers of grandparents who are raising young grandchildren, there may be many more grandchildren as primary or secondary caregivers of older adults in the future (Levine et al., 2005).

The Dynamic Exerted by Family Members Not Present

Unbeknownst to nurses and other professionals, family members who do not present to the interprofessional team may be exerting a powerful influence upon family members. These family members may be distant geographically or may simply choose not to present to the team on the unit or at the nursing home. In these situations, these absent family members may be influencing the decision making of the present family members around decisions such as trusteeship, placement, and healthcare. These unseen alliances are one reason why it is important for nurses or other professionals to complete a genogram (picture of a family tree) (Wright & Leahey, 2013) to understand who is a part of the family system. Also, it is important to meet with the family members together in a scheduled family meeting. The professional can question the family members present about siblings or other members of the family who are not in attendance but are part of the caregiving and decision making on behalf the older adult.

Also, the genogram provides the opportunity for the professional to assess who is in the family, but no longer physically present due to death. Sometimes, a family member may not be present bodily, because he or she is deceased, but the individual is still a powerful presence in the family (McGoldrick, 1991). When completing the genogram, the nurse or professional can ask about the deceased member. When did the individual die? What were the circumstances? How is the family member remembered? If the family member was present today, what would

he or she suggest happen with the older adult? The nurse or other professional not only is attempting to examine the influence of unseen family members, but also to assess the responses of family members to these questions. Are family members uncomfortable? Do family members appear to be hiding a family secret about the unseen individual? Sometimes those who are not present, particularly due to death, can exert powerful influences in the decisions that are made and how family members relate to each other and talk about the past (McGoldrick, 1991).

Unpleasant memories of the deceased family member, or a negative experience in the death of that individual, can strongly influence the emotions and choices of adult children in the end-of-life decisions for the second parent.[3] The answers to the questions asked and the emotions displayed, as well as how family members react to each other's responses gives the health care team valuable information about what the family, not simply the patient, will need.

Who Really is the Patient?

Sometimes in working with families, we realize that the "identified patient" is not really the problem. Or perhaps stated better, the identified patient is behaving in certain ways that are considered problematic, due in part because of unhealthy family patterns. This is sometimes the case when adolescents present as the family problem. When a therapist works with a family where an adolescent is causing significant problems, sometimes the problem is not simply that of the adolescent, but in actuality, the adolescent is responding to family patterns. Part of the work of the therapist involves deconstructing the reasons behind the adolescent's behavior and connecting it to the family pattern that is troubling, and then working to disrupt this family pattern. Interestingly, a similar dynamic may sometimes occur in families with older adults.

Sometimes older adults are admitted to hospital units for problems related to addictions. The adult children may be sincere in their wish for their parent to be free of addiction; the statement "We just want our mom (or dad) back!" is completely heartfelt. However, the adult children may not realize to what extent particular family patterns depend upon the older adult being addicted to a substance, and therefore not fully functional as an adult/parent. In a drunken state, the older man may capitulate to his adult children's requests for money. While the adult children truly *want* a fully functional father, they also *need* his money. When through professional treatment the older man becomes sober, he may start to develop a sense of self that feels more confident and able to make decisions.

---

[3] Responses to the questions asked by the nurse or other professional also can elicit positive information. Favorable memories of a deceased parent and meaningful experiences in that parent's death can, for example, reveal to nursing staff the "tools in the toolbox" for the end-of-life decisions for the second parent. "We've been through this before" gives professionals the reassurance that a family has some preparation for what lies ahead.

When his children ask for more money, he may now say "no," recognizing that the request is unreasonable and that he does not have to give in to gain acceptance. (He now recognizes that his own self-respect and self-acceptance means much more than the approval of his children). The children, not anticipating that their financial source would dry up as a result of treatment, may stop visiting their father. The father will then need support not to give in to his children, or return to his drinking patterns, out of frustration over the rupture in this relationship. Although the children were genuine in their desire to have a sober father, their continued use of his monies depended upon him being mentally compromised through drinking.

The above scenario is not infrequent in relation to addictions in a family or other family patterns that develop around an illness. In these situations, the older adult may be the identified patient, but in actuality, there may be several individuals who are in need of professional assistance.

Nurses and other professionals may also see this type of situation occur with spouses of older adults. Although an older woman is admitted to hospital due to her inability to cope with multiple sclerosis and refusal to manage the activities of daily living (when healthcare professionals believe, based upon their assessments, that she is capable of completing these tasks), her husband may be unwittingly contributing to these issues. For instance, if the husband is busy and does not offer time or emotional support to his wife unless she is symptomatic, she may become focused upon her pain and disability in order to gain her husband's support and attention. In these circumstances, neither individual is "bad"; however, the wife cannot secure the emotional and physical support she wants when she is self-sufficient, and the husband may be oblivious to the emotional yearnings of his wife. By being overly engaged in his own pursuits when his wife is reasonably stable and by only providing nurturance when his wife is ill, he inadvertently gives the message that sickness is necessary to bring attention and support. In a situation like this, the professional works to disrupt this pattern so that the couple provides nurturance to each other, in both ill and stable health.

The work of nurses and other professionals involves recognizing the patterns that are occurring among family members and gently identifying the patterns. In regards to the first example with the alcohol-dependent father and the adult children, the professional can reinforce to the father the importance of not jeopardizing his sobriety due to his children's withdrawal. The strength of this older man is reinforced and staff can question the man about what his ability to stop drinking says about himself; the goal of this question is to help this man begin to develop a sense of self that includes personal strength and resilience. Staff can inquire of this man about other times in his life when he demonstrated strength and resilience. If the individual responds with descriptions of physical feats, such as mountain climbing, running, or sports, professionals can use metaphors in their work with him to reinforce his strength. Knowing that individuals with struggles with addictions can return to substances when returning home or when

under stress, professionals ensure that this man has supports for sobriety when he returns home, such as an addictions counselor and a support group (Alcoholics Anonymous, for example).

What if the Older Adult Who Is Admitted to Hospital Has One or Two Very Aged Parents?

Sometimes an older adult is admitted to hospital because of particular health or mental health problems, but the driving force behind admission is that the very aged parents can no longer care for the older adult, or, out of fear for when one or both of them dies and the need to ensure that placement occurs. This may be because the older adult has been living with the very elderly parents all of her life due to significant mental illness, a developmental disability or some kind of physical disability that prohibits independence. I (AML) remember working with one older woman—Agnes—who was admitted to hospital. She was in her late 70s and had been diagnosed with schizophrenia in early adulthood. Agnes had lived with her parents all of her life and by now, her parents were of very advanced years. One parent had reached the century mark, and the other was 98 years of age! Agnes was initially admitted due to a new-found "rebellion" toward her parents and the fact that her parents felt they could not handle her. The second admission, however, was related to the need for placement. Agnes' parents were very afraid that they would pass away preventing them from ensuring that she had found a suitable accommodation.

Agnes absolutely loved being on the hospital unit. She developed relationships with other patients and now had a roommate that she could talk with throughout the day. Staff took an interest in her and recognized her strengths, including playing musical instruments. When time came for her transfer to a nursing home, she screamed, begged, and pleaded. She cried out in a mournful wail that she loved the hospital unit and wanted to stay there forever. Myself, the psychiatrist, and nurse tried to console Agnes and tell her that we would love to keep her, but due to the unit being in an acute care hospital, this was not possible. Our hearts and our voices were pained as we truly cared about Agnes and loved seeing her happy on the unit. Sadly, Agnes screamed all the way down the hallway, outside the hospital, and into the transfer vehicle. Initially, we were told that she was not doing well in the nursing home. However, some months later we were informed that she was doing well, had adjusted to the nursing home transition, and was enjoying her new environment.

Regrettably, many aged parents fail to make caregiving plans for their aging child with a disability (Dillenburger & McKerr, 2011) or mental illness (Smith, Hatfield, & Miller, 2000). They may be afraid that staff in an institution will not provide personalized care and may also not want to place the burden of the disabled adult child upon their other children (Gilbert, Lankshear, & Petersen, 2008). It is vital for professionals to encourage very aged parents to make future

plans for their aging disabled or mentally ill children. When very aged parents have been caregiving for a child for 50 to 60 years, they may not be aware of housing options besides residential housing. Very aged parents should be aware of the waiting time on placement lists, as well as the dangers of delaying the placement process until precipitated by a crisis, as an inappropriate option may be the only available option in an emergency (Gilbert et al., 2008).

From the perspective of developmental stages in the family life cycle, it is important to note the impact of caring for an older, developmentally delayed child, or an adult child with any significant disabilities, on a very aged couple. The couple may struggle to have the time or energy to engage in activities together that fosters a sense of "couple functioning" (Wright & Leahey, 2013, p. 109). The very elderly couple may not be able to attend to issues of preparation for their own deaths, for instance, life review, as they are too busy caring for their elderly, disabled child.

Longstanding Issues between the Parent and Adult Child/Children

In our experiences, we have found that it is not uncommon that adult children, who may be approaching their fifth or sixth decade of life, are afraid of one of their aging parents. In fact, some adult children are petrified of an older parent. The fear is not related to a current danger at being in the presence of the parent, as the parent may be frail, cognitively impaired, and quite helpless. The fear stems back to their childhood. Adult children may cry over the significant dilemma they now face; they dearly want to help the older, frail adult who needs assistance, but they have such fear and revulsion within their souls due to extensive abuse in childhood. While cognitively they recognize that the older individual is no longer the abusive individual that he or she once was, the scars, pain, and revulsion are reopened and reawakened through contact with the parent. The predicament is this: Morally, they cannot turn their backs on the frail parent who needs help, but psychologically, spiritually, and physically, they tremble at the thought of being involved.

The work of the professional involves several aspects. First, the professional validates the experiences of fear and, sometimes, sheer terror that the adult children may be experiencing. This is important as adult children may be surprised by their overwhelming emotions; they might honestly say to the nurse or other professional, "But I thought I had dealt with the abuse! Why am I feeling so terrified now?"

Second, the professional helps the adult children decide what they can and cannot do for the older parent. Perhaps they can supply cigarettes and clothes for the parent but cannot come on the unit and visit the parent. This is perfectly acceptable. Or maybe they can be involved in monitoring finances through trusteeship, but cannot see the parent or can only do so sporadically. Again, this is very appropriate and the adult children should be commended for this. If the adult

child does not feel that he can be involved due to painful experiences in the past, he should not be guilted or goaded into helping. If however, he wants in some way to be involved, there may be long-term benefit. For some adult children, involvement in helping an aging parent can have a healing effect. By responding in kindness toward the parent who frightened them, they finally achieve some measure of peace and closure regarding painful childhood events.

To illustrate, in one case, a retired woman was afraid to visit her mother in a palliative setting due to a lifetime of emotional abuse; for this adult daughter, it was a "double bind." Ethically, she felt she could not live with herself unless she saw her mother in her dying. On the other hand, it caused profound fear. On her mother's last day, this gentle lady stood, shaking and supported by the chaplain, at the end of her mother's bed, to say "Goodbye, Mom" and "I love you." In this, she confronted her fear of seeing her mother, satisfied her deep moral and spiritual need to acknowledge her mother, and, in this situation, heard the words back from her mother, "I love you, too."

Disagreements about the Course of Action for an Aging Parent

Even when families are emotionally close and live in relative harmony, disagreements can occur regarding the course of action that should take place for an aging parent. While aging parents may be able to manage better as a pair, both in day-to-day functioning and decision making, when one parent is placed in a nursing home or dies, adult children may step in to assist the one remaining parent now living alone in the community. Disagreements between adult children can abound for several reasons.

First, adult siblings within the same family may hold very different views regarding how long a parent should be maintained within her home, when that parent, for a variety reasons, should be moved to an assisted living facility or a nursing home. Disagreements may abound with end-of-life treatment decisions, as well. Family members, just like healthcare professionals, may hold varied views about the importance of maintaining autonomy within the home, or the preeminence of protecting the parent at all costs (and thus removing the parent from potential danger that comes with living alone).

Second, adult siblings who live in close proximity to the aging parent may feel that they should have more "say" in what happens with the parent than siblings who live far away. Their rationale is that because they see their parent regularly, they better understand the parent's challenges and deficits. Also, as they physically do much more for the parent, in comparison to siblings who live far away, they should have greater decision making power.

Third, disagreements regarding an appropriate course of action for the remaining parent may soon move beyond the actual disagreement and tap into power struggles of the past. Siblings who argued as children may now unwittingly enter into a similar

dynamic that they engaged in as children. They may be certain that they are arguing for the betterment of their parent, but can actually be re-enacting power struggles of the past. Why does this happen? When individuals and families are under great stress, they often revert to previous methods of coping and interaction, even when these coping methods and patterns of interaction were unhealthy. Unknowingly, siblings can return to past methods of relating and working out arguments.

The work of nurses or other professionals involves helping adult children recognize that varying opinions on what should happen with the aging parent are usually based upon care and concern; thus the adult who argues for keeping the parent at home loves his aging father no less than his sister who argues for a move into an assisted living facility. It also involves looking at how family members make decisions among themselves, who are usually the decision makers and how they have come to a resolution in the past. Further, the work of professionals involves educating family members regarding the process of placement and navigating the system. Adult children may not be aware of how long it can take to bring about placement. Once they become aware of the length of the process, as well as the steps involved, they may be able to come to a consensus. Even if family members (with input from the older adult) agree that placement in a nursing home is not currently necessary, this topic has been raised for discussion and the family may have a better sense of when the time will be appropriate for them.

The Influence of Grief and Guilt upon Family Members' Decisions

Decision making on behalf of older adults can be a perilous situation. Family members, both spouses, and adult children may wrestle with significant grief and guilt in the decision to place the older adult (Dellasega & Nolan, 1997; Grau, Teresi, & Chandler, 1993; Johnson, Morton, & Knox, 1992; Kao, Travis, & Acton, 2004; Kellett, 1999; Logue, 2003; Reuss, Dupuis, & Whitfield, 2005; Sandberg, Lundh, & Nolan, 2001). The emotional turmoil family members undergo may be even greater when they feel that they had to make the decision on their own, with little support form professionals (Davies & Nolan, 2003). In our clinical experiences, family members weep over the placement process and they struggle as they make the decision to place, during the placement process, and sometimes after placement occurs.[4] Often the placement decision is delayed due to guilt and grief around placement.

Despite the magnitude of emotional turmoil that family members experience, professionals often do not acknowledge the grief and guilt involved in placement. Dellasega and Nolan (1997) interviewed 54 family caregivers in the United States and the United Kingdom to examine the positive and negative responses

[4] Sometimes the weeping continues after that parent's death and can impact the decision making for other older adult family members in the future.

to placement. They discovered that family members suffer overwhelming guilt in placing their older adults, and yet this guilt was rarely acknowledged by healthcare professionals (Dellasega & Nolan, 1997). Family members also reported that they were usually not encouraged to talk with staff in nursing homes about the challenges in placement and that these difficulties were not acknowledged (Davies, 2005). And when family members did not receive emotional support during the transitional period, they felt overwhelmed and resentful (Reuss et al., 2005).

For professionals working with family members, it is important to recognize that family members may have been experiencing some measure of grief *for years* in relation to the older adult. This is particularly the case when the older adult is suffering from a dementia. The spouse or the parent they once knew is no longer present and they suffer as they view their spouse/parent suffering. The compounding nature of grief—watching loss after loss after loss in the older adult—the current grief-evoking event of placement added on top can seem overwhelming. Family members may struggle with whether they can even place the older adult, as the grief is too suffocating and they feel unable to make decisions any longer. Professionals who come alongside family members, who verbally recognize the grief experienced by family members, who listen to the confused thought processes of family members and help them sort out their thoughts and decision making rationale, and who gently offer counsel and understanding, are invaluable.

Family Members May Be Exhausted

As mentioned earlier in this book, by the time adult children are examining housing and/or treatment options (e.g., palliative care) for an older parent, some or all of the children may be physically and/or emotionally exhausted. Particularly when one or both parents have/had suffered from a dementia, caregiving may have occurred for many years prior. Many years ago, Mace and Rabins (1981) wrote a book entitled *The 36 Hour Day*. This was a guide for family caregivers who were providing care for an older adult with Alzheimer's disease or a related dementia. The authors outlined the various symptoms and behaviors that could be exhibited by someone with a dementia and practical tips for dealing with these behaviors. The notion of the "36-hour day" was an acknowledgment that caregiving occurs day and night and simply never stops, except upon the death of the older adult. As just mentioned, caregiving for a parent with dementia can be especially draining, not only because the individual needs continuous assistance. The exhaustion is also emotional, as the experience is punctuated by losses, including the loss of the person as the adult children once knew. Family members may be totally exhausted, yet unable to recognize the degree to which they are depleted. For their own health, they may need to access more assistance for the aging parent, yet be unable to see this, or make the decision to access more care.

Part of the role of the nurse or professional is to help the adult child (or spouse) recognize how exhausted she is, as well as understand the need for

additional help to share the load of caregiving. Sometimes an adult child feels that if she places her older parent in a continuing care facility, such as a nursing home, that she is reneging on her duties as a child and that her caregiving will end. The professional should help this woman realize that caregiving does not end just because her mother will be placed. While the relationship may change, in terms of the mother living in a facility, the caregiving continues. One of the tips we often offer to family members is that if they are going to continue to care for their aging spouse or parent, they need to care for themselves so that they will be alive and healthy to continue caring. This takes the issue of caring for the self out of the realm of selfishness (some caregivers believe that to access professional help means that they are selfish) and moves it into a caring act. By caring for themselves, adult children can continue to provide emotional and relational support to the parent.

If the older adult is relocated to an assisted living facility or a nursing home, the work of nurses and other professionals is to help the older adult and spouse/adult children redefine the spousal or parent/adult child relationship, in a way that still honors the older adult. One of the developmental tasks of the aging family involves "making room in the system for the wisdom and experience of the seniors" (Wright & Leahey, 2013, p. 109). This means that even if the older adult relocates to a nursing home, he still needs to feel like he is valued and that his experience is acknowledged and honored. The aging individual and his spouse or adult children can be helped to talk about how they would like their relationship to look, despite the move; this involves talking about how family members will connect, in what ways (e.g., visits, phone calls, email) and how they will continue to foster emotional bonds.

When the Older Adult is Exhibiting Aggressive Behavior

Spouses and family members are often bewildered, devastated, and mortified when their older adult behaves aggressively toward them, healthcare professionals or other patients. They express deep humiliation regarding the behaviors and are sometimes desperate to explain that the aggression is not representative of who the older adult actually is as a person. They can also experience panic when home care, hospital, or nursing home staff is unable to manage their family member's aggression. "This is not my dad!" the distressed daughter may exclaim.

In these situations, family members require the patient understanding of nurses and other professionals. Family members need to feel that the professionals involved in the care of their older adult recognize that this behavior is not indicative of the older adult, but may be caused by a dementia, delirium, or perhaps delusions (Krishnamoorthy & Anderson, 2011). Or, the aggressive behavior may be in response to some unexpressed need that the older adult is not able to communicate (Keady & Jones, 2010). The work of professionals to *separate the*

aggressive behavior from the older adult is key, as family members usually strongly identify with the older adult and feel that the behavior of their family member is a reflection on them.

Regardless of the setting, family members need reassurance from professionals that they understand the impetus behind the aggressive behavior of the older adult and that they will assess the older adult for the triggers to this behavior. This demonstrates to family members that professionals view the older adult with respect and that they do not view the current behavior as a representation of the individual's entire life. If the older adult with aggressive behavior is still living within his home environment, it is imperative the professionals assess the safety of those living at home. If the spouse of the older aggressive adult is still living with her husband, this may necessitate a 911 call with police taking the aggressive individual to hospital for assessment. The protection of the spousal caregiver, who may be frail herself, is of paramount concern.

If the older individual is already in hospital, professionals can inform family members that they will conduct a thorough assessment of their family member, will try a variety of non-pharmacological treatments, such as decreasing environmental stimuli (King, 2012), music (Kyomen & Whitfield, 2008), walking (King, 2012), and animal-assisted activities (Kyomen & Whitfield, 2008). If non-pharmacological approaches are not effective, medication, such as an antipsychotic, can be considered and used to decrease aggressive behaviors (Krishnamoorthy & Anderson, 2011). When professionals can verbalize a comprehensive understanding of aggressive behavior in older adults to their family members, as well as knowledge regarding treatment options, some of the distress in family members may be assuaged.

Family members sometimes are concerned at the impact their loved one's behavior may have on the staff. It can also be helpful for professionals to verbalize to family members that such behaviors are not taken personally by them and that in situations such as these (dementia, delirium, etc.), these behaviors can occur. This can relieve family members from the sense that they need to care for, or "make up for" the older adult's behavior toward staff.

The following case example will demonstrate some of the concepts discussed within this chapter. We will also thread information from the case example into the subsequent section on Principles in Assessment and Intervention with Families.

Case Example

Janie is a 55-year-old woman with Down syndrome and early stage dementia. All of her life she lived with her mother and father. Her mother and father provided all of her care, with occasional help from Janie's sister and brother. Over the past number of years, Janie's parents had talked about the eventuality of one of them passing away. They worried about

who would provide care to their daughter; in the earlier years of Janie's life, they could not imagine her outliving them. Ironically, the extended life span of those with Down syndrome was a mixed blessing; they loved having their daughter for a good number of years, but they worried intensely about what would happen to her when they are gone.

Recently, Janie's mother (Sarah) passed away. Her father, Bob, is 85 years old and has significant COPD (chronic obstructive pulmonary disorder). He has worried that one morning, he will not wake up and Janie will find her father dead. Bob has spoken with both of his children regarding his worries. Janie's sister offered to look after her sister, but admits that she could not look after Janie during the day, as her work income is necessary for her and her husband to make ends meet. Janie's brother has expressed reluctance to assume care for his sister, as he lives in another city and is concerned what he will do if caring for Janie is too difficult.

Bob has wondered what he should do. He has been reluctant to burden his two children, figuring that their childhood was compromised in part by the extra care Janie needed. He has not known whether to place Janie in a residential home or a nursing home. Bob has been concerned that staff in residential homes may not know how to manage the challenges of dementia. He is also aware that staff in nursing homes often do not know how to meaningfully connect with individuals with intellectual disabilities. With his questions regarding what placement direction he should initiate, Bob has not explored options. He has continued to hope that circumstances would somehow work out. In the meantime, he has watched his daughter change from a previously affectionate and happy woman to a sullen and withdrawn individual.

Six months after his wife's death, Bob had a health scare and was hospitalized for almost three weeks. Janie was immediately placed in a nearby nursing home that had an open bed. Although Bob was discharged home with some home care support, he is grief-stricken. He feels like he has lost his wife and his daughter. At times, he cries when he visits his daughter. Although Janie is still alive, she is having trouble adjusting. She is withdrawn and only occasionally initiates conversation; when she does communicate, she tends to abruptly and loudly call out to residents that are passing by. The residents are not comfortable with Janie; she has the characteristic facial differences that come with Down syndrome, is much younger than they are, and is ungainly in how she walks and talks.

The nursing unit manager, recreational therapist, and social worker are not sure how to help Janie. They do not know how to make sense of her behaviors. Is she grieving the death of her mother and the move to the nursing home? Is this sullen behavior just part of her Down syndrome, or is this part of her dementia?

They have decided to seek the assessment of a consulting psychiatrist. In the meantime, staff are trying very hard to reach out to Janie, and her father visits daily trying to help her adjust.

PRINCIPLES IN ASSESSMENT AND INTERVENTION WITH FAMILIES

Throughout this chapter, we have attempted to describe particular challenges that family members may encounter when faced with an older adult who is experiencing transitions related to health, and thus may be forced to examine a transition in living location. We offered suggestions that can guide nurses and other professionals when facilitating transitions for older adults and family members. These suggestions were specific to the examples given. Now, we will suggest some general principles that can guide professionals in helping family members through transitions faced by their older adults. Throughout our discussion of principles, we will weave in our case study of Janie and her father, where applicable.

Family Systems Approach and Life Course Perspective

We agree with Wright and Leahey (2013) and Carter and McGoldrick (1989, 2005) regarding the importance of understanding individuals within the context of the family system. And as we mentioned earlier in this chapter, this tenet is particularly important with older adults because they may be quite physically and/or cognitively compromised.

So what does a family-systems approach entail? It involves conceptualizing the older adult as part of a family system in which individuals have patterns of relating and various ways of communicating. It entails more than finding out who is in the family, but examining how they support each other, instrumentally (tasks of daily living) and emotionally.

In regard to the case example, a family-systems approach includes understanding who is in this family. Now that Janie is in a nursing home, her physical needs are being largely met. However, who has she had for emotional support? Do her sister and brother provide some support? For Bob, what kinds of instrumental and emotional support does he need? Does he need home care support? Should an occupational therapist come into his home to assess his home for safety and convenience aids? Does he have neighbors or friends who check on him on a regular basis to offer emotional support, as well as rides to appointments or to the nursing home?

However, a family-systems approach goes beyond merely considering the needs of single individuals within a family. It also involves looking at patterns

of relationships within families (Wright & Leahey, 2013). Thus, staff within the nursing home can look at how Bob and Janie can continue their relationship as father and daughter. Staff might ask Bob and Janie about what they most enjoy in their relationship and seek to replicate, to some degree, what they enjoy together. For instance, they can consider how to support Bob and Janie in having some "private" family dinners. For instance, Bob and his other daughter (who lives in the community) may bring takeout food into the nursing home and have a family dinner with Janie in a room away from the busyness of the unit. Nursing staff may support these dinners by bringing coffee and tea. If Bob and Janie enjoy going out to a concert or a play, staff can make sure that Janie is ready for Bob when he comes. Besides the physical tasks of helping Janie get ready, however, they can verbally support the specialness of the event. During the day of the concert, staff can talk to Janie about her excitement in going to the concert and her special relationship with her father. When she returns from the concert, staff can ask questions about her experiences with her father at the event.

We also strongly espouse a Life Course Perspective approach. How an older adult responds to crucial transitions is not only impacted by their family context, but also by previous experiences with transitions. A history of successful or unsuccessful responses to transitions will affect how an older adult thinks about, and responds to, current transitions. As part of an individual's life history, previous experiences with health and human service professionals will also impact how this older adult seeks help in times of transitions and his responses to professionals who are attempting to assist them.

In relation to the case example of Janie, she needs to be understood within the context of her family and her life history. Due to her Down syndrome, Janie has lived with her parents all of her 52 years of life. As such, she has not experienced many of the transitions faced by her non-intellectually disabled counterparts. She did not leave home, go to college, get married, or have children. As she also has not previously transitioned to another location, such as a residential home, the transition to the nursing home is likely very difficult for her. She has never developed coping skills to help her manage transitions. Coupled with the lack of experience with transitions, she also has recently experienced the death of her mother and the hospitalization of her father. When her father was hospitalized and Janie was placed in the nursing home, she experienced much confusion and grief. She could not understand why her father was not visiting her.

It is also important to conceptualize Bob's experiences with transitions from the Life Course Perspective. Has Bob had previous experiences with transitions that were particularly negative? For instance, if, decades earlier, his mother entered a nursing home and did not do well, he may be particularly frightened about this transition for Janie. Further, if he and his siblings did not help his father when his mother was placed in the nursing home (and subsequently passed away quickly),

he may fear that his son and daughter may pay little attention to him now that his wife is gone and their sister is placed.

View families from a strengths-based perspective

As healthcare systems within developed countries tend to be focused upon health problems (Gottlieb, 2013), rather than strengths, it is easy for professionals working within the system to unwittingly adopt a deficit-based perspective and approach. What is a strengths-based approach? A strengths-based approach:

> considers the whole person, focuses on what is working and functioning well, what the person does best, and what resources people have available to help them deal more effectively with their life, health, and health care challenges. (Gottlieb, 2013)

When working with older adults and their family members, professionals need to consciously hold onto a strengths-based approach, especially as sometimes transitions in these families are due to such extenuating and difficult situations (e.g., older husband dies; elderly wife has cognitive impairment and significant cardiac disease; wife is still living in the home; wife does not recognize children). This is respectful toward and empowering for the family; it enables them to recognize their resilience in what may have been years of caregiving, and it also encourages them to continue to support the older adult, whether the older adult continues to live independently within his home, moves to an assisted living facility, is placed in a nursing home, or is expected to die soon and is now receiving palliative care.

It is also an empowering stance for professionals to utilize a strengths-oriented approach. By utilizing this approach, professionals as less likely to feel defeated by the degree of challenges faced by older adults and their family members, and they can remain open and curious about how best to intervene (Wright & Leahey, 2013). In adopting an open and interested stance, creativity in professionals is fostered and they are less likely to feel frustrated and angry about their work with families.

Embracing a strengths-based approach involves more than just believing families have strengths. It also involves verbally acknowledging those strengths to families so that they are aware that you see them as having strengths. Nurses and other professionals can ask family members how they managed to make it through previously difficult transitions. Specifically, what have been their strengths? They can then ask the family members how they can use particular strengths to make it through the current transition. By inviting them to talk about previous experiences with transitions and how those encounters can help them in the present, family members may make a mental shift. They may begin to conceptualize themselves as strong and able to face the difficulties ahead.

It may be very difficult for nurses and other professionals to conceptualize those with developmental disabilities or dementia from a strengths-oriented

perspective. However, we suggest that the *greater the deficits*, the more important it is to work from the premise that individuals and families have strengths. This approach is much more than naïve idealism, it is based upon the history of the family. For example, Janie's parents have raised and supported her for 52 years. They also raised two other children. Despite the work involved to support Janie over 52 years, monitor the health conditions that are prevalent among those with Down syndrome, and help Janie with some of the challenging behaviors and mental health problems that can occur with developmental disabilities (although these problems tend to be less with those with Down syndrome than with other developmental disabilities) (Spendelow, 2011), Bob and Sarah prevailed. Janie, herself, was a happy individual for much of her life; her demeanor only changed when her mother passed away and she moved into the nursing home.

Professionals who conceptualize Bob and Janie as having strengths will seek to assess and intervene in a way that promotes these strengths. While nurses and other professionals can utilize tools for assessment and intervention, unfortunately, most tools are deficit-based, rather than strengths-based. Further, most strengths-based assessment tools are designed for children (Hirst, Lane, & Stares, in press).

However, the lack of strengths-based assessment tools does not preclude professionals from conducting a thorough assessment; based upon the assessment, they can then tailor interventions that are appropriate for the family. Professionals can ask Bob how he has managed other challenges in the past and help him to use these positive coping methods to help him currently. (When under stress, many individuals forego their usual methods of coping, such as reading, exercise, visiting with friends). They will also ask Bob about how Janie copes; specifically, what can staff in the nursing home do to help her feel more comfortable, perhaps express her grief, and engage her in activities that are meaningful to her? They will ask Bob what activities Janie has enjoyed in the past and try to engage her in these (Brown, Dodd, & Vetere, 2010). They will also inquire if Janie worked in the past and what this work entailed. If there are elements of a previous job that can be built into her new environment (for example, helping sweep the floor in the nursing home dining room), this may build self-esteem.

In an interesting Australian study, Buys, Aird, and Miller (2012) interviewed professionals who work with older adults with intellectual disabilities to ascertain their perceptions of how these individuals age, and more specifically, what active aging would look like for one of their clients. They found that professionals described their clients as eager to be active and desiring to learn new things. They emphasized the importance of engaging older adults with intellectual disabilities in meaningful activities—specifically, activities that are important and valuable to individual clients. Professionals described a wide variety of possible activities, such as volunteer work, reading, arts and crafts, caring for pets, social outings,

and others. The professionals stressed the importance of variety and flexibility in activities, as well as the need for productivity to continue in older age (Buys et al., 2012).

Recognize the Importance of Culture in How Families Relate

Nurses and other professionals certainly cannot be knowledgeable about all or even many cultures, as not only are there many cultures within our world, there are even variations in how individuals from the same ethnic background practice culture within one country. However, within the 21st century, where multiculturalism is prevalent in many developed countries, it behooves professionals to recognize that culture does influence how individuals age, how the family is defined (Hines, Preto, McGoldrick, Almeida, & Weltman, 2005), how families communicate with each other and their older members, and how families view aspects of care for their elders, such as hospitalization, use of continuing care facilities, such as nursing homes, as well as accessing hospice. Further, families may vary in how much they express their cultural beliefs; for some, their cultural beliefs may not be held onto as tightly as others, as they may have adopted some beliefs within the dominant culture (Hines et al., 2005).

As part of working with families of varied cultures, nurses and other professionals should assess how cultural beliefs impact family beliefs, in particular in how family members relate to each other and their aging members. Beliefs about moving older adults out of a family home into institutions of care should also be assessed. As noted in the example in Chapter 3, some cultures do not readily accept individuals placing parents into nursing homes (like the caregiving daughter in her 60s caring for her aging mother in her mid 90s). This may involve some time on the part of the professional to assess the rationale for such decision making, for describing the concerns of the professional about the parent, as well as the adult caregiver, and to look for options that might be palatable for both the adult child, as well as the professional (in terms of the professional's concern about the safety and health of both the adult child and the parent). While sometimes the older adult and adult caregiver may make choices that are not in line with what the professional would choose, the nurse or professional needs to respect the self-determination of the individuals involved.

Attention to How Professionals Communicate

We do not mean to be condescending when we stress that professionals, as well as future professionals, need to attend to how they communicate. However, the importance of the "ministry of presence" (as discussed in Chapter 5) cannot be overstated. Empathy, humility, and a commitment to the family being worked with is absolutely essential.

Professionals may be excellent in *what* they communicate (content), but not necessarily attentive to how they communicate (nonverbal and paraverbal communication). And, the importance of attending to how one communicates cannot be exaggerated. While there is some variation regarding how much of our message is communicated verbally in comparison to nonverbally, generally, there is agreement that a significant amount of what we communicate is transmitted nonverbally or paraverbally.[5] When older adults and their family members are undergoing transitions, they are often stressed and can even be feeling like they are in shock. This is particularly the case when family members are told that their parent is dying and may be moved to hospital or palliative care. They may need the information to be given a number of times, for that information to be given patiently, and to be given with sensitivity and kindness. Not only do professionals need to speak slowly and with patience, but they need to attend to the tone of their voices.

These principles about communication especially apply to older adults. Older adults are acutely sensitive to the mood and tone of voice of professionals. When professionals appear too rushed and frustrated to listen to older patients or clients, older individuals may shut down emotionally and verbally. They may stop talking out of embarrassment and a sense of not being understood (Wengryn & Hester, 2011). Professionals who work well with older adults will sit down at the same level as the older adult, maintain eye contact with the older adult, and speak with kindness and sensitivity. They will also ask the older patient if he understands and has any questions. They will pay careful attention to factors that may hamper the understanding of an older adult, such as hearing and sight deficits, or not understanding English.

In our case example, both Janie and Bob are the "older adults." While Janie does not typically fit the older age category, she is considered older age due to her Down syndrome, as individuals with Down syndrome exhibit signs of aging that non-intellectually disabled adults do not experience for another 20 or more years (Strax, Luciano, Dunn, & Quevedo, 2010). Both Bob and Janie have been experiencing shock from Bob's sudden transition to the hospital, as well as Janie's placement in the nursing home. They are now adjusting to living life apart after 52 years and the sudden transition for Bob to the hospital and of Janie's move to the nursing home. While literature suggests that staff in nursing homes do not always attend to the emotional challenges, including grief reactions, to the placement for family members (Givens, Prigerson, Kiely, Shaffer, & Mitchell, 2011; Perry, Dalton, & Edwards, 2010), Bob's adjustment to his daughter's move will be aided by staff who ask about how he is doing, listen to his concerns, and reassure him about the normalcy of what he is experiencing. Similarly, if staff pay extra

[5] We use the term *paraverbal* due to our familiarity with the Crisis Prevention Institute. They define *paraverbal* as being how we say what we say. Hence, paraverbal can refer to the tone of our voice. For more information, please see the Crisis Prevention Institute (www.crisisprevention.com).

attention to Janie and understand that she will have difficulty understanding what is happening to her (due to the Down syndrome and dementia), it may help her in beginning to adjust to the new environment.

Not only is it important what staff communicate to Janie, it is of paramount importance *how* they communicate to her. Although adults with Down syndrome generally communicate better than those with some other forms of developmental disabilities (Buckley, 2000), patterns of communication will still be different from adults without a developmental disability. For instance, adults with Down syndrome often utilize shorter sentences and simple grammar (Orange & Zanon, 2005; Rondal & Comblain, 1996) and some may stutter (Rondal & Comblain, 1996). They also have trouble comprehending the speech of others (Rondal & Comblain, 1996). These communication challenges can be compounded by hearing deficits and early dementia. As such, professionals working with Janie need to patiently learn how she communicates and learn what kinds of communication works best for her (e.g., rephrasing questions, changing formats of questions) (Finlay & Antaki, 2012). This nuanced understanding involves time, patience, and insight.

Finlay and Antaki (2012) conducted an ethnographic study to examine how professionals communicate with adults with intellectual (or developmental) disabilities. They videotaped how staff interacted with adults in two residential homes and one outdoor activities setting in Britain. The researchers examined videotapes to determine how staff asked questions, how the adults with intellectual disabilities responded to the questions, and then, how staff reacted when a question failed to achieve results. (As an example, when the adult with intellectual (developmental) disabilities did not respond verbally or nonverbally to the question, or when the response seemed inappropriate to the question, this was determined to be a failed question). Professionals used various techniques to address failed questions, such as rephrasing a question, differentiating between questions that tap into intention versus desire, changing the question format (such as changing an open-ended question into a closed-ended one), and using nonverbal communication to reassert the question (Finlay & Antaki, 2012). More than just a technique, however, the sophisticated and nuanced understandings of each client's mode of communication, as well as effective professional responses, allowed for understanding and camaraderie between adults with intellectual disabilities and professionals (Finlay & Antaki, 2012).

Be Prepared to Address Emotional Responses to Transitions

It is imperative for nurses and other professionals to address the emotional transitions of older adults and family members undergoing transitions. This seems obvious, and yet, many professionals are uncomfortable with specific emotions, such as anger (Smith & Hart, 1994), or are uncomfortable with the *depth* of emotions. They may also be concerned about the amount of time it takes to listen to

older adults and their family members express their grief, anger, confusion, and so on. We understand this hesitation and recognize that in many healthcare settings, nurses and other professionals are completely strapped for time. However, we suggest that if professionals do not provide the opportunity for individuals to express their emotions, they may be forced to address these emotions in other ways. For instance, when family members are feeling much guilt around placing their older adult and they are not able to work through that guilt, they may express this through hypervigilant monitoring of the care of the older adult and outright criticism of the efforts of nursing home staff. Staff may become very angry and frustrated with family members and consider the resident's relatives as being a "problem family." And yet, staff members may not be aware of how much of the critical vigilance is actually unresolved grief.

How can grief and other emotions involved in experiencing a transition be addressed? First, we suggest that it is important for professionals to sit down with the older adult (where possible) and family members and specifically state that the transition can be filled with overwhelming emotions, such as grief, guilt, fear, and confusion. If the transition involves a move to a nursing home, the nursing unit manager, social worker, or Clinical Nurse Specialist can purposely meet with the family, not just to talk about specifics regarding costs, programs, routines, but also to address family members' concerns and issues. It is important that the professional set up the meeting, as well as set the tone of the meeting, clearly stating that the transition to a nursing home is a life-changing event for older adults and family members that can evoke very difficult emotions; it is important that the professional verbally names the emotions that family members may experience. This process normalizes (Wright & Leahey, 2013) the overwhelming emotions that may come with this transition. When a professional informs family members that it is very common to feel guilt about placing a spouse or parent, some of the guilt may be alleviated. Family members may also give themselves the permission to feel the uncomfortable emotions, because in their minds, a knowledgeable professional has authorized the normalcy of feeling what they are feeling.

Beyond acknowledgment and normalization of these tumultuous emotions, however, there also needs to be room for *expression* of these emotions. In our experiences with older adults and their family members, there can be weeping and even wailing over transitions, whether this involves a relocation transition to hospital or nursing home, or the transition of death for the older adult. When the nurse, social worker, or chaplain is able to literally just *be* with family members, talk when the family needs to talk, or sit in silence with them as they try to digest the events, this can be enormously helpful to family members. In their aloneness with grief (even in a room full of family members, each family member is alone with his or her own grief), they are not quite as alone because of the presence of the professional.

How do these ideas about acknowledging and encouraging the expression of grief apply to Janie and Bob? First, it is important to recognize the compounding

nature of several transitions—the death of Bob's wife and Janie's mother, transitions to hospital for Bob and nursing home placement for Janie. Not only is there a compounding effect of stress caused by multiple transitions in a relatively short period of time, there is a compounding effect of grief. Both Bob and Janie are grieving the loss of Sarah and now they are grieving the loss of each other living under the same roof. Although Bob and Janie have not died, the relationship as it once was, is now gone.

While both Bob and Janie will be grieving, the death of a parent can be catastrophic for the older adult with an intellectual or developmental disability. Not only did Janie lose the support of her mother that she had lived with since birth, the death indirectly precipitated the relocation to the nursing home. When Bob was hospitalized, there was no other parent who could care for her, so she had to be placed (Dodd et al., 2008; Dodd, Dowling, & Hollins, 2005). Once placed, however, Janie likely lost her main support in grieving—Bob. Unfortunately, staff working with adults such as Janie may have felt unprepared to help with the grieving process (Persaud & Persaud, 2003). Or, they may have believed that those with developmental disabilities do not experience emotional responses to death (Dowling, Hubert, & Hollins, 2003). However, rather than experiencing no grief, some research suggests that older adults with developmental disability experience *greater* emotional reactions to the death of a parent and that this grief can then progress to signs of mental illness (Dodd et al., 2008). Hence, the transition to a nursing home for someone like Janie is laden with grief; not only is Bob not as physically present to help her with the grief stemming from the death of her mother, but now she is in new surroundings with staff and residents who do not understand her.

Where Possible Include Older Adult in Decision Making

Although we advocate for family involvement in assisting older adults through crucial health, moving, and life and death transitions, we feel strongly that family members' opinions should not supersede the older adult, unless the older adult is unable to make decisions due to cognitive impairment, a developmental disability, or is unable to make decisions (e.g., is unconscious related to a medical condition). If the older adult is of sound cognition, the older adult should be able to make her own decisions. Even in situations of early dementia, the older individual should be able to express his opinions about what he would like to see happen in his care.

If an older adult is no longer able to make decisions due to cognitive impairment, delirium or other health problem, then the older adult's wishes can still be honored through personal directives and guardianship. These legal documents can, in essence, speak for the older adult when she is no longer able to. These forms also provide comfort and assurance for family members in that they can feel assured that their decisions are congruent with their family member's wishes.

SUMMARY

Working with older adult families can be tremendously rewarding. However, it can also be challenging, especially during times of transition. Understanding how to help older adult families during transitions can help ease the emotional turmoil for all members involved.

Critical Thinking Exercise

You are the recreational therapist in the nursing home in which Janie now resides. As you walk down the nursing home hallways, you see Janie looking sad and withdrawn and this troubles you. You decide that you will do your utmost to get Janie involved.

- How will you decide what activities are best suited for Janie?
- How will you convince her to get involved in group recreational activities? What will be your approach when you talk to her?
- When you finally convince Janie to attend and participate in an event, other residents stare and laugh at her when she attempts to participate. How will you respond to the reactions of the other residents? After the event, what will you say to Janie about the responses of others?

REFERENCES

Benner Carson, V., & Koenig, H.G. (2004). *Spiritual caregiving: Healthcare as a ministry.* Philadelphia: Templeton Foundation Press.

Brainy Quotes. (2012). Retrieved December 28, 2012, from www.brainyquote.com/quotes/keywords/family_3.html.

Brown, J., Dodd, K., & Vetere, A. (2010). "I am a normal man": A narrative analysis of the accounts of older people with Down's syndrome who lived in institutionalised settings. *British Journal of Learning Disabilities, 38*(3), 217–224. doi: 10.1111/j.1468-3156.2009.00596.x

Buckley, S. J. (2000). Speech, language, and communication for individuals with Down Syndrome—An overview. *Down Syndrome Issues and Information.* Retrieved December 20, 2012, from www.down-syndrome.org/language/information/overview

Buys, L., Aird, R., & Miller, E. (2012). Service providers' perceptions of active ageing among older adults with lifelong disabilities. *Journal of Intellectual Disability Research, 56*(12), 1133–1147. doi: 10.1111/j. 1365-2788.2011.01500.x

Canadian Study of Health and Aging. (1994). Canadian study of health and aging: Study methods and prevalence of dementia. *Canadian Medical Association Journal, 150*(6), 899–913.

Carter, B., & McGoldrick, M. (2005). *The expanded family life cycle: Individual, family and social perspectives* (3rd ed.). New York: Pearson.

Carter, B., & McGoldrick, M. (1989). *The changing family life cycle: A framework for family therapy.* Toronto: Allyn & Bacon.

Davies, S. (2005). Meleis' theory of nursing transitions and relatives' experiences of nursing home entry. *Journal of Advanced Nursing, 52*(6), 658–671.

Davies, S., & Nolan, M. (2003). "Making the best of things: Relatives' experiences of decisions about care-home entry. *Ageing & Society, 23*(4), 429-450. doi: http://dx.doi.org/10.1017/S0144686X03001259

Dellasega, C., & Nolan, M. (1997). Admission to care: Facilitating role transition amongst family carers. *Journal of Clinical Nursing, 6*(6), 443–451. doi: 10.1111/1365-2702.ep11545295

Dellmann-Jenkins, M., Blankemeyer, M., & Pinkard, O. (2000). Young adult children and grandchildren in primary caregiver roles to older relatives and their service needs. *Family Relations, 49*(2), 177–186.

Dillenburger, K., & McKerr, L. (2011). "How long are we able to go on?" Issues faced by older family caregivers of adults with disabilities. *British Journal of Learning Disabilities, 39*(1), 29–38. doi: 10.1111/j.1468-3156.2010.00613.x

Dodd, P., Guerin, S., McEvoy, J., Buckley, S., Tyrrell, J., & Hillery, J. (2008). A study of complicated grief symptoms in people with intellectual disabilities. *Journal of Intellectual Disability Research, 52*(5), 415–425. doi: 10.1111/j.1365-2788.2008.01043.x

Dodd, P., Dowling, S., & Hollins, S. (2005). A review of the emotional, psychiatric and behavioral responses to bereavement in people with intellectual disabilities. *Journal of Intellectual Disability Research, 49*(7), 537–543.

Dowling, S., Hubert, J., & Hollins, S. (2003). Bereavement interventions for people with learning disabilities: "My mother's name was Marjorie." *Bereavement Care, 22*(2), 19–21. doi: 10.1080/0268262030865769

Edwards, A. P., & Graham, E. E. (2009). The relationship between individuals' definitions of family and implicit personal theories of communication. *Journal of Family Communication, 9*(4), 191–208. doi: 10.1080/15267430903070147

Finlay, W. M., & Antaki, C. (2012). How staff pursue questions to adults with intellectual disabilities. *Journal of Intellectual Disability Research, 56*(4), 361–370. doi: 10.1111/j.1365-2788.2011.01478.x

Gilbert, A., Lankshear, G., & Petersen, A. (2008). Older family-carers' views on the future accommodation needs of relatives who have an intellectual disability. *International Journal of Social Welfare, 17*(1), 54–64. doi: 10.1111/j. 1468-2397.2007.00485.x

Givens, J. L., Prigerson, H. G., Kiely, D. K., Shaffer, M. L., & Mitchell, S. L. (2011). Grief among family members of nursing home residents with advanced dementia. *American Journal of Geriatric Psychiatry, 19*(6), 543–550. doi: 10.1097/JGP0b013e31820dcbe0

Gottlieb, L. N. (2013). *Strengths-based nursing care: Health and healing for person and family.* New York: Springer.

Grau, L., Teresi, J., & Chandler, B. (1993). Demoralization among sons, daughters, spouses and other relatives of nursing home residents. *Research on Aging, 15*(3), 324–345.

Hamill, S. B. (2012). Caring for grandparents with Alzheimer's disease: Help from the "forgotten" generation. *Journal of Family Issues, 33*(9), 1195–1217. doi: 10.1177/0192513X12444858

Hines, P. M., Preto, N. G., McGoldrick, M., Almeida, R., & Weltman, S. (2005). Culture and the family life cycle. In B. Carter and M. McGoldrick (Eds.), *The changing family life cycle: A framework for family therapy* (3rd ed.; pp. 69–87). New York: Pearson.

Hirst, S. P., Lane, A. M., & Stares, R. (in press). Health promotion with older adults experiencing mental health challenges: Strength-based approaches. *Clinical Gerontologist.*

Ihara, E .S., Horio, B. M., & Tompkins, C. J. (2012). Grandchildren caring for grandparents: Modeling the complexity of family caregiving. *Journal of Social Service Research, 38*(5), 619–636. http://dx.doi.org/10.1080/01488376.2012.711684

Johnson, M. A., Morton, M. K., & Knox, S. M. (1992). The transition to a nursing home: Meeting the family's needs. *Geriatric Nursing, 13*(6), 299–302.

Kao, H. F., Travis, S. S., & Acton, G. J. (2004). Relocation to a long-term care facility: Working with patients and families before, during and after. *Journal of Psychosocial Nursing & Mental Health, 42*(3), 10–16.

Keady, J., & Jones, L. (2010). Investigating the causes of behaviours that challenge in people in with dementia. *Nursing Older People, 22*(9), 25–29.

Kellett, U. M. (1999). Transition in care: Family carers' experience of nursing home placement. *Journal of Advanced Nursing, 29*(6), 1474–1481.

King, C. (2012). Managing agitated behaviour in older people. *Nursing Older People, 24*(7), 33-36.

Krishnamoorthy, A., & Anderson, D. (2011). Managing challenging behaviour in older adults with dementia. *Progress in Neurology and Psychiatry, 15*(3), 20–27. doi: 10.1002/pnp.199

Kyomen, H. H., & Whitfield, T. H. (2008). Agitation in older adults. *Psychiatric Times, 25*(8), 52–57.

Lane, A. M. (2007). *The social organization of geriatric mental health.* Unpublished doctoral dissertation, University of Calgary.

Levine, C., Hunt, G. G., Halper, D., Hart, A. Y., Lautz, J, & Gould, D. A. (2005). Young adult caregivers: A first look at an unstudied population. *American Journal of Public Health, 95* (11), 2071–2075. doi: 10.2105/AJPH.2005.067702

Logue, R. M. (2003). Maintaining family connectedness in long-term care. An advanced practice approach to family centered nursing homes. *Journal of Gerontological Nursing, 29*(6), 24–31.

Mace, M. L., & Rabins, P. V. (1981). *The 36 hour day: A family guide to caring for persons with Alzheimer disease, related dementing illnesses, and memory loss in later life.* Baltimore: Johns Hopkins University Press.

McGoldrick, M. (1991). Echoes from the past: Helping families mourn their losses. In F. Walsh and M. McGoldrick (Eds.), *Living beyond loss: Death in the family* (pp. 50–78). New York: W.W. Norton.

Office of the Public Guardian—Alberta Human Services. (2012). Office of the Public Guardian. Retrieved November 15, 2012, from http://humanservices.alberta.ca/guardianship-trusteeship/office-public-guardian.html

Orange, J. B., & Zanon, M. V. (2005). Language and communication in adults with Down syndrome and dementia of the Alzheimer type: A review. *Journal of Developmental Disabilities, 12*(1), 53–62.

Orel, N. A., Dupuy, P., & Wright, J. (2004). Auxiliary caregivers: The perceptions of grandchildren within multigenerational caregiving environments. *Journal of Intergenerational Relationships, 2*(2), 67–93. doi: 10.1300/J194v02n02_05

Perry, B., Dalton, J. E., & Edwards, E. (2010). Family caregivers' compassion fatigue in long-term facilities. *Nursing Older People, 22*(4), 26–31.

Persaud, S., & Persaud, M. (2003). Does it hurt to die? Bereavement work to help people with learning disabilities. *Bereavement Care, 22*(1), 9–11.

Piercy, K. W. (2007). Characteristics of strong commitments to intergenerational family care of older adults. *Journal of Gerontology: Social Sciences, 62B*(6), S381–S387.

Reuss, G. F., Dupuis, S. L., & Whitfield, K. (2005). Understanding the experience of moving a loved one to a long-term care facility: Family members' perspectives. *Journal of Gerontological Social Work, 46*(1), 17–46. doi: 10.1300/J083v46n01_03

Rondal, J. A., & Comblain, A. (1996). Language in adults with Down syndrome. *Down Syndrome Research & Practice, 4*(1), 3–14. doi: 10.3104/reviews.58

Sandberg, J., Lundh, U., & Nolan, M.R. (2001). Placing a spouse in a care home: The importance of keeping. *Journal of Clinical Nursing, 10*(3), 410–416.

Smith, G. C., Hatfield, A. B., & Miller, D. C. (2000). Planning by older mothers for the future care of offspring with serious mental illness. *Psychiatric Services, 51*(9), 1162–1166.

Smith, M. E., & Hart, G. (1994). Nurses' responses to patient anger: From disconnecting to connecting. *Journal of Advanced Nursing, 20*(4), 643–651. doi: 10.1046/j.1365-2648.1994.20040643.x

Spendelow, J. S. (2011). Assessment of mental health problems in people with Down syndrome: Key considerations. *British Journal of Learning Disabilities, 39*(4), 306–313. doi: 10.1111/j.1468-3156.2010.00670.x

Statistics Canada. (2012). Portrait of families and living arrangements in Canada. Retrieved November 22, 2012, from www12.statcan.gc.ca/census-recensement/2011/as-sa/98-312-x2011001-e

Strax, T. E., Luciano, L., Dunn, A. M., & Quevedo, J. P. (2010). Aging and developmental disability. *Physical Medicine and Rehabilitation Clinics of North America, 21*(2), 419–427. doi: 10.1016/j.pmr.2009.12.009

Wengryn, M. I., & Hester, E. (2011). Pragmatic skills used by older adults in social communication and health care contexts: Precursors to health literacy. *Contemporary Issues in Communication Science & Disorders, 38*(Spring), 41–52.

Wright, L. M., & Leahey, M. (2013). *Nurses and families: A guide to family assessment and intervention* (6th ed.). Philadelphia: F.A. Davis.

Chapter 8

FUTURE DIRECTIONS

Aging is not lost youth but a new stage of opportunity and strength.
(Betty Friedan, one of the founders of the feminist movement)

Reflective Questions

- In your future work with older adults, what do you think will be the most rewarding aspects of your work?
- What will be the most challenging facets of working with this population?
- In the future, what changes would you seek to enact? How would you go about this?

In the past number of decades, media advertisements for products that enhance youthful appearance, or erase—even if temporarily—the signs of aging, have burgeoned. It seems that as life spans have increased, so has the impetus to appear younger. And yet, as noted by one of the founders of the feminist movement (Betty Friedan), aging presents new opportunities and a different kind of strength. More than wishful thinking, with increasing life spans and many enjoying better health well into later life, advancing age provides individuals with many opportunities to be creative, engage in meaningful activities and causes, and move toward the end of life with strength and purpose.

In order to support older individuals to experience aging as a time of new opportunities, energy, growth, and purpose, we suggest the following strategies that are targeted at multiple levels. First, we offer ideas directed towards a grass roots level—this involves enhancing childhood experiences and exposure to older adults. Second, we offer changes in education for future healthcare and human service professionals working with aging adults. We then explore future directions in services in the community and housing options for seniors, including those in various sub-populations, such as those with mental illness, who are homeless, developmentally delayed, those who are dying, as well as incarcerated older adults. Finally, we explore the area of advocacy; specifically, we examine older adults advocating for older adults. We recognize that these suggested directions are merely "skimming the surface" of what can and should be done in the future.

Early Age Exposure to Older Adults and Education

It is commonly acknowledged that developed countries tend to be youth-oriented and death-denying societies. Not only does this lead to some aging individuals trying valiantly to stave off signs of aging, but it can also result in a huge chasm dividing older individuals from youth. Youth may avoid older adults, particularly those who are infirmed, out of fear, and older adults may pass up opportunities to interact with youth, out of concern for being misunderstood and undervalued. By the time youth are considering careers, they often have had little exposure to aging individuals. Thus, we wonder about when college and university programs try to attract professionals to work with older adults, if they are too late. At this point, young adults have formed beliefs about what aging entails; unfortunately, their beliefs may not include the humor, richness, and strength that many older adults possess. Could strategies targeted toward increasing exposure to positive aging, as well as programs aimed at integrating older adults with younger children, facilitate comfort with and interest in older adults?

Influence of the Media

As the media exerts enormous influence on children and as they watch on average, three to four hours of television per day (Healy, 2012), the importance of the positive portrayal of aging cannot be overstated. There are a number of actors in their late 70s or over the age of 80 who are vibrant, excellent at their craft, and very engaging. As a few examples, Betty White is over 90 years of age and is still acting in television shows and commercials. Similarly, William Shatner is hosting a television show. Dame Judy Dench continues to act in movies, including the James Bond movies (although her character died in the most recent of this series). All three actors are intelligent, very successful, and committed to their work. When these actors are interviewed on talk shows, all of them articulate that they love their work and want to work for as long as they can. Clearly, work gives them purpose and enjoyment. Their visibility helps to combat the myth that all older adults are feeble and useless. They are examples of how aging individuals can not only survive, but thrive in advancing years.

Although nurses and other professionals do not influence who is hired for acting roles, professional bodies can lobby against particular portrayals of older adults. A number of years ago, a local Alzheimer Society contacted a television station to complain about a documentary that portrayed an individual with Alzheimer's disease as violent. While those working within this local organization did not deny that sometimes individuals with dementia can exhibit aggressive behaviors, they opposed the notion that all individuals with dementia act aggressively. Nurses and other professionals can advocate, through letters and emails, for media examples to represent aging as growth-promoting, rather than as causing dotty and infirmed, or angry and aggressive individuals.

Intergenerational Programs

Intergenerational programs are those that match older adults and children/youth together in shared activities. These programs allow children and older adults to share talents, learn from each other, enhance socialization of both groups, and help to combat inaccurate stereotypes about older adults (Aging Initiative, 2011). Further, they challenge the current trend to separate programs and activities via age groups, thus separating children from older adults. They allow older adults and children/youth to see each other in a positive light. They also permit both age groupings to contribute meaningfully to society. Activities can focus on environmental concerns, such as building an electronic recycling center or helping restore a wildlife sanctuary (Steinig & Butts, 2009-10), growing gardens, and school mentoring (Cooper, 2011). Not only do children and youth report better attitudes toward older adults (Taylor, LoSciuto, Fox, Hilbert, & Sonkowsky, 1999), but research also suggests that older adults experience improvements in mental and physical health and overall well-being (Larkin, Sadler, & Mahler, 2005; Morrow-Howell, Hinterlong, Rozario, & Tang, 2003; Taylor et al., 1999).

Intergenerational education can move beyond shared activities that occur, perhaps once a week, however. In 2000, an intergenerational school was started in Cleveland, Ohio (George, Whitehouse, & Whitehouse, 2011). This school has inner-city students from kindergarten to grade 8 learning alongside older adults. They even have a formal mentorship role for older adults with dementia. The older individuals with dementia are integrated into classroom curriculum, such as giving a talk on the African American experience before and during the civil rights movement. Reciprocally, adolescent students teach older adults computer skills. According to George and his colleagues (2011), the school received an "excellent" score from the Ohio Department of Education for six out of seven years. Similar to the results of intergenerational programs just mentioned, older adults noted that they received a number of benefits from their participation, including: increased cognitive stimulation and better mood, a greater sense of purpose in life and the establishment of meaningful relationships with students (George et al., 2011).

We suggest that there needs to be more intergenerational programs available and greater advertisement and importance placed on these kinds of programs (e.g., through the media and in schools). Despite the fact that there are some intergenerational programs within developed countries, there still is an emphasis on "silos" between the generations; that is, programs remain geared for single age groups, such as children, adolescents, or seniors. Further, research needs to be conducted on intergenerational schools, both in the immediate, and longitudinally. For instance, graduates from these schools can be interviewed years after their attendance, in order to examine the long-term benefits of having attended this kind of school. This will provide a basis through which to evaluate aspects of the programs that have been effective or unsuccessful, thereby providing feedback for change.

EDUCATION FOR CURRENT AND FUTURE HEALTH AND HUMAN SERVICE PROFESSIONALS

Education for current and future health and human service professionals needs to accurately and meaningfully address the normal changes of aging, as well as how pathophysiological changes impact the physical, mental and spiritual health of older individuals. In particular, it is crucial that professionals recognize how illnesses, such as depression, may present differently in older adults. Additionally, professionals should be cognizant of the impact of transitions in older adulthood, and how, despite the resilience and strength that many older adults possess, transitions may affect older adults mentally and spiritually, awakening questions about meaning and purpose in life. And it is vital that gerontological education not only address the *what* of content, but the *how* of it being delivered most effectively.

Education of Future Health and Human Service Professionals

As mentioned in Chapter 2, most future professionals, be they nurses, social workers, or physicians, do not specifically choose to work with older adults (Wray & McCall, 2007). For years, there has been ongoing discussion within the literature regarding how best to attract future professionals to gerontology. The dialogue partly focuses on whether a gerontological curriculum should be integrated into curriculum (that is, included within adult content), or if there should be stand-alone courses (Hirst, Lane, & Stares, 2012). We suggest that there is a need for older adult content to be integrated within the curriculum, as well as for stand-alone courses. This will address possible pitfalls of educators teaching gerontological content when they are not knowledgeable about older adults and transitions (which may happen in integrated curriculum); it will also protect against potential problems of stand-alone courses, that being, that they are offered as options and the only students who take the courses are already committed to working with older adults or choose these courses because they fit within their timetable.

The continuous dialogue of how to attract students to careers with older adults, especially within nursing education, also concentrates on the type of clinical educational experiences students receive. The question is raised if the type of clinical placement influences students' attitudes in a negative or positive way. For instance, it was common during the 1970s and early 1980s for nursing students to experience their first clinical placement in a nursing home. Within this environment, they could learn how to give bed baths, change bed linens, and take temperatures, blood pressures, and pulses. Students tended to rate these experiences negatively and educators also wondered about the ethics of students learning basics of nursing on a vulnerable population—older individuals within continuing

care facilities, such as nursing homes. Educators also began to wonder about the timing of experiences that impact how health and human service professionals feel about working with older adults. Hence, it is not just the *type* of clinical education experience, but also the *timing* of the placement that may affect attitudes (Lane & Hirst, 2012). For example, some students enjoy a placement within the nursing home setting, not within their first year of education, but when they are in their final year. Within their final year of education, they can appreciate the complexities of providing care to older adults, can appreciate the privilege of working with families, and can understand the sophistication of skills needed to work effectively with families, as well as exercising leadership skills. Using this same reasoning, a palliative care placement is generally a student's practicum in her final year.

Although an understanding of timing of the clinical experiences with older adults begins to address the question of how to interest and excite students in gerontology, this is only a partial answer. The question is actually much more complex. Our work, as well as a search of the research indicates that improved knowledge of and attitudes toward older adults does not necessarily translate into a desire to work with older adults (Hirst et al., 2012). Clearly, much more research needs to be conducted to further unravel the complexities of what strategies will help engage students in working with older adults.

Education for Professional Currently Working with Older Adults

Many health and human service professionals work with older adults, but not necessarily by choice. Due to the nature of their work that cuts across age groupings, they will, regardless of preference, work with seniors. This does not mean, however, that they feel comfortable or knowledgeable enough to work with older adults. For instance, in one study, nurses and physicians admitted to not feeling confident in their assessments of pain in cognitively impaired older adults within nursing homes (Kaasalainen et al., 2007). In another study, delirium, a frequent and potentially life threatening condition experienced by hospitalized older adults, was recognized by less than one-third of registered nurses (Dahlke & Phinney, 2008). Similarly, we have worked with social workers, ministers, and psychologists who admit to experiencing much dis-ease (lack of ease) in working with aging individuals or death and dying.

We believe that it is critical for these professionals to receive education about aging, illness in older adulthood (such as dementias and mental illness) and the issues faced by older individuals and their family members, including the challenges faced in transitions. While some professions, such as registered nurses and physicians, have mandatory continuing education requirements that are enforced by their professional bodies, other professions do not necessarily require ongoing upgrading. For these professionals, such as the clergy, the onus to remain current

in their fields is entrusted to individuals. While some may choose to educate themselves about issues outside of faith, others may not. Thus, some ministers are not knowledgeable about the signs of depression in older adults or the need for professional treatment.

Even for professionals who are mandated to update themselves yearly, the focus of the educational upgrading is not stipulated. Thus, these professionals may not choose to read about older adults or attend educational seminars on issues facing this population group. It behooves all professionals to be mindful of population trends, such as the rapid aging of developed countries, and to educate themselves so that they are prepared to respond knowledgeably to changes in demographic trends, as well as the issues and transitions faced by those who may be affected by demographic trends, such as older adults.

While clergy may not be knowledgeable about how to assess and intervene with depression in older adults (at least not to the level of other professionals, such as registered nurses, psychologists, and social workers), clergy are often much more comfortable and adept in addressing existential issues then their aforementioned counterparts. As mentioned earlier in this book, many nurses and social workers do not know how to address these issues and actively steer away from them. They may not know how to talk about issues of meaning and purpose, bringing a sense of integration to life, as well as concerns about forgiveness of/from self, others, or God. Education about how to broach these matters, even to a limited degree, should be a goal of professionals who work with older adults. Even though most professionals are not trained to advise in spiritual matters, the connection between spiritual and emotional health is strong in older adults (Ramsay, 2008), so professionals working with older adults need to know how open up existential issues in conversation. If older adults admit to strong existential issues, professionals can then refer to clergy or other professionals who are comfortable discussing these transitional issues.

Ongoing Education for Para-Professionals

Although para-professionals[1] provide much of the direct care received by older adults within their homes (such as bathing) or within nursing homes, they receive minimal education. This is a significant deficit, as individuals who provide the *most* hands-on care, have the *least* knowledge to recognize and respond to reactions to transitions in older adults, such as grief, depression, suicidal ideation, and anger. This dilemma is not fair to older adults, or to the para-professionals who work with them.

Due to the high turnover of para-professional staff in home care agencies, as well as in nursing homes, education needs to be ongoing to ensure that every individual receives training. Education should focus on the challenges of transitions for older adults, such as relocation to other facilities (assisted living, nursing

[1] The term para-professional is used to denote healthcare aides or personal care attendants.

homes, and hospices, to name a few), as well as how to address these challenges. In studies examining the impact of the transition of placement into nursing homes upon new residents, staff rarely talked with older adults about the challenges of relocation (Wiersma, 2010). While staff may be aware of the magnitude of the transition and the grief incurred, they reported that they just do not have the time (Wiersma, 2010). Our belief is that this is not out of callousness on the part of the staff, but rather, in addition to the overwhelming workload, they may not know how to help older adults through this life changing transition and how to address grief, depression, and confusion. Further, as will be discussed under the "Sub-Population" section of this chapter, education should be provided to para-professional staff regarding how to give effective palliative care, as some older adults choose to die within the nursing home (or their families make this decision), rather than be transferred to hospital.

Education for Professionals Working within Prisons

Professionals working within the prison system should be given education about aging and its effect upon prisoners (Williams, Stern, Mellow, Safer, & Greifinger, 2012). This education can include the some of the expected changes of aging, including hearing and sight impairment, as well as information on disease processes, such as arthritis, and how this affects mobility of aged prisoners (Smyer & Burbank, 2009). Healthcare staff in prison facilities need information and policies that guide the regular assessments and screening (Sumner, 2012), as will be discussed in the housing section of this chapter.

Before embarking on a discussion of services in the community and housing options for aging individuals, we want to note that the changes we suggest are based upon our belief about the need to move toward more age-friendly communities, as discussed in Chapter 4. While how changes are made will depend upon the type of community and the population of that community (rural versus urban), we support the underlying premise of making living environments more meaningful and accessible for aging individuals.

SERVICES IN THE COMMUNITY

Services in the community should assist aging adults in preparing for retirement, help older individuals to access health services, live independently within their homes of choice for as long as possible, and promote growth and meaning in the latter decades of life. We recognize that some communities have these types of services, but others, particularly small or rural communities, have limited services that are tailored for the needs of older adults. The kinds and amounts of rural services are often dependent upon the size of the

town, as well as the proximity to a larger urban center (Niemeyer et al., 2006). The other factor is cost; depending upon the country and the healthcare benefits available, the cost of some of these services may be prohibitive for some individuals.

Services in Rural Areas

In some developed countries, such as the Canada, United States, and Australia, there is a larger proportion of older adults living within rural areas than in urban centers (Forbes & Edge, 2009; Niemeyer et al., 2006). It is recognized that older adults living in rural areas are at particular risk for being underserved and also that they may underutilize what services are available. Access barriers include limited services (related in part to lack of government support for rural services), inadequate numbers of professionals who work in rural areas, difficulties securing transportation and homemaker services (Li, 2006), and limited assisted living facilities (Averill, 2012). The inability or unwillingness to access services may result in older adults delaying seeking professional help when needed. This may have deleterious effects upon health and necessitate transitions to hospitals and ultimately, to facilities which provide 24-hour care. What are some possible solutions that may assist rural older adults to maintain their health and remain in the living setting of their choice for as long as possible?

Creative and Comprehensive Models to Organize Services

There is a need for creative models that provide a balance of services in and through various modalities. These models will assist aging rural adults to access services in larger urban centers, but also provide services within their own communities. They will address the lack of gerontological professionals within rural areas, and utilize technology and other supports to counterbalance the lack of gerontological specialists. Necessary services span across the healthcare spectrum (healthcare professionals and services) and support service sectors (volunteer and paid transportation services).

There is a deficit of geriatricians, geriatric psychiatrists, and other gerontological healthcare professionals working in rural areas in developed countries. In part, this is due to limited numbers of healthcare professionals committed to working with older adults in general, but also, most geriatricians (Peterson, Bazemore, Bragg, Xierali, & Warshaw, 2011) and specifically trained gerontological healthcare providers work in urban centers. Besides aging individuals traveling to urban centers to receive consultation from geriatricians and geriatric psychiatrists, other options should be available. For example, teleconferencing can be utilized for physicians, nurses, and other healthcare professionals

to consult with specialists about their clients. Further, teleconferencing could include older adults with geriatricians and geriatric psychiatrists. We realize that this technology is currently being used in some rural areas to benefit aging adults, but recognize that these services need to be part of an larger model of care offered to rural seniors.

While the use of specialists "flying in and flying out" to remote (Margolis, 2012) or rural areas can be every effective, it is an expensive form of healthcare delivery. In many rural areas, the family physician provides much of the care for older adults and may feel that he or she lacks time to offer significant psychosocial or mental healthcare (Bocker, Glasser, Nielsen, & Weidenbacher-Hoper, 2012). Thus, the use of nurse practitioners and interprofessional teams should also be utilized (Peterson et al., 2011). However, it is imperative that these professionals receive ongoing support and education in order to avoid burnout (from not being confident with decision making in regard to their clientele) (Bulbrook, Carey, Lenthall, Byers, & Behan, 2012). Examples of such programs include workshops to educate rural physicians on how to diagnose Alzheimer's disease (Galvin, Meuser, & Morris, 2012), or educational sessions for nurses and other professionals on how to assess for mental illness in older adults.

Additionally, nurses and other healthcare professionals can offer education to rural seniors on various aspects of healthcare. For instance, in one study, nurses and dieticians visited with older adults through the use of telehealth to set goals with older individuals regarding diabetes management (West, Lagua, Trief, Izquierdo, & Weinstock, 2010). This program was very successful, with 68 percent of the behavioral goals being met or improved upon (West et al., 2010). Similarly, nurses can utilize telecommunications or videoconferencing to educate older adults in rural areas about management of chronic heart failure (Clark et al., 2008). Additionally, telehealth can be used to provide psychosocial intervention for older adults with dementia and their caregivers (Li, Kyrouac, McManus, Cranston, & Hughes, 2012).

Telehealth services for clients, as well as teleconferencing among healthcare professionals, need to be evaluated through research. Even though they appear to be a promising and cost-effective means to offer education and consultation, there are challenges in using technology. For example, rural older adults may not have sufficient technology to access telehealth, or, they may be unfamiliar and uncomfortable in accessing this approach. Further, the usage of teleconferencing by interprofessional teams over geographical distance can result in challenges navigating team work and communication; this is especially the case when discussing complex client health or family issues (Forbes & Edge, 2009).

Pre-Retirement Education

Over the past number of decades, there have been some major changes in societal expectations around retirement. For a number of years, individuals in

some developed countries presumed that they would work until 65 years of age, the age that they could access national pension plans. However, in the 1980s, some financial institutions were touting programs that could help individuals retire comfortably earlier, including some that promoted retirement at 55 years of age. Much has changed over the last several decades, though, derailing early retirement for many individuals who are approaching older age. Some of these changes make the decision to retire more complex, resulting in the importance of pre-retirement education.

One such change is that many companies have done away with company pensions. While some employers still offer work pension plans, the numbers that do have dropped dramatically (MacEwan, 2012). If individuals approaching older age have not consciously saved for the future, they will have fewer monetary resources during their non or reduced working years. This will not only affect their ability to enjoy recreational activities such as traveling, working out at health clubs, and eating out at restaurants on a regular basis, but may impact their access to healthcare services that are not covered by the government or insurance plans.

Additionally, a number of countries, such as Canada and Australia, are pushing the current age of access to full government pensions or subsidies to a later age. As an example, Australia is implementing a change so that by 2017, Australians need to be 65.5 years of age to access the "age pension." The required age is set to increase by increments yearly, and by 2023, Australians will have to be 67 years of age to claim their age pension (Australian Government – Department of Human Services, 2012). In Canada, adults 54 years of age and older by March 31, 2012, will still be able to claim Old Age Security Pension at the age of 65 years. However, those born in 1958 and onwards, until and including January 1962, will have additional months added to the 65 years of age. Individuals born in February 1962 or later will all have to wait until age 67 to claim the Old Age Security Pension (Service Canada, 2012). Therefore, individuals in mid-life (example 40 to 50 years of age) who do not have a company pension and are not able to save substantial monies, will need to plan on working later to receive their full pensions.

Another factor to consider is the increasing life expectancy of individuals within developed countries. With the oldest-old (those 85 years of age and older) growing at a fast rate within the older adult population in many developed countries (Himes, 2001; Statistics Canada, 2008), adults can expect to live much older than those decades ago. While this is considered to be positive for many individuals, a stark reality remains: How will individuals fund their longer life spans? I (AML) remember interviewing an older couple with their adult daughter for my doctoral dissertation about the transition from a hospital mental health unit to an assisted living facility. This delightful couple—in their late 80s and living in a rural setting—talked about financial resources. Although they had sold their farm for a

substantial amount of money, lack of resources was now an issue. Their daughter poignantly stated:

> We thought we had enough in the bank and so on *to last us the rest of our lives at home*, but then we needed more help and, and the municipality has a program but they've got no people to fill the program. (italics ours)

For this couple, there were two major concerns. Their life span exceeded the amount of money they had to continue to fund living within their home. This was complicated by the fact that they lived in a rural setting. Within the rural setting, there were limited government programs to help older adults within their homes. And as noted by their daughter, the program that was available did not have professionals to service the program to assist older adults. The reality of the situation was that this couple did not have the resources to pay for all the services—bathing, housekeeping, etc.—that they needed.

Another important factor to keep in mind regarding the importance of pre-retirement education is the opportunities that are available for older adults. Although 24 percent of Canadians age 65 years to 70 years of age continue to work (MacEwan, 2012), generally, most employment is part-time, which has lower pay scales than full-time work. There is a greater proportion of workers 65 years of age and older who work in low-paid sales and service occupations than their counterparts between the ages of 25 to 55 (25 percent of those over 65 years of age compared to 20 percent of those 25 to 54 years) (MacEwan, 2012). Although this income may be augmented by government pensions, the amounts may not be enough for some seniors to live comfortably and afford what they need to maintain enjoyable activities, such as traveling, *and* their health.

Assistance to Access Health Services

As noted earlier, older adults often have mobility challenges due to arthritis and chronic pain. Further, problems with vision, hearing, and cognition may result in the loss of a driver's license. This means that some older individuals may have difficulty accessing medical appointments, getting blood work and other tests completed, and filling prescriptions; they cannot walk lengthy distances, and neither can they drive.

Transportation is a huge barrier for a number of older adults, as many Canadian neighborhoods, and some American ones, are designed for car use (Turcotte, 2012). This problem is further compounded if there are no family members available to transport the aging individual, or if the older adult lives in a rural area, on a reserve (Aboriginal), or has limited financial resources to pay for transportation services.

So what are the options for older adults? For aging individuals whose mobility is not severely compromised, they may be able to take the bus. If their city or town

offers discounts for seniors' bus passes, then this can be a viable option. However, according to the 2009 Canadian Community Health Survey, most older adults do not use public transit (Turcotte, 2012). Depending upon the size of the community that the older adult resides in, she may be able to afford a special lower cost pass for seniors that enables her to take a taxi for appointments and errands. The challenge of this is that often older adults need to book the taxi well in advance in order to ensure availability. This may work fine for a scheduled time booked well in advance, but less well for sudden or urgent appointments. Another option is that some seniors' not-for-profit organizations will have volunteers that can drive older adults.

Transportation then, becomes much more than transportation; it is the means through which older adults can attend healthcare appointments and manage their physical and mental health. It also becomes the means for older adults to participate in social activities and programs, thereby decreasing their sense of isolation and loneliness within the home (Turcotte, 2012). Viable options for transportation, which are affordable and reliable for all older adults, is a must in terms of maintaining older adults within their homes, and thus prematurely decreasing admissions to hospitals and nursing homes.

Living Independently within Their Homes

In order to live independently as long as possible within the home, some older adults need adaptations made to their living environment. These adaptations may include a shower seat, bath rails, and raised toilet seats, for example. Further, some older adults require home health aides to help them bathe or a housekeeper to clean their home. These services need to be affordable. Although the costs of these services may be based upon a sliding scale rule (cost is based upon the income of the older adult), the amount of services that are offered may not be enough for some older adults. Thus, they may need to pay more out of pocket for private services to augment the publicly offered services.

Cohabitation of Older Adults and Young Adults

Literature addressing cohabitation of older and younger adults can include various permutations. For instance, research on intergenerational cohabiting may involve older adults and their adult children. However, research on this kind of arrangement often involves individuals living outside North America, or individuals living within North America but representing various ethnicities (Choi, 1995; Kato, 2009; Ng, Northcott, & Abu-Laban, 2007). There is also literature examining the phenomena of grandparents raising grandchildren (Copen, 2006; Poindexter, 2007; Smith & Beltran, 2003; Smith, Beltran, Butts, & Kingson, 2000).

Intergenerational housing is also conceptualized as older adults living in vacated university dorms (Hedden, 1974) or living in a residence on or near an academic campus (Ward, Spitze, & Sherman, 2005). There are also reports describing specific communities/neighborhoods (such as Hope Meadows in Illinois) that were intentionally constructed for older adults and children, with the aim of older adults mentoring and helping children, and children helping older adults (Eheart & Hopping, 2001; Heimpel, 2011; Kennedy, 2010; Mattimore, 2006; Power, Mitchell, Erheart, & Hopping, 2011; Thomas & Blanchard, 2009).

Another variation of the cohabitation of older adults and young adults are programs that match up adults to live with older adults within their homes. These adults may be college-aged students or adults in mid-life. There are many such programs scattered throughout North America, the United Kingdom, Europe, and Australia; for example, as mentioned in Chapter 4, there are approximately 100 homesharing programs throughout the United States (Steinisch, 2007). The purpose of the match-up is for the mutual benefit of the older adult and the younger adult. The young adult lives for very little money in the home of an older adult and provides services such as grocery shopping, raking leaves, shoveling snow, driving, or other mutually agreed upon tasks. The older adult then has services done for her home that she does not need to pay for, and the younger adult can live for free, or next to free, in order to facilitate studies at university or college. Proponents of these programs suggest that they delay institutionalization (e.g., Fox, 2010); the safety of having another individual in the home, as well as the services the individual can provide, delay the need to move to more supervised levels of care.

Anecdotally, these types of programs are believed to be very effective for older adults and young adults. However, there is a lack of research empirically proving their effectiveness. It will be important to research both the benefits and the difficulties in running such programs. For example, in one study (Rhoades & McFarland, 1999) 61 individuals (31 to 79 years of age) who shared their home with mentally ill individuals were interviewed. They were asked why they opened up their homes and lives to the mentally ill. These individuals responded with answers that were categorized by the researchers as altruism, self-actualization, and existential (or life purpose). However, the homesharing individuals admitted to challenges of dealing with client disability or difficult behaviors. The second most often cited difficulty was the challenges the homesharers had in working with the program, such as bureaucracy issues causing problems in accessing resources. Because this study does not solely focus on older adults as homeowners and young adults who are engaged in post-secondary education, the application and findings need to be interpreted with caution.

However, several observations can be made. First, there needs to be more research conducted on these programs regarding the benefits for older adults and young adults. Further, besides the altruistic and existential benefits (which are important), what kind of impact does having a young adult in the home have upon delaying moves to assisted living, nursing homes, or other arrangements

for older adults? What are the potential risks for older adults and their younger homesharers?

Technology within the Home

Healthcare has become increasing technologically oriented within hospitals and clinics. But what about technology in the homes to enable older adults to live independently longer? Available today are a variety of technologically advanced aids that may be used for older adults to promote independence, as well as monitor their health and safety.

Designed to allow older adults to function independently within their homes, these technological apparatuses also promote safety and monitoring. In terms of mobility devices, manual wheelchairs, powered wheelchairs, and canes are considered to be robots that aid mobility and enhance safety, both inside and outside of the home (Hirst, 2010). While powered wheelchairs may be easier for older adults to use than the non-powered counterparts, the older adult who uses a powered wheelchair still needs to perform a number of small adjustments to maneuver (Hirst, 2010). This can be tiring and difficult for some, particularly for older adults with rheumatoid arthritis or multiple sclerosis. Currently, the technology already exists for wheelchairs to automatically avoid obstructions and be partially self-navigating (Hirst, 2010 Kang et al., 2010;). Similarly, there are walkers that can steer away from obstacles and be retrieved via remote control, as well as a cane that can detect when an older adult is in danger of falling (Hirst, 2010). Additionally, there are GPS (Global Positioning System) shoes that have a built-in GPS that can help track older adults who wander away from home due to Alzheimer's disease. These shoes will provide the location of the individual wearing the shoes and provide a virtual fence around the older adult; this will enable the person to walk in familiar places but alert him if he is off track (Hirst, 2010).

Technology that monitors safety within the home (that is not embedded into mobility devices) includes personal emergency response systems (Mihailidis, Cockburn, Longley, & Boger, 2008), as well as sensors and motion detectors. The personal emergency response system is worn on an individual within her home, and if she is in trouble, she can push the button on the pendant or the "watch." This will alert an operator who can then talk with the individual and/or send emergency help (Mihailidis et al., 2008). Similarly, sensors and motion detectors can monitor if the house door opens (safety) or if a medication cupboard door or the refrigerator is opened (offering caregivers some assurance that the older adult is taking medication and eating) (Kang et al., 2010).

There are also devices that monitor health within the home; these include such things as heart rate monitors, glucose monitors, pulse oximeters , as well as activity monitors (Kang et al., 2010).

As promising as technological advances are in helping to keep older adults within their homes longer, there are practical and ethical considerations involved (Demeris, Doorenbos, & Towle, 2009). Practically, older adults may have trouble programming some technology; for example, individuals with Alzheimer's disease may not be able to program a GPS due to cognitive deficits (Hirst, 2010). There may also be concerns regarding the reliability of the technology and that there be accessible technical support (Mihailidis et al., 2008). From an ethical perspective, there are some issues. For example, older adults are concerned about privacy and confidentiality of personal information (Demeris et al., 2009). Issues regarding privacy include recordings of data, storage of data, and the possibility that the transmission of data may be intercepted by other communication lines, such as telephone lines. Ethically, who should make the decision about using technology, such as a GPS system, for aging individuals with dementia (Landau, Auslander, Werner, Shoval, & Heinik, 2011)? Informed consent can be ethically sticky when there is a concern about capacity in the older adult (Demeris et al., 2009). Thus, we suggest that policies and procedures need to guide how technology is used and monitored. As well, research needs to examine the ethical issues involved in the use of technology to enhance the safety of older adults within their homes, as well as possible solutions to address the dilemmas.

Personal Growth and Meaning

Programs that promote personal growth and meaning are imperative for older adults. As previously stated in this chapter, intergenerational programs where seniors are mentors for children or youth add to their sense of meaning and purpose. The sense of meaning helps with transitions such as retirement or changes in health. In fact, older adults report better mental and physical health when their lives are imbued with meaning.

Post-Secondary Education

Some provinces/states offer university or college courses to older adults for free or reduced rates. This allows older adults to study topics of interest, to learn, and, perhaps, to fulfill an unrealized dream—to achieve a university or college degree. In one study examining life regrets and pride among older adults with lower income, almost half of the older respondents stated they wished they could have, or would have, finished high school or college education (Choi & Jun, 2009). Post-secondary learning can be deeply fulfilling for some older adults; not only do they enjoy learning for the sake of learning (rather than learning for the sake of obtaining future employment), they garner a sense of purpose in and structure to their lives. By learning in a post-secondary setting, they also have the satisfaction of repairing regrets from the past; this chance is meaningful to older adults, as they may feel that due to their age, their opportunities to rectify past decisions are limited as compared to younger adults (Choi & Jun, 2009).

Volunteer Work or Paid Work

As one strategy for addressing personal growth in aging, some older adults volunteer (as discussed in Chapter 5). Not only does the volunteer work provide a sense of structure and offer personal meaning, it can also become part of the self-identity of individuals (Bradley, 1999–2000). This may be especially significant for older adults who feel they lost some of their identity upon retirement. As mentioned earlier, the gains of volunteer work include improved physical and mental health. However, the benefits can also include cognition. In one study, the impact of late life volunteering or work activities upon the mental health of older adults from Singapore was examined (Schwingel, Niti, Tang, & Ng, 2009). Volunteering and work had a very positive effect upon the mental health of aging individuals from Singapore, but also, both had significant impact on cognitive functioning (Schwingel et al., 2009). As such, there should be advertisements about volunteering, information about volunteer agencies that connect older adults with opportunities, as well as literature that promotes the rewards. As noted in the research, sometimes older adults are not aware of the volunteer possibilities in their vicinity.

There is a problem, however. Most of the time, volunteering by older adults is predicated upon good physical and mental health. What about older adults whose health or mobility is significantly compromised? Can they volunteer and what are the benefits? In one study, the impact of volunteering upon older adults with fair health was examined (Barron et al., 2009). Within this study, the researchers investigated how intensive volunteering (greater than 15 hours per week) in a Baltimore, Maryland, elementary school affected 174 older adults who reported their health as "good," "fair," or "poor." Although most of the volunteers in each category showed improvement in strength and energy, those in the "fair" category demonstrated the greatest level of improvement. Most individuals in this category exhibited greater speed in climbing stairs than those in the excellent or good category and a number became faster in walking speed (Barron et al., 2009). Although this is just one study, the findings suggest that older adults can benefit greatly from volunteer experiences, even when their health may not be strong and when the volunteer experience requires extensive involvement. Obviously, more research should be conducted on the impact of volunteering upon older adults who have a number of health conditions.

What about older adults who want to volunteer, but are limited in mobility or are housebound? Older adults can still volunteer through offering phone support to socially isolated older adults (Cattan, Kime, & Bagnall, 2011), or can become involved in "virtual" volunteerism (Mukherjee, 2010). Studies reveal that older adults who volunteer through virtual or phone work have a sense purpose and a feeling like they are giving something back to society. They also report feeling less isolated (Cattan et al., 2011). As we noted in an earlier chapter, reducing social isolation is important as this can reduce depression in housebound older adults.

So what are some future considerations with regards to volunteer opportunities for older adults? First, attention needs to be given to how best interest older adults in volunteering and make them aware of opportunities, including those that are episodic, those that require minimal levels of commitment, and those that are time intensive. Generally speaking, adolescents and younger adults are more aware of opportunities through their schools or work situations and thus have more chances to volunteer than their older counterparts (Morrow-Howell, 2010). Older adults who are poorly informed of the varieties of experiences and the variations in time commitment may be less inclined to volunteer, not because of a lack of interest, but because of a lack of knowledge. By becoming more knowledgeable about the types of experiences (both the focus and the work), as well as the time commitments involved, older adults can select opportunities that resonate with their life philosophies, belief systems, and passions.

Second, we propose that research and attention needs to be directed not only towards recruitment of older adults to volunteer work, but also retention factors. Specifically, what factors in their volunteer experiences assist older adults to remain committed and interested? At the present time, research has largely focused on specific characteristics of older individuals that motivate them to volunteer. There is a need for research to address the organizational aspects that impact the volunteer experience for older adults, as well as how life transitions—such as cessation of work, caregiving and health changes—impact volunteering for older adults (Morrow-Howell, 2010).

Third, we suggest that organizations examine how volunteer programs can be geared toward older individuals who have significant health and mobility issues. This means that organizations that rely upon volunteers can begin programs that involve outreach through the Internet or phones. These organizations need to build in mechanisms not only to assess the satisfaction of older volunteers who provide phone or Internet support to others, but also, the benefits received by clients. Further, there should be research into the best means to reward and thank these volunteers that are largely unseen by the organization's staff members.

HOUSING OPTIONS

Over the last several decades, more housing options have become available for older adults within Canada, the United States, and other developed countries. However, housing options are much more readily available in large urban centers than in rural areas. Also, the stipulations for admission, as well as the costs incurred, may prohibit some older adults from accessing various kinds of housing. Further, with the significant increase in the older adult population within developed countries, finding appropriate housing for older adults may become more difficult in the decades to come. Some of the options include seniors' complexes (these can be low-cost housing or condominiums that are designed for

higher-income seniors), lodges, assisted living, designated assisted living (assisted living facilities where there is some nursing support), and continuing care facilities, such as nursing homes. Seniors' low-income housing is available in many large urban areas, but often the waiting lists for these facilities are long; some older adults have to wait years for this option. Also, group homes for older adults exist in some cities, but often availability is limited and accessibility is limited to those with specific illnesses or conditions. We suggest the following changes in housing options for older adults.

Independent or Semi-Independent Living Arrangements

Seniors' low-cost housing provides a nice option for aging adults who are on fixed incomes. Individuals rent low-cost condominiums or apartments that are often in a complex. This provides both privacy and community, if older adults desire the companionship of others. While these arrangements are a good alternative to older adults renting a single home dwelling (house with yard to tend and walks to shovel), the waiting lists are often very long. More low-cost seniors' complexes should be created to address the current need for seniors' housing, as well as help to meet the future need with the projected explosive growth in the older adult population.

Assisted living facilities provide very nice accommodations, and like seniors' complexes, allow for privacy and togetherness. However, as some assisted living facilities are privately owned, the cost may be prohibitive for older adults on fixed incomes (Lane, 2007). We propose that there need to be more assisted living facilities that are government subsidized, so that this option is accessible to aging individuals with lower incomes. Designated assisted living (living in an assisted living facility but with healthcare support on site 24 hours per day) can occur within an assisted living facility, or actually be a facility that is categorized as a designated assisted living facility. This means that older adults can live semi-independently within their suites, but also have a healthcare professional on site for emergencies (Lane, 2007). (In non-designated assisted living facilities, older adults can access some home care services and visits from a healthcare professional, but there is no healthcare professional on site throughout the 24 hour day). While costs are less than private assisted living facilities, still, rates are higher than found in nursing homes, which may be problematic for some older adults. Aside from cost, there are differences in the particulars of the services. For instance, health/home care services may include helping an elderly resident dress in the morning. However, the services do not include "cueing" the older individual to dress. There is a significant difference, as cueing involves letting the older adult dress himself, with prompts from the professional, rather than dressing the individual (Lane, 2007). Not only does cueing promote self-mastery and autonomy on the part of the aging individual, but it also maintains functional abilities longer. Finally, depending upon

the city and province/state, designated assisted living "beds" are limited. As such, there should be more designated assisted living arrangements with some tailoring of services to maximize the functional abilities of older clients.

Dependent Living Arrangements

Older adults often do not enter continuing care facilities, such as nursing homes until very frail, significantly cognitively impaired, or very elderly. Nursing homes provide daily support and care for older adults when they are unable to care for themselves due to physical illness or cognitive impairment.

Person-Centered Care

Originally, nursing homes were organized according to a hospital model. This meant that like in hospitals, there were specific times to rise in the morning and to retire in the evening. Bath and shower times were regulated and care was often governed by routines. However, in the last number of years, there has been a move toward a culture of person-centered care. While there are still routines that guide some of the work of staff in nursing homes (to enhance the smooth running of a unit), there is much more attention paid to acknowledging the uniqueness of individuals and enabling residents to make choices in their daily living. We applaud this move toward a person-centered culture within continuing care facilities, such as nursing homes, especially as these facilities often become the permanent *home* of older adults. *How* the person-centered culture is operationalized, however, will differ from nursing home to nursing home. We advocate, therefore, for the widespread adoption of the person-centered culture that maximizes, as much as possible, autonomy and choice of older residents. While routines are a fact of institutional life, owing to the large numbers of older adults that need care, we propose that routines continue to be relaxed to promote individuality within nursing home settings. When older adults have more control over how they regulate their daily activities, autonomy is promoted, which may then enhance mental health. In order to enhance the person-centered culture in nursing homes, where the home is somewhat closer to the notion of "home" that older adults espouse, there would need to be *fewer policies* dictating routines and *more staff* to facilitate individual choice. Understandably, this will cost governments more money (or companies, for privatized nursing homes). However, residents and family members may be much happier and less likely to pursue legal avenues due to events where staff and residents are caught in conflict, trying to carry out nursing home routines.

Single Occupancy Rooms

Also, we believe that there should be a move toward more single occupancy rooms within nursing homes (Lane, 2007). Not only can this decrease acts of aggression between roommates, particularly when individuals have dementia and

misread the behavioral cues and intents of others, but single occupancy spaces allow for residents to personalize their space. Personal space promotes privacy in an environment where there is limited privacy. Residents can also exercise autonomy about when they want to watch TV or when they want the room lights out, for example, without concern about disturbing a roommate.

Presence of Pets

As part of making nursing homes less medicalized, more person-centered, and more like a home, we fully support the movement toward animals within facilities. In Chapter 4, we discussed the importance of pets for some aging adults living within their homes. In order to create a friendly, home-like environment within continuing care facilities, we advocate for resident cats, visits by dogs, or other options. While some nursing homes have animals that can be petted and lie on residents' laps, not all do. Additionally, some nursing homes have pets, generally cats or birds, that reside full time in the facility, while others have animals, such as dogs, that come for time-limited visits. What is the impact of such programs upon aging residents?

In an interesting study, researchers compared the effects of dog visits (with a volunteer) as compared to human visits (Lutwack-Bloom, Wijewickrama, & Smith, 2005). By using the Geriatric Depression Scale and the Profile of Mood Disorders, the researchers compared residents in two nursing homes over a six-month period; one group received visits without a dog and the other group received visits from a volunteer who brought a dog. The results revealed that the residents who received regular visits from the dog showed a significant positive effect upon their mood. Further, the residents receiving dog visits also experienced improvement in depression, although the results were not significant (Lutwack-Bloom et al., 2005).

How do pets affect aging adults with Alzheimer's disease or related dementias? Baun and McCabe (2003) suggested that dogs can be helpful for individuals with Alzheimer's disease who pace. They can go on walks with the dog, although someone else will actually have to handle the pet. They can also toss a ball or object to the dog to discharge the energy that is normally managed through pacing. Dogs are also known to calm the agitated behaviors of those with Alzheimer's disease (McCabe, Baun, Speich, & Agrawal, 2002). Further, as language abilities become compromised in individuals with dementia, dogs will still maintain eye contact with the affected persons and provide companionship. When the aging adult with dementia becomes bedridden, a dog (or cat) can lie next to the person and provide warmth, security, and comfort (Baun & McCabe, 2003).

Beyond research results, anecdotal reports of the impact of animals upon older adults, particularly very vulnerable older adults, abound within the literature. Stories also emerge from clinical practice. I (AML) have one such anecdote. A number of years ago, I supervised a geriatric mental health unit. My husband

(Dave) and I had a new dog—Suzie, a basset hound. Staff on my unit wanted to see her. One day near the end of the shift Dave brought Suzie up to the unit. Suzie was just a young puppy and Dave was carrying her in his arms. Suzie had the typical sad expression of the basset hound, facilitated in part by sad eyes set within square eye sockets (which gave the appearance of drunkenness), long floppy, soft ears, and gigantic paws (in relation to her size). A fair distance across the unit a patient spied Suzie. This woman had frontal lobe dementia and could be very verbally, and even physically, aggressive. Even though she was physically frail and used a cane, she shuffled amazingly quickly across the unit to us. Her normally hard and angry face appeared soft, even tender, and awestruck. She quietly, even reverently asked, "Where did you get that dog?" "How much did you pay for her?" As she gently petted Suzie and the three of us talked about her, the woman was kind, respectful, and truly serene. As Dave and I reflected upon the experience and shared what had happened with my sister (MBR) afterward, Marlette responded, "Suzie did the work of God that humans could not do." We agreed. The ability of Suzie to produce gentleness and serenity within this woman was in stark contrast to our best efforts of professionals. Suzie, as an innocent and gentle puppy, touched an area in this woman's heart and soul that was unreachable by professionals.

Costs

Another issue about continuing care facilities, such as nursing homes, is cost. Even though the Canada Health Act covers medically required costs and some costs related to residency in a nursing home, some aspects of nursing home life are left up to provinces and territories to determine what is funded (Fernandes & Spencer, 2010). While provinces and territories foot a significant part of the costs of residency within nursing homes, there are some private costs that are assumed by residents and families. In their study examining nursing home cost disparities across Canada, Fernandes and Spencer (2010) found that private costs incurred were dependent upon where residents lived, their marital status, and income level. Thus, a single older adult living in Atlantic Canada with an average income will pay double the cost of his or her counterpart in Quebec. Further, a couple living in Newfoundland with one member in care will pay almost four times more than a similar couple in Alberta (Fernandes & Spencer, 2010). This means that even though a number of the costs of nursing home residency are covered for aging adults in Canada, the remaining costs may still be considerable for some living in the Atlantic region. This disparity in cost should be reduced.

Education for Para-Professionals

As mentioned earlier within this chapter, para-professionals within nursing homes should have regular education. This education should cover issues such as how to work with older adults with dementia, but also, how to work with

sub-populations of older adults that may increasingly come into nursing homes, such as the mentally ill, those with HIV/AIDS (Lane, Hirst, & Reed, 2013), and older adults who have developmental disabilities (Hirst, Lane, & Seneviratne, 2013) and for aging individuals who are dying.

Housing Options for Sub-Populations of Older Adults

The above section addressed general issues related to housing for older adults. However, there is increased recognition about sub-populations that fall between the housing cracks. In light of this, we will discuss several sub-populations of older adults that require housing, but face access challenges. While some may question why housing should be provided for those who cannot afford it, housing and health are undeniably linked (Bottomley, 2001). If older adults do not have secure housing, their health suffers.

Shelters for Older Adults Experiencing Abuse

Abuse of older adults within developed countries is becoming more widely recognized (Solomon & Reingold, 2012). Sometimes aging individuals continue to live with an abusive relative, because the older person does not have anywhere else to go. In order to provide a safe place to go, shelters for abused aging adults opened. The Kerby Rotary House in Calgary, Alberta, was the first shelter to be built for abused aging individuals (Special Senate Committee on Aging, 2009) in North America. However, since the opening of the Kerby Rotary House in Calgary, more shelters have sprung up across North America. These shelters may be housed with continuing care facilities (not-for-profit nursing homes in the United States) (Reingold, 2006; Solomon, 2006; Solomon & Reingold, 2012). Older adults receive crisis intervention, assistance from an interprofessional team, including legal advice, as well as housing (Reingold, 2006; Solomon, 2006). These services provide the space and opportunity for aging individuals to make decisions about future living options. More of these kinds of shelters need to be available for older adults, as many aging individuals do not feel comfortable in shelters that service younger, homeless adults.

Mentally Ill Older Adults

Depending upon the geographic location, housing options for mentally ill older adults may be limited. If older, mentally ill individuals behave in socially unacceptable manners, they may not be considered appropriate for assisted living facilities (Lane, 2007). Additionally, if mental illness has been persistent and severe over a number of years, they most likely do not have the money to afford an assisted living facility. Some older, mentally ill individuals have lived in precarious living situations for much of their lives; they may have spent time on the

streets and in homeless shelters, as well as living in unsuitable apartments for short periods of time.

At some point in time, mentally ill older adults may be brought to hospital for a mental health assessment. If deemed to be mentally or physically unable to care for themselves, these individuals may be admitted to hospital for further assessment and planning for alternate housing arrangements. As discussed in Chapter 3, however, finding appropriate living arrangements for these older adults can be difficult. Assisted living facilities may be reluctant to accept those with mental illness out of concern that these individuals may be too disruptive (Lane, 2011). Although living in a group home could be an option, depending upon the geographical location, availability may be an issue.

Further, nursing homes may be reluctant to accept older adults with mental illness. In my doctoral research, I (AML) examined the process of placing older adults from hospital mental health units in a western Canadian city into nursing homes (Lane, 2007). Staff working on mental health units (physicians, nurses, social workers) spoke about the difficulty of placing older adults into nursing homes, due in part to the reluctance of staff in nursing homes to accept them. The professionals on hospital units discussed how some staff within nursing homes expressed fear that those with mental illness are violent.

Professionals who were interviewed also described how the requirements of placement, in terms of the degree of physical and cognitive incapacitation necessary for nursing home placement, precluded this option. Ironically, some older adults with mental illness are too physically well to be admitted to nursing homes, and too ill (mentally) to live independently. By virtue of being able to dress themselves, eat independently and take care of bodily functions, they do not fit the requisites (as stipulated by assessment forms) to be placed (Lane, McCoy, & Ewashen, 2010). We propose that exceptions to the usual requirements of nursing home placement (extreme physical and functional difficulties) need to be made for those with mental illness in order to ensure that they have safe housing (Lane, 2011).

We also suggest that within larger urban settings, some nursing home units be designated for older adults with mental illness. This would promote ongoing staff education to work with those with such issues. Education would not only include the pathophysiology of mental illness, but also how to respond to the behavioral manifestations of mental illness, such as the delusional utterances of residents. Education may decrease apprehension to work with this sub-population of older adults and may therefore enhance the retention of staff.

Older Adults with Developmental Disabilities

As discussed in Chapter 7, some individuals with developmental disabilities are now living into their 50s and 60s, which for this population is considered old (Hirst et al., 2013). The term *developmental disability* refers to a lifelong mental or physical functional limitation that is evident soon after birth (Crews,

2011). This term is commonly used for neurological disorders such as Down syndrome (Sherman, Allen, Bean, & Freeman, 2007). The loss of a parent is often the impetus for placement for older adults with developmental disabilities. As noted in Chapter 7, however, family members often fear placement, wondering about how the aging adult with a developmental disability will adjust. The concerns are well-founded, because group homes for individuals with developmental disabilities are often geared for younger adults and workers may lack knowledge of how aging and dementia impacts their clients. Similarly, staff in nursing homes may be uncertain of how to effectively work with someone with a developmental disability. With the growth in this sub-population of older adults, staff working in group homes need education on how aging and dementia impact their clients, and staff in nursing homes should receive education on how to provide effective care to aging individuals with developmental disabilities. Further, as individuals with developmental disabilities often have trouble communicating and describing sensations or symptoms experienced, it is imperative that staff are educated on how to patiently and astutely assess these clients (Hirst et al., 2013).

Further, future directions should also include research on what kinds of living environments are best suited for aging individuals with developmental disabilities. If one kind of setting is deemed to be more effective than another (for example, group homes considered better than nursing homes), then this type of living option could be designated for aging individuals with developmental disabilities. This would not only promote staff education, but might also enhance the comfort level of individuals with developmental disabilities, as others around them would be similar in age and also understand their functional deficits.

Homeless Older Adults

Older age in homeless adults is often considered to be about 50 years of age (Donley, 2010); this benchmark can vary, however, depending upon the researcher or clinician; for some, the suggested older age may range from 50 to 65 years of age (Crane & Warnes, 2001). The criteria for old age is set earlier, as the stress of living on the streets results in premature aging and problems such as cardiac disease, diabetes, respiratory problems, and communicable diseases, as well as substance abuse and mental illness (O'Connell, 2004). Older adults who are homeless may have been homeless for many years (perhaps due to issues such as severe mental illness) or may have become homeless in older life. When individuals become homeless in later life, this is generally related to marital breakdown, alcoholism, widowhood, death of a family member (Gonyea, Mills-Dick, & Bachman, 2010), and sometimes, retirement (in particular, when housing is attached to employment) (Crane & Warnes, 2001). Homeless older adults who are in their 50s are in a particularly vulnerable situation, because they are not eligible for full government pensions (Donley,

2010). This sub-population of older adults has been relatively invisible for policymakers, professionals who work in programs for the homeless, and healthcare providers (Gonyea, et al., 2010). However, with the burgeoning of the older adult population in developed countries, the homeless older adult population is expected to grow.

In order to address the complex challenges of homeless older adults, there needs to be better communication between governmental departments, both *within* provincial (or state) governments and also *between* provincial/state and federal governments. Departments responsible for services that assist individuals to remain in their homes should collaborate with the departments responsible for housing in order to develop policies that enhance the chances of these individuals to be housed. For instance, in one Canadian study, the researchers examined the impact of a housing program to assist older adults who were homeless or at risk of becoming homeless (e.g., being evicted due to living in squalor) (Ploeg, Hayward, Woodward, & Johnston, 2008). The housing support workers in the program found that older adults who were at risk of being evicted from current living environments could not access appropriate homemakers to clean their apartments. They were therefore at risk for eviction. If they had been able to access appropriate homemaking services (prior to the cuts to services), their home environments might have been clean enough to avert eviction. Thus, a lack of coordination between government departments/programs works against vulnerable, homeless, or nearly homeless, older adults (Ploeg et al., 2008).

Additionally, there needs to be more low-income housing available within Canada, the United States, and other developed countries (Gonyea et al., 2010; Ploeg et al., 2008). Typically, there are long wait lists to access low-income housing (Donley, 2010; Ploeg et al., 2008). This is problematic, as older homeless adults cannot, or may not necessarily want to, access the shelters that their younger counterparts use. They may not be eligible for shelters accommodating women with young children, and they may fear exposure to illness and violence at shelters for the general adult population (Bottomley, Bissonette, & Snekvik, 2001). Further, McDonald, Dergal, and Cleghorn (2007) suggested that the housing needs of the recently homeless elderly should be addressed quickly in order to prevent these individuals from becoming rooted in the homeless life.

In general, housing options for vulnerable older adults (not including the situation of incarcerated seniors that will be discussed momentarily) need to be affordable and available in both urban and rural locations (in order that vulnerable seniors can remain close to their support systems, such as family and friends) (Weeks & LeBlanc, 2010). Housing should be suitable for the health and social situations of the elderly adults, so that those with disabilities can live as independently as possible, for as long as possible. Further, services should be available and affordable that aging adults can maintain their homes (Weeks & LeBlanc, 2010).

Dying Older Adults

Currently only a small percentage of dying older adults receive specialized palliative care (Lee, Coakley, Dahlin, & Carleton, 2009). As we have emphasized in this text, the population of developed countries is living longer, so providing appropriate holistic care to dying people is vital. Not only is it vital, we suggest that such provision of care during dying is a basic human right. That being said, owing to the pressures on the healthcare systems in developed countries, some are skeptical that such care will be delivered to more aging individuals. Scottish geriatrician Colin Douglas (1992) caused a great stir in the United Kingdom when he said, "The hospice movement is too good to be true and too small to be useful" (p. 579).

A number of studies have called for better palliative methods in a number of different settings (Field & Addington-Hall, 2000; Sidell, Samson Katz, & Komaromy, 2000). The variety of settings for palliative care is growing. For instance, in Canada, there are a number of options for palliative care in different settings: hospices attached to nursing homes, palliative wards within hospitals, hospices within the hospital setting, and palliative home care. Often, however, these services are available in large urban centers, rather than in smaller towns. Like others, we believe that palliative care must be accessible for those in rural settings, not just for dying older adults in larger cities (Ley & van Bommel, 1994). Further, comprehensive palliative care should reach into the worlds of those who are sequestered from the mainstream, such as the incarcerated (addressed later in this chapter) as well as those who are marginalized (Ley & van Bommel, 1994), such as the mentally ill (Kissane & Kelly, 2000) and those with developmental disabilities.

As a vast number of Canadian and American older adults will die in nursing homes on the units where they have resided for years, there is a recognition that effective palliative care needs to be provided. However, for this to occur, much education needs to take place on multiple levels. First, there needs to be greater awareness of what palliative care entails and who is entitled to this type of care. Predominantly, palliative care is still conceptualized as measures taken at the end of a cancer patient's life (Sidell et al., 2000). The healthcare community and the public needs to become aware about the importance of multifaceted care for older adults and ask for it. Second, staff need to be prepared to deal effectively with their palliative patients. In all health settings where the dying are present—home, hospitals, nursing homes—staff need to be able to recognize the signs of pain (Sidell et al., 2000) and delirium (Dahlke & Phinney, 2008) and deal with them. They need to have the skills and presence to speak to and be with dying people and their families (Benner Carson & Koenig, 2004; Ryan, 2005). And they need to have resources to turn to, when they encounter situations they cannot handle on their own, such as in the case of specialized medical needs, or complex spiritual distress (Benner Carson & Koenig, 2004).

In this day and age of monetary pressures on healthcare systems, can this be done? Sidell and colleagues (2000) believe this aspiration is attainable. Others put it more strongly: "[P]alliative care is the only moral, intellectual and practical way forward" (George & Sykes, 1997, p. 252).

Incarcerated Older Adults

As mentioned in Chapter 2, there is a sub-population of older adults within the prison system of Canada, the United States, and other developed countries that have been incarcerated for years. These adults are usually in their 50s, but are considered to be old due to the health problems that they have related to lifestyle choices (e.g., smoking) and incarceration (Beckett, Peternelj-Taylor, & Johnson, 2003).

Prisons were not designed for older inmates, so the current living environments are unsuitable for some older prisoners (Duffin, 2010). They may need walkers or wheelchairs, oxygen, raised toilet seats, commodes, and hospital beds (Beckett et al., 2003; Duffin, 2010). The doorways may be too small for older prisoners to navigate through with a wheelchair. The noise of the prison may be confusing and upsetting for those with Alzheimer's disease or other types of dementia (Beckett et al., 2003).

Public policies should address issues of safety for aging prisoners. For instance, prisons need to make accommodations to help older adults navigate through the hallways with safety. There also need to be changes in routine to accommodate older inmates, such as affording them a longer time span to get to the dining room or being allowed to bring food back to their cell if they are unable to finish their meals. Hearing-impaired inmates may have trouble with noise at visiting times, so can be accommodated by situating them away from other prisoners and their visitors (Sumner, 2012). Other important adaptations include large-print informational brochures that enable sight-impaired older inmates to receive the information they need, as well as large-print books (Sumner, 2012). Additionally, there should be educational and recreational programs designed specifically for older adults, rather than expecting older adults to fit into programs designed for healthier and stronger inmates (Snyder, van Wormer, Chadha, & Jaggers, 2009).

As part of policy and procedure, older inmates need regular preventive healthcare and screening. Some authors suggest screening upon entry to the prison (if 55 years of age or older) and yearly screening thereafter for sensory impairment (sight, hearing) and dementia (Williams et al., 2012). Women need regular mammography and cervical screening (Duffin, 2010). Stress management programs are also recommended (Smyer & Burbank, 2009).

Prison units that are designated for physically frail individuals or for older adults may be helpful and desirable for some (Smyer & Burbank, 2009). The units can include adaptations such as handrails, wheelchair accessible ramps, and showers. As noted by Williams and colleagues (2012), however, older prisoners should

have a choice as to whether they want to be placed within these units or stay within the general population. Although they could have easier access to assistance in the geriatric unit, they may prefer to stay with their friends (Williams et al., 2012).

Some older adults will be released from prison into general society. If they have spent years in prison, they are generally unprepared to reintegrate into everyday life; they often have little education, few job skills, and may have no family (Smyer & Burbank, 2009). Months prior to release, there should be regular consultation between the prison officer who is responsible for resettlement, the prison healthcare department, and the parole officer (Sumner, 2012). Transitional work should involve helping older inmates connect with healthcare, social services, and case management in the community prior to their release. Then, when in the community, follow-up should occur to make certain that older adults have accessed services and support (Roberts, Kennedy, & Hammett, 2004).

A number of older inmates die within the prison, and as the older population within correctional facilities grows, more are expected to die within custody. In response to this reality, there is beginning recognition within the literature that better palliative care services are needed within the correctional system (Reviere & Young, 2004). Even when prisons have some kind of end-of-life care, most likely the number of services offered will be fewer than those offered through hospice care in the community (Turner, Payne, & Barbarachild, 2011). Staff in both areas—palliative care and corrections—may feel intimated about the challenges in providing care to the dying incarcerated. Healthcare staff in prisons often have little experience in palliative care, and sometimes even less experience in grief and spiritual support, thus requiring education and guidance in providing end-of-life care (Turner et al., 2011). Prison staff may also be concerned about dying prisoners distributing pain medication to other prisoners, either because they are pressured or for the money. As such, there should be an interface between hospice care and prison healthcare to facilitate the care of aging, dying prisoners within custody (Turner et al., 2011). In the United States, the National Prison Hospice Association was established in the 1990s to address the issues of prisoners dying with AIDS and standards of practice were formulated; however, this is not the case for all developed countries (Bolger, 2005).

Aging prisoners who are very frail may be given compassionate release and discharged early to a nursing home or to a hospice, if terminally ill (Beckett et al., 2003; Duffin, 2010). Compassionate release may be given when the prison environment is believed to cause serious deleterious effects to the physical or mental health of the aging prisoner. However, as noted by Beckett and colleagues (2003), the early release of prisoners for compassionate reasons is controversial; the general population may question why grace is extended to individuals who have committed violent crimes, even if committed decades earlier. Also, receiving facilities, such as nursing homes, may be reluctant to accept released prisoners (Beckett et al., 2003).

SUPPORT FOR FAMILIES (CAREGIVERS)

As illustrated throughout this text, family members provide much care, and expend much physical and emotional energy in caring for their aging members. They truly provide the bulk of care for aging individuals (Special Senate Committee Report on Aging, 2009). Although provision of care by family members helps maintain bonds between older members and their spouses/adult children/relatives and friends, it is not without cost to the caregivers. As recognized in the 1990s by the proliferation of research conducted on caregiver burden, caregiving for older adults, whether they are experiencing cognitive, physical, or mental challenges, exacts a toll. With the burgeoning of the older adult population, in concert with fewer adult children available to care for aging parents (from factors such as decreased birth rates, increased geographical mobility, and increased numbers of women in the workforce), the stress upon family caregivers may become greater. This particularly the case when family caregivers themselves are elderly, whether they are spouses or adult children. Not only do family caregivers need supportive services such as respite care for older adults (Special Senate Committee Report on Aging, 2009), they also need direct support themselves, through support groups (e.g., Alzheimer Society chapters), telephone-based support (Glueckauf et al., 2007), and financial support for caregiving (as provided by other countries, such as the Netherlands, Germany, the United Kingdom, and Australia) (Special Senate Committee Report on Aging, 2009).

Further, it is imperative that nurses and other professionals provide supportive understanding for caregivers, especially aging caregivers as they make decisions for their younger, yet aging children. Aging caregivers of adult children with mental illness (Smith, Hatfield, & Miller, 2000) and developmental disabilities (Gilbert, Lankshear, & Petersen, 2008) often struggle greatly regarding the decision to place their children, when relocation becomes an eventuality. Professionals need to respond to these diligent parents with gracious awareness of their commitment to their children, albeit, balancing the impact that caregiving may be having on their health and the abilities to provide care to their children.

ADVOCACY: BY OLDER ADULTS FOR OLDER ADULTS AND THE VULNERABLE

The importance of advocating for vulnerable populations cannot be overstated. Some older adults feel marginalized and believe that government and society are not recognizing their issues and strengths. For instance, 60 percent of older adults in the UK believe that there is age discrimination (Age Concern and Help the Aged, 2009). Sixty-eight percent of older adults in the UK believe that politicians do not give priority to the issues of older adults. Further, 76 percent of UK

adults believe that their talents and skills are not being recognized or used by their country (Age Concern and Help the Aged, 2009).

Generally speaking, we tend to assume that the role of advocacy is assumed by health or human service professionals or by younger adults, and certainly, this is important. However, we propose that *advocacy for older adults be conducted by older adults*. Older adults can advocate for changes to housing options for older adults, as well as for other living or environmental conditions that impact their age cohort. The beauty of older adults advocating for other older adults is multifold. First, older adults are involved in meaningful activities that add purpose in their lives (and hence address some existential issues). Second, older adults can experientially understand some of the issues faced by older adults. While they may not be homeless or have a particular illness or condition, they can understand the changes that occur with aging and how illness or other challenging circumstances could impact the changes they have encountered with aging. Third, by virtue of being retired or working part-time, older adults may have more time for advocacy than middle-aged adults.

An interesting example of older adults advocating for older adults includes grandmothers in Canada advocating for grandmothers in Africa. In the Grandmothers to Grandmothers campaign, Canadian grandmothers advocate for African women who are raising their grandchildren, due to their adult children dying from AIDS. These older women have gone to Parliament to advocate for the responsibility of Canada to send medications to Africa to assist in the AIDS crisis (see http://grandmotherscampaign.org). Another example involves older adults advocating for homeless older adults. In the early 1990s, seven older woman who had had extensive experience in housing, health, and human services pooled their knowledge and formed the Committee to End Elder Homelessness in the United States (Gonyea et al., 2010). In 2005 the name of this organization was changed to Hearth, Inc. This organization offers over 100 long-term supportive housing units for formerly homeless older adults in the Boston area (Gonyea et al., 2010).

Older adults may also advocate for those who are aging by participating in a movement toward making cities age-friendly (as discussed in Chapter 4). An interesting example of this was offered by McGarry and Morris (2011). They described how Manchester, England, was chosen by the World Health Organization (WHO) in 2010 to sign a commitment to move toward an age-friendly city (after they had established a Valuing Older People program). Since the establishment of the Valuing Older People program, as well as making the agreement with the WHO, aging individuals have taken an active, consultant role in project design and delivery to make Manchester a more age-friendly city for older adults. They have and are partnering with community agencies and are active leaders in the process (McGarry & Morris, 2011).

Advocacy roles for older adults can be for other vulnerable populations besides those who are aging, and these "populations" do not necessarily have to be human. Recreational staff within assisted living facilities (whose residents tend

to be stronger physically) can arrange a dog assistance program. Within such a program, aging adults may volunteer weekly to walk dogs that are currently staying in an animal shelter. Not only do these older adults get exercise, they share in the camaraderie of working together for the good of vulnerable animals. Hence, this activity addresses their physical, social, and existential needs.

SUMMARY

Older adults experiencing transitions can be very vulnerable. How nurses and other professionals respond to the health and psychological needs of older adults as they progress through the transitions, address issues regarding relocation for older adults and their family members, as well as wade into concerns about life's meanings, can impact how seniors experience the transitions. Becoming aware of the significance of transitions for older adults, as well as the challenges involved in these transitions, can better equip nurses and other professionals to respond in meaningful and effective ways. However, changes need to be made in service delivery, the education of healthcare professionals, as well as the development of policies and procedures at a governmental, as well as service level, if the needs of older adults experiencing transitions will be adequately addressed in the coming years with the significant growth of the aged population. All of this ideally occurring within a society that becomes more attuned to, and valuing, of older adults, will allow old age to be a "new stage of opportunity and strength" (Betty Friedan).

Critical Thinking Exercise

- You have decided that you want to work with older adults. Within what focus in gerontology would you like to work?
- One of your aging clients is feeling that life is boring and holds much less meaning than it used to. You want to guide him toward incorporating meaningful activities within his life. How would you assess his existential/spiritual needs and how would you intervene to help him find more meaning within his life?
- You believe that professionals should actively advocate for older adults at the governmental level. What do you see as the most pressing needs for aging adults and how would you go about advocating for them?

REFERENCES

Age Concern and Help the Aged. (2009). *One voice: Shaping our aging society*. Retrieved January 12, 2013, from www.ageuk.org.uk

Aging Initiative. (2011). Benefits of intergenerational programs. Retrieved December 27, 2012, from www.epa.gov/aging/ia/benefits.htm

Australian Government—Department of Human Services. (2012). Retrieved December 28, 2012, from www.humanservices.gov.au/customer/enablers/centrelink/age-pension/eligibility-for-age-pension

Averill, J. B. (2012). Priorities for action in a rural older adults study. *Family & Community Health, 35*(4), 358–372. doi: 10.1097/FCH.0b013e318266686.e

Barron, J. S., Tan, E. J., Yu, Q., Song, M., McGill, S., & Fried, L. P. (2009). Potential for intensive volunteering to promote the health of older adults in fair health. *Journal of Urban Health: Bulletin of the New York Academy of Medicine, 86*(4), 641–653. doi: 10.1007/s11524-009-9353-8

Baun, M. M., & McCabe, B. W. (2003). Companion animals and persons with dementia of the Alzheimer's type: Therapeutic possibilities. *American Behavioral Scientist, 47*(1), 42–51. doi: 10.1177/0002764203255211

Beckett, J., Peternelj-Taylor, C., & Johnson, R. L. (2003). Growing old in the correctional system. *Journal of Psychosocial Nursing & Mental Health Services, 41*(9), 12–18.

Benner Carson, V., & Koenig, H. G. (2004). *Spiritual caregiving: Healthcare as a ministry.* Philadelphia: Templeton Foundation.

Bocker, E., Glasser, M., Nielsen, K., & Weidenbacher-Hoper, V. (2012). Rural older adults' mental health: status and challenges in care delivery. *Rural and Remote Health, 12*(4), 1–13. www.rrh.org.au

Bolger, M. (2005). Dying in prison: Providing palliative care in challenging environments. *International Journal of Palliative Nursing, 11*(12), 619–621.

Bottomley, J. M. (2001). Health care and homeless older adults. *Topics in Geriatric Rehabilitation, 17*(1), 1–21.

Bottomley, J. M., Bissonette, A., Snekvik, V. C. (2001). The lives of homeless older adults: Please tell them who I am. *Topics Geriatric Rehabilitation, 16*(4), 50–64.

Bradley, D. B. (1999–2000). A reason to rise each morning: The meaning of volunteering in the lives of older adults. *Generations, 23*(4), 45–50.

Bulbrook, K. M., Carey, T. A., Lenthall, S., Byers, L., & Behan, K. P. (2012). Treating mental health in remote communities: What do remote health practitioners need? *Rural and Remote Health, 12*(4), 1–3. www.rrh.org.au

Cattan, M., Kime, N., & Bagnall, A. M. (2011). The use of telephone befriending in low level support for socially isolated older people—an evaluation. *Health and Social Care in the Community, 19*(2), 198–206. doi: 10.1111/j.1365-2524.2010.00967.x

Choi, N. G. (1995). Racial differences in the determinants of the co-residence of and contacts between elderly parents and their adult children. *Journal of Gerontological Social Work, 24*(1-2), 77–95. doi: 10.1300/J083v24N01_07

Choi, N. G., & Jun, J. (2009). Life regrets and pride among low-income older adults: Relationships with depressive symptoms, current life stressors and coping resources. *Aging & Mental Health, 13*(2), 213–225. doi: 10.1080/13607860802342235

Clark, A. M., Freydberg, N., Heath, S. L., Savard, L., McDonald, M., & Strain, L. (2008). The potential of nursing to reduce the burden of heart failure in rural Canada: What strategies should nurses prioritize? *Canadian Journal of Cardiovascular Nursing, 18*(4), 40–46.

Cooper, C. (2011). Jefferson Area Board for Aging intergenerational programs in development. *Journal of Intergenerational Relationships, 9*(4), 481–484. doi: 10.1080/15350770.2011.619914

Copen, C. (2006). Welfare reform: Challenges of grandparents raising grandchildren. *Journal of Aging & Social Policy, 18* (3/4), 193–209. doi: 10.1300/J031v18n03_13

Crane, M., & Warnes, A. M. (2001). Older people and homelessness: Prevalence and causes. *Topics in Geriatric Rehabilitation, 16*(4), 1–14.

Crews, J. (2011). Aging, disability, and public health. In D. Lollar and E. Andresen (Eds.), *Public health perspectives on disability: Epidemiology to ethics and beyond* (pp. 163–183). New York: Springer.

Dahlke, S., & Phinney, A. (2008). Caring for hospitalized older adults at risk for delirium: The silent, unspoken piece of nursing practice. *Journal of Gerontological Nursing, 34*(6), 41–47.

Demeris, G., Doorenbos, A. Z., & Towle, C. (2009). Ethical considerations regarding the use of technology for older adults: The case of telehealth. *Research in Gerontological Nursing, 2*(2), 128–136.

Donley, A. M. (2010). Sunset years in sunny Florida: Experiences of homelessness among the elderly. *Case Management Journals, 11*(4), 239–244. doi: 10.1891/1521-0987.11.4.239

Douglas, C. (1992). For all the saints. *British Medical Journal,* (February 29), *304,* 579.

Duffin, C. (2010). Doing time: Health care in the criminal justice system. *Nursing Older People, 22*(10), 14–18.

Eheart, B. K., & Hopping, D. (2001). Generations of Hope. *Children and Youth Services Review, 23*(9/10), 675–682.

Fernandes, N., & Spencer, B. G. (2010). The private cost of long-term care in Canada: Where you live matters. *Canadian Journal on Aging, 29*(3), 307–316. doi: 10.1017/S0714980810000346

Field, D., & Addington-Hall, J. (2000). Extending specialized palliative care to all? In D. Dickinson, M. Johnson, and J. Samson Katz (Eds.), *Death, dying and bereavement* (pp. 91–106). London: Sage.

Forbes, D. A., & Edge, D. S. (2009). Canadian home care policy and practice in rural and remote settings: Challenges and solutions. *Journal of Agromedicine, 14*(2), 119–124. doi: 10.1080/10599240902724135

Fox, A. (2010). HomeShare—An intergenerational solution to housing and support needs. *Housing, Care and Support, 13*(3), 21–26. doi: 10.5042/hcs.2010.0707

Galvin, J. E., Meuser, T. M., & Morris, J. C. (2012). Improving physician awareness of Alzheimer disease and enhancing recruitment: The Clinician Partners Program. *Alzheimer Disease and Associated Disorders, 26*(1), 61–67. doi: 10.1097/WAD.0b013e3182c0df

George, D., Whitehouse, C., & Whitehouse, P. (2011). A model of intergenerativity: How the model of intergenerational school is bringing the generations together to foster collective wisdom and community health. *Journal of Intergenerational Relationships, 9*(4), 389–404. doi: 10.1080/15350770.2011.619922

George, R., & Sykes, J. (1997). Beyond cancer. In S. Ahmehdzai, D. Clark, and J. Hockley (Eds.), *New themes in palliative care* (pp. 239–254). Buckingham: Open University Press.

Gilbert, A., Lankshear, G., & Petersen, A. (2008). Older family-carers' views on future accommodation needs of relatives who have an intellectual disability. *International Journal of Social Welfare, 17*(1), 54–64. doi: 10.1111/j.1468-2397.2007.00485.x

Glueckauf, R. L., Sharma, D., Davis, W. S., Byrd, V., Stine, C., Jeffers, S. B., Massey, A. et al. (2007). Telephone-based cognitive-behavioral intervention for distressed rural dementia caregivers: Initial findings. *Clinical Gerontologist, 31*(1), 21–41. doi: 10.1300/J018v31n01_03

Gonyea, J. G., Mills-Dick, K., & Bachman, S. S. (2010). The complexities of elder homelessness, a shifting political landscape and emerging community responses. *Journal of Gerontological Social Work, 53*(7), 575–590. doi: 10.1080/01634372.2010.510169

Healy, M. (2012). U.S. kids exposed to 4 hours of background TV daily. Retrieved December 27, 2012, from www.usatoday.com/story/news/nation/2012/10/01/background-tv-viewing-pediatrics/1599995

Hedden, L. J. (1974). Intergenerational living: University dormitories. *The Gerontologist, 14,* 283–285.

Heimpel, D. (2011). A hub of innovation in Easthampton. *CWLA, 20,* 4.

Himes, C. L. (2001). Elderly Americans. *Population Bulletin, 56*(4). Washington. DC: Population Reference Bureau.

Hirst, S. P. (2010). *Health promotive technologies: Life in my own home.* NGNA National Conference, Palm Springs, CA.

Hirst, S. P., Lane, A. M., & Seneviratne, C. C. (2013). Growing old with a developmental disability. *Indian Journal of Gerontology, 27*(1), 38–54.

Hirst, S.P., Lane, A.M., & Stares, B. (2012). Gerontological content in Canadian nursing and social work programs. *Canadian Geriatrics Journal, 15*(1), 8–15. doi: http://dx.doi.org/10.5770/cgj.15.21

Kaasalainen, S., Coker, E., Dolovich, L., Papaioannou, A., Hadjistavropoulos, T., Emili, A., & Ploeg, J. (2007). Pain management decision making among long-term care physicians and nurses. *Western Journal of Nursing Research, 29*(5), 561–580. doi: 10.1177/0193945906295522

Kang, H. G., Mahoney, D. F., Hoenig, H., Hirth, V. A., Bonato, P., Hajjar, I., & Lipsitz, L. A. (2010). In situ monitoring of health in older adults: Technologies and issues. *Journal of the American Geriatrics Society, 58*(8), 1579–1586. doi: 10.1111/j.1532-5415.2010.02959.x

Kato, A. (2009). The relationship between aged parents and cohabiting unmarried children: Results from the Tokorozawa Living Arrangement study. *Journal of Intergenerational Relationships, 7*(1), 78–83. doi: 10.1080/15350770802629032

Kennedy, C. (2010). The city of 2050—An age-friendly, vibrant, intergenerational community. *Generations, 34*(3), 70–75.

Kissane, D. W., & Kelly, B. J. (2000). Demoralisation, depression and desire for death: Problems with the Dutch guidelines for euthanasia of the mentally ill. *Australian and New Zealand Journal of Psychiatry, 34*(2), 325–333. doi: 10.1046/j.1440-1614.2000.00692.x

Landau, R., Auslander, G. K., Werner, S., Shoval, N., & Heinik, J. (2011). Who should make the decision on the use of GPS for people with dementia? *Aging & Mental Health, 15*(1), 78–84. Doi: 10.1080/13607861003713166

Lane, A. M. (2007). *The social organization of placement in geriatric mental health.* Unpublished doctoral dissertation, University of Calgary.

Lane, A. M., McCoy, L., & Ewashen, C. (2010). The textual organization of placement into long term care: Issues for older adults with mental illness. *Nursing Inquiry, 17* (1), 3–14. doi: 10.1111/j.1440-1800.2009.00470.x

Lane, A. M. (2011). Placement of older adults from hospital mental health units into nursing homes: Exploration of the process, system issues, and implications. *Journal of Gerontological Nursing, 37*(2), 49–55.

Lane, A. M., & Hirst, S. P. (2012). Placement of undergraduate students in nursing homes: Careful consideration versus convenience. *Journal of Nursing Education, 51*(3), 145–149. doi: 10.3928/01484834-20120127-04

Lane, A. M., Hirst, S. P., & Reed, M. B. (2013). Housing options for North American older adults with HIV/AIDS. *Indian Journal of Gerontology, 27*(1), 55–68.

Larkin, E., Sadler, S. E., & Mahler, J. (2005). Benefits of volunteering for older adults mentoring at-risk youth. *Journal of Gerontological Social Work, 44*(3-4), 23–37. doi:10.1177/0164027511414916

Lee, S. M., Coakley, E. E., Dahlin, C., & Carleton, P. F. (2009). An evidence-based nursing program in geropalliative care. *Journal of Continuing Education in Nursing, 40*(12), 536–542.

Ley, D., & van Bommel, H. (1994). *The heart of hospice.* Toronto: NC.

Li, H. (2006). Rural older adults' access barriers to in-home and community-based services. *Social Work Research, 30*(2), 109–118.

Li, H., Kyrouac, G. A., McManus, D. Q., Cranston, R. E., & Hughes, S. (2012). Unmet home care service needs of rural older adults with Alzheimer's disease: A perspective of informal caregivers. *Journal of Gerontological Social Work, 55*(5), 409–425. doi: 10.1080/01634372.2011.650318

Lutwack-Bloom, P., Wijewickrama, R., & Smith, B. (2005). Effects of pets versus people visits with nursing home residents. *Journal of Gerontological Social Work, 44*(3-4), 137–159. doi: 10.1300/J083v44n03_09

MacEwan, A. (2012). *Working after age 65: What is at stake?* Alternative federal budget 2012 technical paper. Canadian Centre for Policy Alternatives. Retrieved January 15, 2013, from www.policyalternatives.ca.

Margolis, S. A. (2012). Is fly in/fly out (FIFO) a viable interim solution to address remote medical workforce shortages? *Rural and Remote Health, 12*(3), 1–6. www.rrh.org.au

Mattimore, H. (2006). Agency briefs: It takes an intergenerational village to raise kids in care. *Children's Voice, 15*(4), 6.

McCabe, B. W., Baun, M. M., Speich, D., & Agrawal, S. (2002). A resident dog in the special care unit: Its effect on problem behaviors of persons with AD. *Western Journal of Nursing Research, 24*(6), 684–696. doi: 10.1177/019394502320555421

McDonald, L., Dergal, J., & Cleghorn, L. (2007). Living on the margins: Older homeless adults in Toronto. *Journal of Gerontological Social Work, 49*(1 / 2), 19–46. doi: 10.1300/J083v49n01_02

McGarry, P., & Morris, J. (2011). A great place to grow older: A case study of how Manchester is developing an age-friendly city. *Working with Older People, 15*(1), 38–46. doi: 10.5042/wwop.2011.0119

Mihailidis, A., Cockburn, A., Longley, C., & Boger, J. (2008). The acceptability of home monitoring technology among community-dwelling older adults and baby boomers. *Assistive Technology, 20*(1), 1–12.

Morrow-Howell, N. (2010). Volunteering in later life: Research frontiers. *Journal of Gerontology: Social Sciences, 65B*(4), 461–469. doi: 10.1093/geronb/gbq024

Morrow-Howell, N., Hinterlong, J., Rozario, P., & Tang, F. (2003). Effects of volunteering on the well-being of older adults. *Journal of Gerontology: Social Sciences, 58B*(3), 137–145. doi:10.1093/geronb/58.3S137

Mukherjee, D. (2010). An exploratory study of older adults' engagement with virtual volunteerism. *Journal of Technology in Human Services, 28*(3), 188–196. doi: 10.1080/15228835.2010.508368

Ng, C. F., Northcott, H. C., & Abu-Laban, S. M. (2007). Housing and living arrangements of south Asian immigrant seniors in Edmonton, AB. *Canadian Journal on Aging, 26*(3), 185–194. doi: 10.3138/cja.26.3.185

Niemeyer, S. M., Cook, C. C., Memken, J., Crull, S., Bruin, M., Laux, S., White, B. J., & Yust, B. (2006). Local housing and service decisions: Planning for aging adults. *Journal of Housing for the Elderly, 20*(4), 5–22. doi: 10.1300/J081v20n04_02

O'Connell, J. J. (2004). Dying in the shadows: The challenge of providing health care for homeless people. *Canadian Medical Association Journal, 170*(8), 1251–1252. doi: 10.1503/cmaj.104008

Peterson, L. E., Bazemore, A., Bragg, E. J., Xierali, I., & Warshaw, G. A. (2011). Rural-urban distribution of U.S. geriatrics physician workforce. *Journal of the American Geriatrics Society, 59*(4), 699–703. doi: 10.1111/j.1532-5415.2011.03335.x

Ploeg, J., Hayward, L., Woodward, C., & Johnston, R. (2008). A case study of a Canadian homelessness intervention programme for elderly people. *Health and Social Care in the Community, 16*(6), 593–605. doi: 10.1111/j.1365-2524.2008.00783.x

Poindexter, C. C. (2007). Older persons parenting children who have lost a parent due to HIV. *Journal of Intergenerational Relationships, 5*(4), 77–95. doi: 10.1300/J194v05n04_06

Power, M. B., Mitchell, E., Eheart, B. K., & Hopping, D. (2011). The power of language: Practice in a shared site. *Journal of Intergenerational Relationships, 9*(3), 281–292. doi: 10.1080/15350770.2011.593438

Ramsay, J. L. (2008). Forgiveness and healing in later life. *Generations, 32*(2), 51–54.

Reingold, D. A. (2006). An elder abuse shelter program. *Journal of Gerontological Social Work, 46*(3-4), 123–135. doi: 10.1300/J083v46n03_07

Reviere, R., & Young, V. D. (2004). Aging behind bars: Health care for older female inmates. *Journal of Women & Aging, 16*(1 / 2), 55–69. doi: 10.1300/J074v16n01_05

Rhoades, D. R., & McFarland, K. F. (1999). Caregiver meaning: A study of caregivers of individuals with mental illness. *Health & Social Work, 24*(4), 291–298.

Roberts, C., Kennedy, S., & Hammett, T. M. (2004). Linkages between in-prison and community-based health services. *Journal of Correctional Health Care, 10*(3), 333–368. doi: 10.1177/107834580301000306

Ryan, P. Y. (2005). Approaching death: A phenomenologic study of five older adults with advanced cancer. *Oncology Nursing Forum, 32*(6), 1101–1108. doi: 10.1188/05.ONF.1101-1108

Schwingel, A., Niti, M. M., Tang, C., & Ng, T. P. (2009). Continued work employment and volunteerism and mental well-being of older adults: Singapore longitudinal ageing studies. *Age and Ageing, 38*(5), 531–537. doi: 10.1093/aging/afp089

Service Canada. (2012). Placing Old Age Security on a sustainable path. Retrieved January 15, 2013, from www.servicecanada.gc.ca/eng/isp/pub/oas/oas.shtml

Sherman, S. L., Allen, E. G., Bean, L. H., & Freeman, S. B. (2007). Epidemiology of Down syndrome. *Mental Retardation and Developmental Disabilities Research Reviews, 13*(3), 221–227. doi: 10.1002/mrdd.20157

Sidell, M., Samson Katz, J., & Komaromy, C. (2000). The case for palliative care in residential and nursing homes. In D. Dickinson, M. Johnson, and J. Samson Katz (Eds.), *Death, dying and bereavement* (pp. 107–121). London: Sage.

Smith, C. J., & Beltran, A. (2003). The role of federal policies in supporting grandparents raising grandchildren families: The case of the U.S. *Journal of Intergenerational Relationships, 1*(2), 5–20. Doi:10.1300/J194v01n02_02

Smith, C. J., Beltran, A., Butts, D. M., & Kingson, E. R. (2000). Grandparents raising grandchildren: Emerging program and policy issues for the 21st century. *Journal of Gerontological Social Work, 34*(1), 81–94. doi: 10.1300/J083v34n01_06

Smith, G. C., Hatfield, A. B., & Miller, D. C. (2000). Planning by older mothers for the future care of offspring with serious mental illness. *Psychiatric Services, 51*(9), 1162–1166.

Smyer, T., & Burbank, P. M. (2009). The U.S. correctional system and the older prisoner. *Journal of Gerontological Nursing, 35*(12), 32–37.

Snyder, C., van Wormer, K., Chadha, J., & Jaggers, J. W. (2009). Older adult inmates: The challenge for social work. *Social Work, 54*(2), 117–124.

Solomon, J. (2006). Sounding the shofar: A wake-up call to the epidemic of elder abuse. *Journal of Jewish Communal Service, 81*(3/4), 211–218.

Solomon, J., & Reingold, D. A. (2012). Creating an elder abuse shelter: A best-practice model for nonprofit nursing homes. *Generations, 36*(3), 64–65.

Special Senate Committee Report on Aging. (2009). *Canada's aging population: Seizing the opportunity.* Retrieved March 07, 2013, from www.parl.gc.ca/Content/SEN/Committee/402/agei/rep/AgingFinalReport-e.pdf.

Statistics Canada. (2008). Census snapshot of Canada—Population (age and sex). Ottawa: Statistics Canada—Catalogue No. 11-008.

Steinig, S. Y., & Butts, D. M. (2009-10). Generations going green: Intergenerational programs connecting young and old to improve our environment. *Generations, 33*(4), 64–69.

Steinisch, M. (2007). Senior homesharing a win-win. Retrieved April 27, 2013, from http://hffo.cuna.org/12433/article/1802/html

Sumner, A. (2012). Assessment and management of older prisoners. *Nursing Older People, 24*(3), 16–21.

Taylor, A. S., LoSciuto, L., Fox, M., Hilbert, S. M., & Sonkowsky, M. (1999). The mentoring factor: Evaluation of the Across Ages' intergenerational approach to drug abuse prevention. *Child & Youth Services, 20*(1 / 2), 77–99. http://dx.doi.org/10.1300/J024v20n01_07

Thomas, W. H., & Blanchard, J. M. (2009). Moving beyond place: Aging in community. *Generations, 33*(2), 12–17.

Turcotte, M. (2012). Profile of seniors' transportation habits. *Statistics Canada, Catalogue no. 11-008.* Ottawa: Statistics Canada.

Turner, M., Payne, S., & Barbarachild, Z. (2011). Care or custody? An evaluation of palliative care in prisons in North West England. *Palliative Medicine, 25*(4), 370–377. doi: 10.1177/0269216310393058

Ward, R. A., Spitze, G. D., & Sherman, S. R. (2005). Attraction to intergenerational housing on a university campus. *Journal of Housing for the Elderly, 19*(1), 93–111. doi: 10.1300/J081v19n01_07

Weeks, L. E., & LeBlanc, K. (2010). Housing concerns of vulnerable older Canadians. *Canadian Journal on Aging, 29*(3), 333–347. doi: 10.1017/S0714980810000310

West, S. P., Lagua, C., Trief, P. M., Izquierdo, R., & Weinstock, R. S. (2010). Goal setting using telemedicine in rural underserved older adults with diabetes: Experiences from the Informatics for Diabetes Education and Telemedicine Project. *Telemedicine and e-Health, 16*(4), 405–416. doi: 10.1089/tmj.2009.0136

Wiersma, E. C. (2010). Life around...: Staff's perceptions of residents' adjustment into long-term care. *Canadian Journal on Aging, 29*(3), 425–434. doi: 10.1017/S0714980810000401

Williams, B. A., Stern, M. F., Mellow, J., Safer, M., & Greifinger, R. B. (2012). Aging in correctional custody: Setting a policy agenda for older prisoner health care. *American Journal of Public Health, 102*(8), 1475–1481. doi: 10.2105/AJPH.2012.300704

Wray, N., & McCall, L. (2007). Plotting careers in aged care: Perspectives of medical, nursing, allied health students and new graduates. *Educational Gerontology, 33*(11), 939–954. doi: 10.1080/03601270701364636

AFTERWORD

We began this text with an explanation of transitions. We stated that to transition is to cross over, to undergo or cause to undergo a process; it involves adaptation and metamorphosis. We posited that if one encounters a circumstance of change, but does not adapt herself, she herself is changed by the position she takes in not transitioning. In Chapter 5 we had the chutzpah to endeavor to "rattle the bars on the cage" of your existence (using Robert Fulghum's expression).

In all of this, our motivation was four-fold:

- To increase your knowledge of the kinds and numbers of transitions experienced by older adults.
- To sensitize you to the complexities of the transitions faced by aging individuals.
- To raise concerns and issues that you yourself will encounter as you age.
- To motivate you, as one training to be a health or human service professional, to choose to work with this marvelous age group; as they have greatly enriched our lives, so they will enrich yours!

We hope that we have succeeded, at least in some measure; and we leave you, the reader, with the following words:

> Old age is not a disease—it is strength and survivorship,
> triumph over all kinds of vicissitudes
> and disappointments, trials and illnesses.
> (Maggie Kuhn, American activist)
>
> and
>
> Those who love deeply never grow old; they may
> die of old age, but they die young.
> (Dorothy Canfield Fisher, American author, activist
> and educational reformer)

May the transitions of your life result in strength and survivorship and triumph—loving life and others deeply, so that in your final transition, you may cross over as one who is young at heart!

OLDER ADULTS

Understanding & Facilitating Transitions

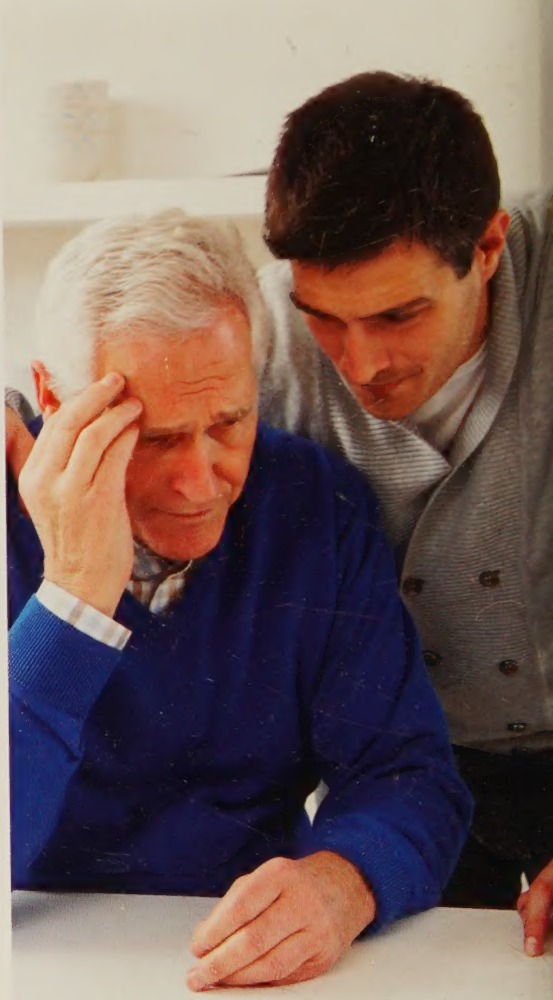
Annette M. Lane, RN, PhD
Sandra P. Hirst, RN, PhD, GNC (C)
Marlette B. Reed, BEd, MA

This book is about transition experiences through the lifespan. In particular, it focuses on transitions that older adults and their families face, such as coping with chronic illness, relocating to new settings, issues of meaning and purpose in life and death and dying.

Annette M. Lane, RN, PhD is an Assistant Professor in the Faculty of Nursing, University of Calgary. Her areas of expertise include geriatric mental health and families.

Sandra P. Hirst, RN, PhD is the Director of the Brenda Strafford Centre for Excellence in Gerontological Nursing and an Associate Professor in the Faculty of Nursing, University of Calgary. Her areas of expertise include long term care and gerontological nursing education. She is a board member of the International Federation on Ageing.

Marlette B. Reed, BEd, MA is a palliative care chaplain in Calgary, Alberta and has also worked as a community chaplain with individuals and their families across the lifespan.



ISBN 978-1-4652-2165-0
43216502
9 781465 221650 90000 >

Kendall Hunt
publishing company