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# The Lived Experience of Aging: Listening to the Oldest-Old

Julia A. Pusztai

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LOMA LINDA UNIVERSITY  
School of Nursing  
in conjunction with the  
Faculty of Graduate Studies

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The Lived Experience of Aging: Listening to the Oldest-Old

by

Julia A. Pusztai

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A Dissertation submitted in partial satisfaction of  
the requirements for the degree of  
Doctor of Philosophy in Nursing

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September 2015

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Each person whose signature appears below certifies that this dissertation in his/her opinion is adequate, in scope and quality, as a dissertation for the degree Doctor of Philosophy.

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## ABSTRACT OF THE DISSERTATION

The Lived Experience of Aging: Listening to the Oldest-Old

by

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Doctor of Philosophy, Graduate Program in Nursing  
Loma Linda University, September 2015  
Dr. Betty Winslow, Chairperson

Although embraced as desirable by most, living into very old age is largely unexplored as a distinct season of life, with increased, varied, and cumulative changes during a unique time of vulnerability and frailty. The purpose of this study was to listen to the oldest-old, and to explore their lived experience of growing old. This hermeneutic phenomenology study examines the experience of finding meaning and living with losses and gains in advanced old age.

This study design included three separate interviews one month apart with participants over 85 years of age. Purposive sampling resulted in 13 participants, 5 being male and 8 female, from 87 to 100 years of age with 8 being Caucasian, 3 Hispanic, and 2 African-American. Semi-structured interviews included topics of life history, daily habits, and experiences of loss and gain in oldest-old age. Verbatim transcriptions of recorded face-to-face interviews, field notes, and observations, were used as meaningful text and analyzed using interpretive thematic analysis methods.

The lived experience of the oldest-old is that of a parallel movement of loss and gain, negative and positive with the acknowledgement that the change toward decline is inevitable. While sharing common experiences, each individual is situated in a particular lifeworld that offers possibilities and constraints for their unique way of being in the

world. Learning new ways of being and doing, changes of the “I am” and “I am not” and the “I can” and “I cannot,” all point to ways of adapting and coping with the challenges that old age has wrought on bodies, minds, abilities, and life circumstances. Through the balancing of these dual courses, the metaphor of the careful walk across the tightrope is reflective of this experience. It is the attitude, inner negotiations, will-power, and habits of positivity and gratitude, that prevent the I cannots and the I am nots from leading to depression or despair.

Recognizing oldest-old age as a distinct time of life is imperative. As such, nursing and helping professionals can offer support and care in more empathic and meaningful ways to address needs of unique possibilities and meaning for the oldest-old.

## CHAPTER ONE

### INTRODUCTION

#### LISTENING AND LEARNING FROM OUR OLDEST-OLD:

##### A CONTINUED NEED

We who are old know that age is more than a disability.

It is an intense and varied experience,

almost beyond our capacity at times,

but something to be carried high.

If it is a long defeat it is also a victory,

meaningful for the initiates of time,

if not for those who have come less far.

*(Florida Scott-Maxwell, 1968, p. 5)*

In a similar sentiment, Billy Graham (2011) at age 93 begins his most recent book declaring to his readers that “Growing old has been the greatest surprise of my life” (p. 1). He also poignantly and honestly reveals that no one ever taught him how to live in the years before he dies (p. vii). While many of our oldest-old teach us by example, how much more we can learn by actually listening to their voices, inviting them to speak of living in these final years. And of course listening to what they share means hearing . . . hearing as accurately as possible what they tell us, without the preconceptions held by younger years, varied cultures and traditions, and differing generational perceptions. The aim of this study was to do just that. It sought to listen to the oldest-old, to gain understanding of the aging experience and its meaning from those growing very, very old, with the purpose of gaining insight into the lived experiences of advanced old-age. It is hoped that what was learned will impact gerontological theory and nursing practice, and inform healthcare providers how best to support and improve quality of life for the oldest-old among us, during this time at the end of a long life.



## **What the Data Is Revealing**

It is an established fact in current epidemiology that a larger percentage of the U. S. population is approaching old age and that more aged persons are living longer. The 65+ population is projected to increase from 40 million in 2010 to 55 million in 2020, a 36% increase (Office on Aging, 2011). Similarly, the population of those 85 years of age and older is projected to increase by 19% by 2020, from 5.5 million in 2010 to 6.6 million over the following decade. Medical technology and advances in pharmacology are enabling the elder populations of developed countries to live well into the eighth, ninth, even tenth decades. While embraced as a desirable advantage by most people, another aspect of living longer to be considered by healthcare providers and caregivers is the increased potential for experiences of loss, disability, and frailty.

Data gathered on health status is largely reported for those 65 and older. In the Profile on Aging for 2011 (Office on Aging, 2011), in only two areas the 85 and over age group is highlighted specifically: disability increases with age as 56% of those over 80 reported a severe disability; and, the need for assistance was reported for 29% of the over 80 group. In other words, the majority of our oldest-old are disabled, with one-third of the total actually needing assistance in daily living. Reported limitations in walking demonstrate a higher level of disability in those 85 and older; 47% for the 85 and older group, compared to 28% of the 75 to 84 age group. Bathing poses difficulties for 33% of the over 85 group compared to 14% of the younger group (Office on Aging, 2011). These reported limitations are indicative of the increased challenges involved when living into very old age. This then, is an age group of high importance to health care workers and social service providers.

## **What a Personal and Professional Perspective Is Revealing**

Living in very old age is recognized as a stage of life in which both multiple and varied losses, and relative well-being are experienced. Bearing witness to the lives of others experiencing joy and despair, losses and gains, challenges and rewards as they have become very old was the impetus for this study. While working with an aging population in a setting of a university-sponsored community wellness center that is located near a community senior center, the researcher had noticed many individuals who were coping with a wide variety of losses of varying intensity and significance. Adding to this impression was the even more intimate involvement of walking with my father into these later years of life. Then at the age of 89, he often said that his life changed when he turned 80. Having more than excellent health up to that point, his physical body began to pose challenges. Arthritis and joint pain led to a knee replacement, which was followed by atrial fibrillation and a pacemaker, followed by a spinal fracture due to osteoporosis, followed by another knee replacement, and further hip pain. Concurrent with all of this were multiple losses of friends and family to death. His impressive positive attitude, optimism, and gratitude continued to prevail, but it was challenged. For this former marathon runner, it had become difficult to walk. I wanted to listen to these stories, these narratives of both challenges and rewards and their significance and meaning in these late years.

As an observer, and through many conversations over time, it seemed the losses, challenges, grief, even fear and worry, dominated over joy, happiness, rewards, and positive experiences. Many individuals were adjusting to new diagnoses, new prescriptions, new physical, mental, and financial limitations, as well as new living and

social circumstances. These changes usually involved losses of some sort: hearing, vision, a loved one, income, a role of significance, a pain free life, a driver's license, loss of physical balance, or the loss of walking freely without a cane or walker, a list that grew with age. As an outsider, this time of life seemed to have an ebb and flow of loss, as well as gain or times of heightened well-being. It has been observed that there were episodes of increased loss during which maintaining well-being required quite a bit of effort. Despite a resilience that is considered an aspect of old age and about which much has been written (Baltes, Staudinger, & Lindenberger, 1999), loss can weigh heavily on the elderly. The growing number of losses in an aging life can be a barrier to a life empowered with value and significance in society (Gilbert, 2004) and as having a general sense of well-being. In response to all of this, a compelling focus and resulting research question grew: What is this experience of living with losses, and likewise gains or rewards, in advanced old age, when longevity is diminished and death moves ever closer?

The aging experience, with its pluses and minuses and multiple losses and gains, holds meaning unique to each individual. It can vary according to resources available both within and without to help "navigate the strange new waters" (Horner, 2004) of older life. Unknowingly giving testimony to Billy Graham's proclamation, a dear friend emphatically stated "I've never been this age before!" as she was expressing frustration with new medical conditions and the unknown territory of cardiac medications. These experiences although highly personal, were also enveloped in evolving social, cultural, and generational views of aging. Historians have offered background to the movement of multidisciplinary and societal western views addressing aging and other gerontological issues. Evident in the attention and amount of written word that researchers and various

disciplines with an interest in aging have offered, is an evolving perspective, understanding, and inquiry into these very late and final years of life.

### **What History Is Revealing**

Thomas R. Cole, a historian of gerontology, insightfully wrote “the Scylla of prejudice is not far from the Charybdis of denial of human differences—differences that ought to be acknowledged, respected, and cherished” (1983, p. 34). This takes some deciphering in order to truly appreciate his thought; a journey to Wikipedia (2012) was helpful. In Greek mythology, Scylla is a female sea monster who was known to eat sailors; Charybdis was a whirlpool opposite of the cave of Scylla. Cole then is proposing to the field of gerontology that there must be consideration of the consequences in a position where avoidance of one danger exposes one to another danger; the monster versus the whirlpool. An in-depth understanding of historical views of aging was not necessary for the purposes of this study but a brief review provided a foundation for this research and why Cole’s caution needed to be considered.

Hirschbein (2001) provides insight into views of old age in America during the first half of the 20<sup>th</sup> century and posits that the aging person’s experience is impacted by the time period in which they live. In the early decades of the century a wide concept of old age was held, with the old members of society themselves being seen as the authorities on the descriptions of old age. Changes came about in the third and fourth decades as old age began to acquire negative meaning, though was not yet attached specifically to chronological age. It was not until later in the 1930s and 1940s that old age became viewed by professionals as a specific medical and social problem needing to be addressed as such. Old persons became a specific population requiring other groups to

organize their care and physicians became the authorities on aging. By the 1940s, older people became a “national problem” needing a solution (p. 1158). They became subjects of interventions by specialists and their memories and voices became subsumed by the medical model. Hirschbein aptly provides testimony of the projected values of society onto old age and suggests that “We will provide better patient care if we can be attuned to how our patients view old age and stay aware of information they are exposed to” (2001, p. 1559). The exhortation is to be aware of not only the biological implications of growing old but also the social and cultural ones; and of course, we are not to forget the personal and individual implications either.

Writing in 1983, Cole describes the “last decade” or the 1970s as a time of efforts targeting negative stereotypes of aging and ageism toward older people that had accumulated during mid-century. Positive images were being substituted for negative ones created by the “myths of old age” (Cole, 1983). Medical and pharmacological advancements were resulting in living longer and healthier allowing for a reconsideration of what was meant by “old age” and “being old.” What this has resulted in, according to Cole, are “new myths of old age;” old age means being healthy (not disabled), self-reliant (not dependent), sexually active (not impotent), engaged (not isolated), and productive (not fatigued). These myths are as politically, morally, and ethically perilous, as were the previous negative myths of old age. They hide and dismiss the reality of many of our oldest-old while masking their existence. As will be discussed more fully below, the recognition that advanced old age is a distinct time of debility and vulnerability, when the sufferings of approaching death often predominate (Baltes & Mayer, 1999) is vital to affirming and caring for the oldest-old among us.

Robert N. Butler, a Pulitzer Prize winner, the founding director of the National Institute on Aging of the National Institutes of Health, and founder of the first department of geriatrics in a U. S. medical school at Mount Sinai Medical Center in New York, wrote a startling book in 1975. In *Why Survive? Being Old in America*, Butler (1975) among other things tells us why our approach to aging has been misguided. It is because the oldest-old remind us of our own immortality. Ageism allows society to ignore the old and poor allowing us to avoid thoughts of our own aging and death.

From the ageism described by Butler, the Scylla, the turn towards the Charybdis was made; the notions of successful aging or positive aging (Rowe & Kahn, 1997; Vaillant, 2002) were the focus of attention for many interested in old age. These trends in aging studies are addressed more fully in the second chapter; however the impact of this more contemporary movement may have the same impact as the former. It needs to be acknowledged that the young-old, and even the old-old are living longer and healthier than ever before. This “successful” focus has brought about new perspectives on health promotion and disease prevention that foster more healthful aging. The insight gained from well-designed studies on subjective health, wellness, life satisfaction, and high quality of life is informative and necessary. However, by focusing on the contemporary phenomenon of what is now the young old, that of health and wellness not seen in former eras, we will exclude the truth of the frailty, disability, decline, and vulnerability that is the experience of many of our very oldest-old (Baltes & Mayer, 1999) and the experience of the poor, disenfranchised and disabled (Minkler & Fadem, 2002).

### **What Three of the Oldest-Old have Revealed Through Their Pen**

It was good fortune to find written narratives rich with meaning and insight directly from those living the experience of interest. While an exhaustive search was not done, three works written by persons considered oldest-old have informed this study. These authors in order of publication date are Florida Scott-Maxwell (1968), Joan M. Erikson (1997) and Billy Graham (2011).

Scott-Maxwell is often cited in literature that addresses the experience of growing old. She treats her readers, in journal format, to insights of an eighty-something woman, with a very active and transparent mind. Writing with the purpose of conveying her thoughts, some entries are very short, only a sentence or two; others are longer, a page or two. A few quotes will be cited here that seem to convey the lived experience of one living in her oldest-old years.

We old people are short tempered because we suffer so. We are stretched too far, our gamut is painfully wide. Little things have become big; nothing in us works well, our bodies have become unreliable. We have to make an effort to do the simplest things (Scott-Maxwell, 1968).

She conveys a body that is both difficult to depend on and that requires thought and effort to get it to respond in desired ways. She is frustrated, she is suffering. The next quote conveys what is often the unspoken duty of the old—to not be a burden.

I have a duty to all who care for me—not to be a problem, not to be a burden. I must carry my age lightly for all our sakes, and thank God I still can. Oh that I may to the end. Each day then, must be filled with my first duty, I must be “all right” (Scott-Maxwell, p. 31).

In a more light-hearted and metaphorical manner she speaks of thoughts about finitude:

“When a new disability arrives I look about to see if death has come, and I call quietly,

‘Death is that you? Are you there?’ So far the disability has answered, ‘Don’t be silly, it’s me.’”(p. 36).

Scott-Maxwell’s pages are in fact, filled with noteworthy comments of the real and vivid experience of a very old person. Her thoughts are lively, filled with passion, humor, and honesty about the everyday struggles that face her. She conveys someone not completely prepared for this time of life, when she is considered one of the oldest-old.

Joan Erikson (Erikson, 1997) writes for another purpose. Writing to amend her lifelong work and that of her famous and now deceased husband, she adds a ninth stage to Erik Erikson’s stages of psychosocial development or life cycle. Conveying the surprising appearance of old age she confesses:

Although at age eighty we began to acknowledge our elderly status, I believe we never faced its challenges realistically until we were close to ninety. . . At ninety we woke up in foreign territory. . . we soon began to face unavoidable—and certainly not amusing—realities (p. 4).

Joan Erikson writes to teach, not only to convey her experience. Yet what she teaches was garnered from her and her husband’s life experience. This insight provides added poignancy and value:

Old age demands that one garner and lean on all previous experience, maintaining awareness and creativity with a new grace. There is often something one might call indomitable about many old people. Erik has called it an “invariable core,” the “existential identity,” that is an integration of past, present, and future (p. 9).

She has urgency about accomplishing what she has set out to do, knowing her capacities are limited. However, as she states she is “growing old” is she implying she may not be old yet?

I am now ninety-three years old and have experienced more of the inevitable complications of *slowly* growing old. I am not retired, serene,



and gracious. In fact I am eager to finish this revision of the final stage before it is too late and too demanding an undertaking (p. 4).

With the articulation of a seasoned writer, Erikson is able to give voice, albeit an academic one, to the changes that have caught her unawares. If anyone should have known shouldn't it have been a human development specialist? Even so, the oldest-old years were unknown territory.

So writes Billy Graham (2011), the renowned Christian evangelist. He too was caught unawares as noted above in the introduction to this chapter. His purpose is also to teach, but to teach his fellow Christians how to prepare for this time of life. He asks:

. . . how can we not only learn to cope with the fears and struggles and growing limitations we face but also actually grow stronger inwardly in the midst of these difficulties? How can we face the future with hope instead of despair (p. viii)?

In searching for answers to these two questions for himself, Graham is seeking to discover God's purposes for extending his life. And further, how he can align himself with these divine purposes. He describes the physical realities of aging which are clearly struggles for him: ". . . like it or not, the longer you live the more its burdens and disabilities will become your companions" (p. 83). In a poignant description of this reality for himself he honestly characterizes what this has meant for him:

If I had to summarize in one word the changes that come over us as we grow older, I'd probably have to use the word decline. Most obvious is the decline in physical strength and the ability to do everything we once did. Gradually our muscles grow still and lose strength; our mobility lessens; our hearing and eyesight begin to deteriorate; our reactions slow down; our physical stamina begins to fade. Much as I might wish otherwise, at the age of ninety-two I no longer can get out of a chair by myself (p. 83).

These three educated, even privileged individuals all describe the physical reality of living into advanced old-age, each in their own distinct way. Scott-Maxwell richly

describes the emotional journey, Graham the spiritual, and Erikson the psychological. In this study, I sought to add more voices to the aging dialogue by listening to the oldest-old, in order to understand, discover, and examine meaning in this most ordinary yet extraordinary experience of growing very, very old.

### **Seeking Further Revelation and Its Significance**

In the words of van Manen (1990), phenomenology is a human science which studies persons (p. 6) and holds the task of constructing “a possible interpretation of the nature of a certain human experience” (p. 41). The experience explored in this qualitative study was that of living with loss and gain in oldest-old age. Addressing this experience through the eyes of a nurse, this time of life was seen as a realm of research significant to the field of nursing. Nurses provide care for all during times of personal physical, emotional, and spiritual challenge. We are caring for more and more very old persons as we experience the “graying” of America. It is therefore vital that we allow these aged folks to inform us about what this experience of living in advanced old age is like, and how it holds meaning. Phenomenology as a research method was seen to be in harmony with this deep interest and inquiry. It offered an approach that could lead to a rich and in-depth understanding able to inform nursing care and practice which seeks to support old age and the potential suffering that seems to be a companion.

Narratives shared by the oldest-old informants in this study and the interpretation of these narratives, were seen to offer insight into this unique and understudied time of life. They had potential to yield meaningful even profound insight of significance that could further inform and enrich gerontological theory of this understudied time of advanced old age and aging. Understandings gleaned from the perspectives of those

living this experience can reveal new knowledge, which can help formulate new practices and policy for nursing and others involved in the social and healthcare arenas. It was anticipated that this study would have important implications for nursing and other health care providers' practices as they work with the oldest-old to offer care that is supportive of creating meaning, purpose, dignity, and even comfort in the final years. Discovering the possibilities in living in very advanced old age with both the very difficult and the very rewarding can lead to the creation of more individualized, effective, and supportive care. These new approaches to care may not only allow for more comfort and meaning in the final years of life but quite possibly be more cost-effective. Developing health policy at multiple organizational levels that recognizes the potential for changing needs, as frailty and challenges increase and dominate, can create more humane and caring ways of supporting our oldest-old. It was hoped that further questions would arise that would stimulate more interest in the experience of those living in these very late years of life, how to care and support them, how to offer dignity and understanding, and result in future research by this researcher and others.

The following chapter will explore in more depth and offer a critique of the state of the research and theoretical literature and how it informed this research study. Chapter three will then address the assumptions and philosophical underpinnings of phenomenological methodology used here, and describe the specific phenomenological approach that was applied to address the research purpose and questions of this study.

## CHAPTER TWO

### REVIEW OF THE LITERATURE

#### WHERE WE HAVE BEEN: WHERE WE CAN GO

In advanced old age, beyond the age of 85, personal, familial, and social problems are most acute, and these very old persons and their caregivers belong to the neglected part of our society.

*(Baltes & Mayer, 1999 p. 386)*

There is no lack of literature involving exploration, inquiry, description, or theorizing about aging and the developmental phase of life of the oldest-old. Aging literature addresses bereavement, quality of life, well-being, successful aging, life satisfaction, resilience, stress, spirituality, and depression, to name just a few of the areas of interest and inquiry. It spans multiple disciplines including gerontology, psychology, psychiatry, social work, behavioral science, medicine, occupational and physical therapy, audiology, sociology, nursing, and more. A comprehensive review of all aging literature is beyond the scope of any one paper. Therefore, after a look at the topical trends of research addressing aging and loss, current and relevant literature of qualitative and quantitative approaches will be discussed.

Although it seems illogical by today's sensitivities, research in and theories of human development and developmental psychology have not always considered the life span or life course perspective that the 21<sup>st</sup> century understanding now assumes. Before the 1960s, the field of developmental psychology centered on the study of child development (Whitbourne, 2007). In the postwar baby-boom era children were being born and growing-up in record numbers. However, beginning in the 1960's sensitivities began to change and new models considering the entire span of life began to emerge (Whitbourne, 2007). This shift toward and understanding that life is better viewed as a

life course from birth to death has resulted in the life span or life course perspective (Moody, 2010; Whitbourne, 2007). Through this lens, biological, environmental, historical, social, and cultural influences among others are all seen to impact development throughout the life span (Blieszner, 2006). While gains and losses, challenge the individual over the entire life span, Blieszner (2006) sees effective management of these as especially crucial during the oldest-old years when personal strength and resources are waning. A parallel to this perspective is the change from thinking of old age as a discrete and separate stage of life, to the contemporary understanding that old age is one phase of a total birth-to-death life course. Old age is now seen as one phase of the complete span of life and the result of influences experienced throughout the earlier years (Moody, 2010).

### **Lifecourse and Lifespan Views of Aging**

Perspectives on aging have had their own life course. Two movements worth noting in contemporary literature are the lifecourse, and lifespan perspectives. Lifecourse is influenced by a more sociological perspective (Dannefer, Uhlenber, Foner, & Abeles, 2005; Pearlin, 2009; Turner, Killian, Cain, 2004) and lifespan by developmental psychology (Baltes, Reese, & Lipsitt, 1980; Baltes, Staudinger, & Lindenberger, 1999; Smith, Borchelt, Maier, & Jopp, 2002). Some writers appear to use them interchangeably (Whitbourne, 2007). According to Turner et al (2004), the lifecourse perspective acknowledges that human development occurs in a complex interplay between life pathways, social and temporal contexts, and family and other interpersonal relationships. The interconnectedness of the individual's developmental and life course with the developmental and life course trajectory of others is a basic tenet of the lifecourse

perspective. The primacy of the concepts of “transitions” and “agency” are seen by Pearlin to be central to this perspective as it applies to his work with the stress process (2009) and life-course “mastery” (Pearlin, Nguyen, Schieman, & Milke, 2007). The notion of transitions refers to the movement into and out of various socially or culturally expected roles and statuses. “Agency” is a concept that conveys the idea that people are able to take action to control and direct their own life course trajectories. The notion of “cohort” contributes the idea that different age groups or generations are “stamped” (Pearlin, 2009) with distinguishing historical contexts and experiences that further impact the individual’s lifecourse, and are reflected in the life course trajectories of the entire cohort. Examples of this impact would be that of the Great Depression and World War II on the lives of the current generation of oldest-old individuals, who are the focus of this study.

Similar to the lifecourse perspective of sociology, lifespan developmental psychology is seen as an orientation or perspective that is concerned with describing, explaining, and optimally modifying the human developmental processes, during the full life course, from conception to death (Baltes, Reese, & Lipsitt, 1980). At the core, is the assumption that human development is not completed during adulthood, but continues throughout the trajectory of the span of a life involving lifelong adaptive processes (Baltes, Staudinger, Lindenberger, 1999). This developmental life span orientation, first beginning in Germany, is said to have a tradition that spans more than 200 years. Starting in the 1970s, this orientation has led to a paradigm shift in the manner in which developmental psychology is viewed, and research and theory conceptualized. A changing focus that encompassed development of the older and aging adult was the

impetus for the sparked interest in life span psychology, away from the stage theories that focused on childhood and adolescence (Baltes et al., 1980).

Baltes et al. (1980) discusses the interest in sociology during the life course: “As in psychology, the sociological interest in a life-span or life-course approach is most pronounced in work on aging” (p. 100). In fact, the earlier interest of sociology in the life-course orientation is identified as one of the factors that led to the prominence of the life-span perspective in North America in the field of developmental psychology (Baltes, Staudinger, Lindenberger, 1999). Baltes and colleagues have offered extensive work on understanding aging using this lifecourse approach as their framework. He is frequently cited in the works of other psychologists, sociologists, gerontologists, and others exploring issues of aging.

Through these two complementary perspectives a lens is provided that helps in understanding the potential for distinct and varied experiences of old age. As the trajectory of life develops, the opportunities for unique experiences and responses only increase leading to greater heterogeneity expressed by oldest-old persons.

### **Erikson’s Life Cycle Stages of Psychosocial Development**

The psychosocial stages of development were originally developed in the 1940s, during the era which focused primarily on child development. Eric Erikson and his co-theorist and wife Joan Erikson established the resulting highly influential and prominent theory of these frequently cited stages that confront human development from infancy through, as of the late 1990s, what is known as the “Ninth Stage” of oldest-old age (Erikson, 1997). Many researchers have used this theory of development as a framework for their studies on aging. What is most salient to the purpose and exploration of this

study is the final stage as seen by Erikson and Erikson as the “Ninth Stage.” So distinct did they see the challenges of advanced age that they added an additional stage to characterize this unique and latest time of life.

There are times when highly important information in a book is in the preface, one reason it should be read and never skipped. It usually explains what is behind the writing of the work. This is so, in regard to aging in oldest-old age as described in the extended version of the Eriksons’ book on the life cycle (Erikson, 1997). Reading these reflections of the 93 year old wife of the respected and now deceased Eric Erikson provides added validity, as it is from one who knows by living it. From the pen of J. Erikson is written “Old age in one’s eighties and nineties brings with it new demands, reevaluations, and daily difficulties. These concerns can only be adequately discussed, and confronted, by designating a new ninth stage to clarify the challenges” (Erikson, 1997, p. 105).

In this last theorizing by one of the original theorists, it is emphasized that during the ninth stage there is a flipping of the factor that promotes growth and expansion with the factor that inhibits it (Erikson, 1997). Old age is seen as a circumstance that requires a reversal of the previously used order. For example, the Basic Trust vs. Basic Mistrust in infancy becomes Basic Mistrust vs. Trust: Hope in the ninth stage; the Intimacy vs. Isolation becomes Isolation vs. Intimacy: Love. Circumstances brought on by oldest-old age may position the growth inhibiting factor in the dominant position. It is placed first in this last stage to emphasize its influence and prominence in the lives of the old. However, the struggle with the conflict between these paired tensions can remain a source of growth in every stage including the ninth (Erikson, 1997).



## Successful Aging

Another profound influence on views of aging is the ‘successful aging’ perspective. Several leading gerontological researchers (Baltes & Baltes, 1990; Baltes & Carstensen, 1996, Rowe & Kahn, 1997, Vaillant, 2002 ), with this viewpoint in mind have developed programs of inquiry about the positive aspects of aging that have originated in developed societies with people who are living long and healthy lives. Acknowledging that more and more people experience a time of growth and productivity in old age, Baltes and Cartensen (1996) called for increased theoretical attention to this late time of life. Successful aging acknowledges and seeks inquiry into old age as a time of life which affords productivity, and continued psychosocial growth. There was a countering of age-based stereotypes and assumptions of old age as a time of frailty and mental senility (Rowe & Kahn, 1997). As the trend progressed, there was discussion of the potential adverse consequences of a one-sided focus. Baltes and Cartensen (1996) quoted Cole who early in the movement cautioned the denial of the reality of aging; “unless this ‘enlightened’ view of ageing is extended to include the existential challenges of physical and social decline in old age, it may very well have baneful effects” (p. 398).

In the mid-1990s, the oft-cited Rowe & Kahn (1997) proposed a more robust consideration of aging that includes successful aging. In this perspective, successful aging is seen as multidimensional and encompasses the three domains of avoidance of disease and disability, maintenance of high physical and cognitive function, and sustained engagement in social and productive activities. It becomes apparent when considering these domains, that those that live the longest have less possibility of aging successfully. While it is beyond the scope of this review to document all the nuances of the successful

aging perspective it is recognized that it should not be based on the denial of the undeniable losses of functioning, abilities, and people, in the last stage of life (Moody, 2010). It can however, encourage older people and those who work with them, to optimize the remaining and even new capacities to compensate for losses. Life satisfaction and a sense of well-being have become accepted measures of successful aging (Moody, 2010) which points to the recognized notion that the process of aging is highly individualized and heterogeneous, not easily given to measurement. Yet, despite difficulties inherent in aging, most people in later life feel good about themselves and their situations (Whitbourne, 2008).

Concurring with this notion, Vaillant (2002), the current primary investigator of the extensive longitudinal Study of Adult Development at Harvard University, states “the fact is that the majority of older people, without brain disease, maintain a sense of modest well-being until the final months before they die” (p. 5). He proposes a third perspective from which to view old age, one that is neither black nor white. Positive aging, his term, must reflect how the oldest-old react to change, to disease, and even to conflict, acknowledging that aging can be both joyous and miserable.

### **Considering the Oldest-Old**

As the development of perspectives on aging is reviewed, a question comes to mind. What about our oldest-old? The successful aging approach has indeed reflected on the fact the people are living longer and healthier than ever before. Decades of life, that have been considered quite old in the past, are now recognized as having possibilities for vitality, growth, and continued productivity. However, it is quite possible that the oldest-old years that can try a person’s resilience and coping skills have only been pushed

back ten to twenty years. There is indeed support from theorists and researchers that this is precisely what has taken place.

A prolific researcher and theorist, cognitive psychologist Paul Baltes and his co-author Jacqui Smith (2003) stress the distinctions between the young-old and the oldest-old. Using the historical terms of the “third age” for the young-old and the “fourth age” for the oldest-old, the distinctions are stressed. Ultimately, the good news about living longer, continued physical and mental fitness, maintenance of intelligence and even new learning, a gain in emotional intelligence and wisdom, and adaptive capacity in the third age, fades when considering the fourth age or the oldest-old. “Based on recent work distinguishing between ‘ages’ of old age, the positivity of the news about human aging begins to crumble” (Baltes & Smith, 2003, p. 128). This age of oldest-old is not simply a continuance of the young-old. The prevalence of dysfunction is higher and the potential for enhanced functioning is reduced. Psychological mortality is increased in the oldest-old, with resulting threats to the brilliance of the human mind, intentionality, self-identity, control over one’s future, and the opportunity to live and die with dignity. It seems to Baltes and Smith (2003) that there are definite age limits to healthy and successful aging. They are bold enough to say, that our societies will have to consider carefully how to allocate resources to age subgroups when pondering human rights and responsibilities in society as a whole. Is there a need to push longevity to its limits, and thereby also push the limits of human dignity?

The Berlin Aging Study (Baltes & Mayer, 1999), a cross-sectional, interdisciplinary gerontological study that focused on persons aged 70 to over 100 years of age, was specifically designed to study the oldest-old. In their final chapter, Mayer et

al. (1999), draw some challenging conclusions that support some of the current thinking that the disregard of negative images of aging may have gone too far. These conclusions are worthy of discussion due to implications for the research reported here.

Could it be that our need for positive images of aging, reflect our unwillingness to face the existence of frailty, suffering, and death and that hopes for a long and even healthy life are beyond our control (Baltes & Mayer, 1999)? If so, this denial can hinder and interfere with efforts of both the individual and society to prepare and compensate for this prospect. While affirming a basic optimism regarding human potential in the third age of the young old, the Berlin Aging Study reveals a much less positive and optimistic view of very old age (Mayer et al., 1999). Very old age is a time when “the finitude and vulnerability of life and the strains and suffering associated with the approach of death become predominant” (p. 513). A push to consider the lives of the oldest-old as research priorities is formed strongly and persuasively in the concluding remarks:

It is necessary to find new ways of life in and with very old age, a period that is at present strongly determined by mental and sensory deficits, frailty, and the need for care. The developmental progress of a society will not only be assessed by the provision of opportunities for the young old, the third age, but also by its achievements in developing and supporting humane ways of life in its final period. In advanced old age, beyond the age of 85, personal, familial, and social problems are most acute, and these very old persons and their caregivers belong to the neglected part of our society (Mayer et al., 1999, p. 519).

What has been done in the past decade in an effort to further this understanding?

Attention will now be turned to a review of this more recent research.

### **Aging Research of the Last Decade**

The flow of research in the area of aging and all its various questions and approaches to seeking “answers” has had a life course of its own. This course has also reflected the influence of what is considered “empirical” and “data.” While aging and

loss theorizing, investigating, and exploring has been vast as multiple disciplines seek to approach an authentic and true understanding of the experience of aging, the literature review here will primarily focus on the last decade. The recent research focus has been on successful aging, yet the focus continues to be on the old ranging from 65 and older; often even younger participants are included. Those studies with participants in the oldest-old years of life are small in number.

As the review of literature has revealed, in the vast realm of studies on aging an extreme minority of studies have focused, through qualitative methods, on the lived experience of aging for the oldest-old. Several of those are considered here. Research conducted since 2000, with an emphasis on the most recent, and the exception of some notable and pertinent earlier works, will be discussed. The purpose of the literature review was to explore the current understanding and knowledge base, and identify the gaps in the research regarding the broad experience of living in very old-age, more specifically with the losses of aging in oldest-old persons, particularly from a qualitative perspective. An investigation of phenomenological research was a primary focus, but studies using other qualitative and quantitative methods were considered if the population of interest was the oldest-old. Nursing literature was specifically searched but the research literature of other healthcare disciplines were considered as well.

Specifically, this review sought to answer the following questions:

1. What phenomenological studies have been done with the oldest-old and aging, and what have they learned?
2. What is the state of the aging research regarding the period of oldest-old age?

3. What qualitative research has been done, specifically in nursing, to understand the experience of loss in aging for the oldest-old?
4. What are the gaps in the aging literature that need to be addressed?

Inclusion and exclusion criteria were also defined. Briefly, studies were to be included that had the majority of participants of oldest-old age ( $\geq 85$  years and older), that were English speaking and in a community living situation. Study publication dates considered were between 2000 to present. Both qualitative and quantitative studies were evaluated for inclusion.

The initial electronic database search was begun by keeping close to the topic and the method to be used here. EBSCO databases, including Academic Search Premier, CINAHL Plus with Full Text, ERIC, Christian Periodical Index, Health Source: Nursing/Academic Edition, MEDLINE with Full Text, Philosopher's Index, Primary Search, PsycARTICLES, PsycINFO, and SocINDEX with Full Text, were selected to obtain the literature used by the varied disciplines with an interest in exploring issues of aging and old age. Search terms used at various times included Ag\*, Aging, Grie\* (to access 'grief' terms) Loss, Life course, Nurs\*, Old Age, Old, Phenomenology, Qualitative, Quantitative. Dates searched were initially narrowed to 1/2000 to 3/2012. Ag\*, Nurs\*, and Phenomenology, in 1/2000 to 3/2012 yielded ten articles that fit the criteria. Additional searches revealed studies of interest in multiple fields yet the vast majority of researchers focus on the young old, fail to define the age range specifically enough, or the oldest-old are not considered apart from the young old.

## *Phenomenology and Aging*

A wide variety of phenomena of aging in nursing have been explored using interpretive and hermeneutic phenomenology methods. Possessing inner strength (Nygren, Norberg, Lundman, 2007), meaning of the future (Nilsson, Sarvimäki, Ekman, 2003), being in transition (Nilsson, Sarvimäki, Ekman, 2000), living in rural areas (Hinck, 2004), living with cancer (Thomé, Esbensen, Dukes, Hallberg, 2004), meaning of being old, (Fischer, Norberg, Lundman, 2007), coping in living alone (Birkeland, & Natvig, 2009), being homebound (Shearer, 2008), living with dementia (de Witt, Ploeg, & Black, 2010), living with chronic illness (Dyess & Chase, 2010), having health and self-care (Gilbert, Hagerty, & Taggert, 2012), dealing with pain (Gillsjö, Schwartz-Barcott, Bergh, & Dahlgren, 2012), fearing falls (Mahler, & Sarvimäki, 2012), and living with loneliness (Smith, 2012) have all been experiences of aging explored by nurse researchers in this last decade. It was clear by scanning these topics, that nurses are drawn to study topics that suggest that getting old is not an easy process. What is not readily apparent is that the majority of the nursing phenomenological research on the oldest-old is done in Scandinavia. And further, research that is done on this period of late life, often has a broad age range making it difficult to isolate what may be occurring uniquely in the years of oldest-old age. As previously stated, studies that focus exclusively on the oldest-old among us are hard to come by.

Although it is understood that age is not the only indicator of well-being or quality of life, it can also be understood, that the number of years one lives is also indicative of how much longer one may live, and the extent of disability, frailty, or number of health conditions one may experience. The age of 96, for example, is

intuitively known to require a different level of challenges and carries with it a differing meaning than the age of 79.

Through a multidisciplinary approach Nilsson, Sarvimäki, and Ekman (2000) illuminated the experiences of 'feeling old' for the oldest-old. Using a hermeneutic phenomenology approach they interviewed 15 Swedish persons from 85 to 96 years of age and used the term transition to help understand the experience. This notion of being in transition was used to describe the movement from the idea of 'being old' to the experience of 'feeling old.' Feeling old involved "being able to date the beginning of feeling old, fear of helplessness and of being unable to manage one's life situation, not recognizing one's former self, and feeling different from others" (Nilsson et. al, p. 43). Using Joan Erickson's (1997) description of the ninth stage of development, the authors' work acknowledged the additional hardship and loss involved in the life experience of the oldest-old.

In a second study, Nilsson, Sarvimäki, and Ekman (2003), using the hermeneutic phenomenology methods of Ricouer (1976, 1984), explored what 'the future' meant to the oldest-old. A strength of this study is that the 15 Swedish, community living, men and women were interviewed three separate times yielding rich narratives. Findings revealed some diversity in positive and negative perspectives although a preponderance of hope for most participants. Trust in God explained some of the difference. The immediate versus long-term futures were considered as well as thoughts about life and death. The focus on this select age group has again revealed the uniqueness of their experience of life.



Exploring the lived experience of the oldest-old living in a rural geographic area in the U.S., Hinck (2004) focused exclusively on this age group by selecting participants aged 85 to 98. Using interpretive phenomenology, she sought to understand the meaning and interpretation given to their lives, how their everyday activities were affected by their health, and how they adapted their living strategies to continue living at home alone. Hinck (2004) reveals the struggles and successes of the experience of rural living in advanced age and how historical, cultural, and environmental contexts impact what was meaningful to them. A particular strength in her design was conducting three interviews with each participant. This repetition allowed her to listen and clarify, and establish a trusting relationship. This relationship showed itself as something that mattered. Participants were eventually able to disclose the difficulty that their fatigue brought; these struggles were withheld in the earlier interviews. The importance of remaining in their home was clearly primary and this group of rural folk demonstrated adaptive strategies to remain active, independent, and self-determining despite chronic illness, deep fatigue, and difficulty with everyday activities. Hinck's (2004) work not only provides well described and utilized phenomenological methodology for exploring the experiences of this age group, she also provides insight into the impact of frailty and coping with losses of physical abilities for this population.

Fisher, Norberg, and Lundman (2007) offer insight into the meaning of living in oldest-old age, or a philosophy of life, in their hermeneutical phenomenology study involving 12 Swedish participants aged 95 and older. With the aim of uncovering the meaning of being oldest-old, two themes were formulated. 'Being in stillness' conveyed the meaning of living in a limited body that requires one to stop doing certain activities.

This stillness however, also allows a stillness of the soul, a quiet, reflective place. In contrast, being old also means being in movement, an internal movement often of reminiscence. The researchers heard of the acknowledgement that the meaning of being old includes the reality that one is at the end of life. Instead of planning for the future, there is a sense that one can't go any further and there is a waiting to let go. Some participants revealed that they were worried about death, or rather the process of dying. While most were able to be optimistic about life in this time of declining health and ability, others waivered in staying positive, and at least one found it impossible. In very rich narrative, Fisher et al. (2007) used the concept of 'hope' to convey trust the oldest-old have for what is ahead. They found a positive and even comforting picture of old age. The phenomenological methods contributed to the understanding of the meanings and experiences of those living in the final time of life.

Seeking to explore the meaning of inner strength in the lives of the very old, Nygren, Norberg & Lundman (2007) also sought narratives from Swedish men and women between 85 and 90 years of age. These participants, in the larger Umeå 85+ study in Sweden, had previously scored high on scales measuring what is seen collectively as inner strength. These scales measured purpose in life, resilience, self-transcendence, and sense of coherence. It is interesting to note that in this larger study of 527 participants, none of those older than 90 years of age scored high enough on the chosen scales to qualify for this study. It is quite possible that this collective resource of inner strength is weakened, even unavailable at former levels for the very oldest in this oldest-old age. Citing Baltes' & Smith's (2003) acknowledgement of the predominance

of loss in the very old, Nygren et al. (2007) may have supported the notion that there comes a time, when frailty challenges the inner resources of the aged.

Using thematic life interviews and a phenomenological hermeneutical method of Ricouer, the narrative texts were interpreted for the revealed possibilities. As is common in the Swedish studies, the three methodological steps described by Lindseth and Norberg (2004) of a naïve reading, thematic structural analysis, and a critical reading were used to identify themes regarding the notion of inner strength. In this admittedly inner resource rich group, the comprehensive understanding of being old revealed through the narratives, is “Life Goes On- Living It All” (Nygren, et al., 2007). Inner strength allows openness to the possibilities and choices in life. Clearly, this group is still able to identify with having options, control, and possibilities that others their age and those older possibly cannot claim. These results contribute the positive and successful aspects of aging that apparently are not available to all, but are important to recognize.

While no further hermeneutical phenomenological studies were found in nursing that focused exclusively on the age group of interest for this study, others that included younger participants are worth noting. One of these is the work of de Witt, Ploeg, & Black (2010). Heidegger’s philosophy of time, and van Manen’s notion of “lived time” (1990) became critical to inform data analysis as the theme of “holding back the imminent inevitable future” was identified (de Witt et al., 2010, p. 1700). The experience of living alone with dementia and the importance of time, in the sense of meaning, or “time in order to” can be useful in considering time at the end of life. The Canadian participants were much younger than the age of interest here, with only one being 87, but the described temporal theme of “holding back time” is seen as useful. In the deep spirit

of Heideggerian phenomenology, the authors ground their approach and analysis with the philosophical roots that connect the “method” with the nursing concerns for the lived experience of aging.

Thomé, Esbensen, Dykes, and Hallberg (2004), while also having younger participants, seek to understand the meaning of living with cancer in old age using van Manen’s (1990) ‘phenomenology of praxis’. Themes which emerged from interviews with ten participants, 75 years and older, hold particular meaning due to age and may be real to the life of those oldest-old. Transition into a more or less disintegrated existence, sudden awareness of the finitude of life, redefinition of one’s role in life for good and bad, meeting disease and illness were examined using van Manen’s (1990) four existentials of lived body, lived space, lived time and lived human relations. Using the resulting insights, Thomé ably provides guidance for those caring for the aged with cancer.

In the spirit of extending research, in this case the age of the participants, the findings of two additional U.S. studies (Gilbert, Hagerty, & Taggert, 2012; Smith, 2012) and two Scandinavian studies (Hauge, & Kirkevold, 2012; Mahler & Sarvimäki, 2012) found helpful, will be noted. Gilbert et al. sought to identify perceptions of the aged regarding both facilitators and barriers of healthy aging. Well-grounded in Orem’s Self Care Nursing Theory, it is hoped that this fore-structure did not impede an unbiased listening. Facilitators revealed were taking care of self, positive attitude, and meaningful activity. Barriers revealed were giving up and giving in, the aging process, and environmental limitations. The ages of the interviewees are not identified along with the excerpts of text; therefore distinguishing the voices of the oldest-old from the young old

is not possible. However, voices of the aged were sought to inform practice and policy for the very old.

Using Benner's (1994) interpretive phenomenology methods of thematic analysis, paradigm cases, and exemplars, Smith (2012) explores the meaning of loneliness and seeks to understand everyday practices of coping with loneliness. Distinct from the philosophical nature of most phenomenological studies, Smith (2012) also used three data collection instruments including the UCLA Loneliness Scale to identify cognitively intact persons experiencing loneliness. Her participants are community living men and women ages 74 to 98. This is quite a broad age range, and rarely are the ages of the narrator identified, making it difficult to consider age-related differences. However, the narratives are rich with experiential text on loneliness. A strength of this study is the three separate interviews conducted with each participant, allowing for slow revelation of previously unrecognized but salient data. Age-related losses, and losses of significant others, physical health, life roles, and meaningful engagement were identified as factors creating the risk of loneliness. Loss and loneliness appear to go hand-in-hand, making both critical to the aging experience and necessary for those in health care to understand.

Hauge and Kirkevold (2012) sought to understand the variations on the experience of loneliness with the aged in Norway. Participants reportedly had varied backgrounds and were from ages 70 to 96, a very wide range in terms of aging. The author's wisely identified age with each narrative excerpt used in the text, allowing consideration of advanced age. Manageable loneliness and agonizing loneliness are identified and supported with text from the narratives from one interview. It is interesting to note that four of the six pieces of text used to describe agonizing loneliness

were from participants, male and female, that were 95 and 96 years of age. Those in very advanced age appear to be at higher risk of living with agonizing loneliness which healthcare providers can perhaps seek to alleviate.

A Danish study (Mahler & Sarvimäki, 2012), used interviews with five women ages 81 to 94 to explore living daily with the fear of falling. Once again however, ages are not provided with the narratives, which is unfortunate. Falling experiences and coping with them at 94 may be quite distinct from those at 81. A weakness of the study is that each participant was interviewed only once. Using well described interpretive phenomenology methods of Benner, and well-integrated philosophical underpinnings of Heidegger and Merleau-Ponty, three themes discovered were of managing daily life necessities, keeping in contact with the outside, and living with fear. Again, the underlying losses experienced have created a life of struggling with fear, vulnerability and loss of control. However, these women learned how to cope through acceptance of the fear of falling, daily discipline, and regulation of life and the home environment.

Just as nursing research can contribute to understanding of the experience of aging other disciplines can contribute to nursing knowledge, and inform the provision of nursing care. Agren's (1998) oft cited qualitative, longitudinal study, from the medical gerontologist's perspective, used phenomenography to explore the variety of ways the Swedish participants experienced and adjusted to life. A strength of this study is its longitudinal nature; the same people who were interviewed at 85, were interviewed again seven years later at age 92. Seven categories of descriptions were developed and ranked from positive to negative in terms of self-actualizing, mature aging, adapting, dependent, resignedly accepting, despairing, and withdrawing. Some 92 year olds moved to a more

negative category, most stayed in the same one, and a few moved to a more positive category, emphasizing the heterogeneity of aging. The greatest change experienced was loss of freedom. Increasing physical frailty and a shortened time perspective were two factors that impacted the perception on life of the 92 year olds. All of these again demonstrate the impact of loss and the adaptable coping abilities of the human spirit.

A second informative phenomenography study (Gillsjö, Schwartz-Barcott, Bergh, & Dahlgren, 2012) focuses on the daily living with musculoskeletal pain. With the ages of 66 to 88 (four participants are > 85 years) the age group is generally too young to be informative for the purposes of this study, but the focus on pain can be. Also, with only one male in the study, it would better be seen as a study on women and pain. Analysis of the narratives resulted in the creation of four categories: ignore, struggle, adjust, and resign. This study highlights the variability in responses to living with chronic pain, yet other than length of time experiencing the pain, little is done to shed light on the varying cultural contexts of the pain experience for each individual; specific ages are also not mentioned. The experience of pain is highly invasive in the very late years of life, and leads to many losses. The individual experience and pain's meaning is important to recognize and explore.

With a focus on the perceived factors of advanced longevity, Freeman, Garcia, and Marston (2013), used a hermeneutic phenomenological approach to secondary analysis of interview transcripts of videos acquired on the internet and freely available to the public. Canadian centenarians were recorded describing in their own words their perceptions of reasons why they lived to be over 100 years old. Interview narratives of 19 men and women between ages 100 to 115, were captured as existing internet based

texts. These texts are analyzed for emerging interpretations within “the hermeneutic circle with emerging interpretation” (Freeman, et al., 2013, p. 721). Themes that emerge from the centenarians’ experiences are lifestyle choices, community and environment, attitude towards life, and goal setting and attainment. Overall, these oldest-old expressed positive outlooks and emotions, and a gratitude for life. All themes are seen to involve human connection and engagement in the world around them, and to focus on personal choices. A unique finding is the perception by these centenarians of the importance of a life-long low level of stress and minimal worrying.

Doctoral dissertations obtained through ProQuest were found that explored various experiences of aging through the narratives of the oldest-old. David (2008) eloquently honors Jewish Holocaust survivors by giving voice to their lived experiences as very old survivors, perhaps with distinct views of dying and death. With lives filled with experiences of profound loss and grief, and love, family, and marriage, David found hope and resilience to be intertwined over the course of their lifetimes. The 10 participants were all between 78 and 90 years of age, with just three individuals over the age of 85. While David’s research was seeking understanding of the unique experience of Holocaust survivors, her study is a reminder of impact of the life history that accumulates in those that live long. The very old come to this late time of life bringing an extensive history with them. This history includes collective cohort experiences as well as very individual experiences which yields a population of very old persons with rich and unique perspectives from which to learn about aging and being old. Time must be spent in understanding some of this individual history in order to provide context for understanding and giving meaning to the experiences of very old age.



It is the work of Weiss (1996) which proved to be most valuable in informing this present study. Through her work with 14 participants ages 80 to 94, she explores and expands concepts addressed by fellow phenomenologists, such as Heidegger's "being-in-the-world," Dreyfus' notions of cultural context, Benner's use of exemplars and paradigm cases, Casey's understanding of embodiment, and van Manen's work on the nature of the phenomenological interview. While several participants are younger than the age group addressed here, their lives have been changed by consequences of aging that have tremendously impacted their sense of self in the world and the meaning of their lives.

Weiss (1996) uses in-depth paradigm cases "to make visible some of the existential skills of 'dwelling' in the world as they are challenged or stretched during the late stages of life" (p. 74) and to be illustrative of the struggle of making life meaningful in response to challenges due to living long. Together these paradigms offer a portrayal of how self-understanding creates different possibilities for meaning as each individual responds within his or her cultural context to create meaning in the midst of unexpected disruptions that will increase with old age. Weiss suggests that these responses are not "chosen" but arise, and are shaped by an individual's distinct life context or "personal and social meanings" (p. 113). Possibilities arise when one is able to shift or adjust one's meaning in life and self-understanding in response to life-altering events which usually occur in very late life. Three existential skills are required to "bridge" personal experiences, changes brought on by aging for example, and social reality: physical and cognitive capacities to engage in habits, rituals, and practices that hold meaning; ways of being together with people which hold shared recognition; and a capacity to care and

value meanings that allow other people and things to matter. Life's meaning can be assaulted if any of these three capacities are threatened by difficult changes to self. Even vulnerability to this is different between individuals. Late life can bring on challenges that lead to compromises to one's ability to dwell-in-the-world. Weiss' work was a helpful stepping stone for applying these methods and understandings to the specifics of experiences of losses and gains in the lives of the oldest-old.

### *Using Other Qualitative Approaches*

As qualitative methods have gained momentum as valuable methods of data collection, analysis, and interpretation, and of gaining understanding of life experiences there has been a corresponding increase in the numbers of qualitative studies seeking to understand the experience of aging. Other aspects of aging explored by qualitative methods are thriving (Stanford, 2006), finitude (da Fonseca, 2011), future hopes and concerns as a part of active aging (Clarke & Warren, 2007); life extension and medical choice (Kaufman, Shim, & Russ, 2006), women living alone (Foster, Neville, 2010), experience of aging (Melin-Johansson, Eriksson, Segerbäck, & Boström, 2014), adapting to life "alone" (Kirkevold, Moyle, Wilkinson, Meyer, & Hauge, 2012), perceptions of weakness (Rush, Watts, & Stanbury, 2011) and use of mobility devices (Kylberg, Löfqvist, Phillips, & Iwarsson, 2013). Studies using ethnography, content analysis, and mixed methods that have added relevance to aging, the experience of aging, and loss are addressed more fully.

In their ethnographic study of the applicability of continuity theory to an understanding of the personal meaning of aging in white and black Americans, Lysack and Seipke (2002) look at the feminine experience of aging and well-being. Using

constant comparative methods of Glazer and Strauss for analysis of transcripts from 23 women over age 85, rich narratives are produced but the significance of the ethnographic approach is not explained. However, their findings highlight the importance of being competent in the feminine sphere of activities, and possessing a sense of self as a competent individual to the overall sense of well-being of the participants. The meaning of loss of ability to perform what are seemingly minor tasks or duties, may in fact profoundly impact the individual's sense of competence if it has significance to one's gender identity. It is possible, that for the oldest-old, identification with gender-based roles have been a part of their well-being for 80 or more years. Therefore, the loss of role fulfillment can be highly significant in these very late years of life.

With a similar goal but the different theoretical lenses of the lifecourse perspective and social work, Gunnarsson (2009) sought to describe, analyze, and interpret how older persons in Sweden experience everyday life. Although having some younger participants (ages 75-90), and without a "label" as to the specific type, the content analysis revealed the importance of keeping up with everyday life. Keeping active was a predominant theme, and adapting to changes of health and other losses with a positive perspective were revealed as the major activities of everyday life for the participants. An unspecified method of analysis has none-the-less described some of the everyday challenges being met by old community dwelling persons in Sweden. With only five of the 20 participants being over 85, it must be emphasized that 75 is often a very different living experience from being 90 and older.

In their multiple case study with Swedish women, Löfqvist, Nygren, Brandt, and Iwarsson (2009) used qualitative and quantitative data to focus on the experiences with

mobility devices in everyday life. Three women is a small sample, yet data gathered during two home visits with interviews, an observation of an experiential walk, and previously collected survey data provided substantial information. This format also allowed for “setting the scene,” or a narrative placing the participant in context of their world. The results add support to the importance of continuing to live an everyday life through adjusting life and adaptation. Accommodating to changes over time, including decreased strength and bodily mobility, are a part of aging as is the effort to adjust to these changes. With a very small sample size, and vague content analysis methods, the results do confirm those of Gunnarsson (2009), the vital desire to stay active and do everyday life things.

Through the lenses of anthropology and gerontology, Covan (2005) offers a qualitative study with a unique data collection method that allowed for 329 comprehensive interviews of women in 4 distinct decades of life—their 60s, 70s, 80s, and 90s. As a university educator in gerontology, students in her “Women and Aging” course have been assigned to “listen to and reflect on the life stories of women of different cohorts” and the meaning of aging to them, resulting in a large set of narrative data for what is essentially qualitative content analysis. A codebook has also been built with demographic and other social variables of each woman interviewed. Covan and her students have then compared their analysis of the data within and between cohorts.

The ages of the interviewees range from 58 to 103. The comparison between age cohorts has yielded a rich description of the attitudes and perceptions of aging by aging women. For the purposes of informing this study of the oldest-old, it was informative to note the distinctions that emerged for the women in their 80s and 90s. Women in their

80s shared in the comfort of getting older and did not deny that they were now “old women” but held exuberance for life and a focus on the positive (p. 12). Life satisfaction was often determined by family involvement. Most of the women lived alone and many were widows, with a fear that ill health could lead to losses of home, autonomy, and ability to take care of others. The change to the 90s was significant. Women at this age were less talkative, and weaker, usually with chronic illnesses. They embraced ‘old woman’ and anticipated death. Loneliness was a common theme due to excessive losses, as they had out lived many friends and family members. Most were ‘very satisfied’ with their lives, although the many that were institutionalized were often just ‘satisfied.’ A pride in survivorship was often expressed. This group of predominately North Carolinians also indicated that they were ready to go ‘live with the Lord’ (p. 14). Overall, women in this study were reported by Covan (2005) to have found meaning in family, home, and in keeping the faith. Covan and her students have offered women’s studies, and studies of aging a comprehensive, and valuable qualitative work.

Some qualitative researchers have approached inquiries into aging by using various grounded theory methods. The purpose of grounded theory is to build theory from qualitatively analyzed data, to go beyond describing the individual experience with a phenomenon as emphasized in phenomenology (Creswell, 2007; Corbin & Strauss, 2008). Several studies were found to have used the grounded theory approach to understanding concepts of interest in very old persons.

Offering very little about her data analysis approach other than using constant comparative analysis, Felton (2000) interviewed seven women over 85 years of age seeking to understand how being resilient helps women over 85 recover and rebound

after a serious illness. Even though there is a small sample size and the exact ages are often hard to decipher, the participants are ethnically diverse and the analysis leads to insight into the themes and roles of frailty, determination, previous hardship, and culture as they promote resilience in old-old age.

Also using constant comparative methods for their qualitative descriptive design, Rush et al. (2011) interviewed 13 older adults on their perceptions of weakness and aging. Making it difficult to know how many participants were actually oldest-old or over 85, the authors only identify 10 participants as in their eighties and one was over 90 year of age; two were in their seventies. The meaning of weakness for these participants was found to be twofold, carrying physical aspects as loss of functional abilities and emotional aspects as “emerging passivity in character and personhood” (p. 7). An important aspect of this emerging passivity is described as an inward turning or internalized weakness expressed as self-pity, frustration, and loss of self-confidence. The aged describe themselves as making efforts to stay strong through encouraging self-talk, balancing activity to not overdo or underdo, staying busy, and identifying as a strong person. These findings are seen to offer insight into preventing further weakness or disability and enhancing active efforts to support this desire of staying strong.

A grounded theory study (Aléx, Hammarström, Norberg, & Lundman, 2006) conducted in Sweden using the emergent design approach, looks at the experience of growing old for Sami women through single in-depth interviews with 9 women aged 75 to 90 years. The Sami are an indigenous group in Northern Sweden. Highlighting the value of narrative in illuminating the experience of the Sami woman, the authors see narrative useful in “gaining a wider and deeper perspective on human lives (p. 888). The

idea of “balancing within discourses,” in this case the art of being ‘old’ and living as a Sami woman created a sensitivity for this study to the lives of others that may have the same experience of ‘balancing’ two different roles as one ages.

Two additional grounded theory studies were found that explored aspects of aging that offer value here. Although the constant comparative analysis and other aspects of grounded theory are not described, and the precise ages of the participants are not clearly evident, Felton’s (2000) focus on resilience in women over 85 is salient to the present study. It is also one of the few studies done in the U. S. exclusively with this age group. The author recognizes that women over 85, as a group, are more vulnerable and impoverished, and have distinctly different life experiences than younger groups. Through the nursing lens, issues of frailty, determination, past experiences with hardship, access to care, cultural health beliefs, family support, and self-care conveyed themes that involved resilience and health experiences in old age.

Through the lens of occupational therapy (Haak, Fänge, Iwarsson, & Dahlin, 2007), a grounded theory approach was used to explore independence in the home by the very old in Sweden. Using a clearly delineated method of constant comparative analysis, a sample of 40 participant interviews were conducted by the four researchers. Results convey the very high importance of the ‘home’ and remaining in the home for the men and women, ages 80 to 89 (median age of 85) that participated. The idea of the continuous struggle to maintain independence was clearly conveyed. A very thought provoking theme that emerged was the change from being independent no longer but at least still an autonomous decision maker that took place when the ability to be perform activities of daily living declined. If one couldn’t continue to remain active and provide

self-care, then preservation of decision-making ability in the home was of great importance. Haak et al. also emphasized their finding that descriptions of the aging process conveyed a highly individualized process of change in living conditions. The oldest-old are a very heterogeneous group, and along with the highly varied living conditions this needs to be considered when maintaining them in the home is considered. The shift to being at least autonomous, when independence is no longer possible, calls nurses and health care providers to recognize and respect the decision making capacity of the very old when the losses of oldest-old age tip the balance to dependence.

Klyberg, Löfqvist, Phillips, and Iwarsson (2013) also offer the occupational therapy perspective in their longitudinal mixed methods cross-case analysis exploring the experiences of three very old men with their use of mobility devices (MD). Using secondary analysis as a retrospective qualitative design, the qualitative component provides participant narrative regarding their experience with mobility device use over time. As this experience implies, some loss of mobility for the aging person and changes in the performance of everyday life activities, reveals losses and adjustments of very old age. Describing the method only as “conventional content analysis” (Klyberg, et al., 2013, p. 400) the results provided three core aspects of being an MD user with some loss of mobility. MD use is seen as having long term consequences for activity. Used to maintain independence in everyday living, the MD is incorporated as a habit, yet one requiring advanced planning, thinking, and problem solving for getting around. This creates feelings of being limited and housebound with both acceptance and sadness being expressed with this reality. As the second theme, being an MD user is also seen to occur in a social context. Family, friends, and the social contacts were important in supporting



the use of MDs. The men express concern with the risk of being seen as different. The Loss of “sameness” is experienced. The final theme surrounded the MD use and the surrounding physical environment. As the MD are crucial to performing everyday life activities, the type of MD equipment chosen has consequences. Whether to use cane or walker with consideration of indoor or outdoor surfaces, anticipation of stairs versus sidewalks, narrow spaces versus wide, and weather conditions all imposed limits and require decisions about MD use. These themes reflect necessary but highly significant changes to independence and mobility. Identifying this experience as a loss of the very old offers recognition of the adjustments to self-identity and everyday life of MD use.

With gerotranscendence theory as their lens, Melin-Johansson et al. (2014) uses qualitative content analysis to explore the experience of aging through reflections of 14 very old people living in nursing homes in Sweden. While participants in my study live independently, insight gained through this population of men and women between the ages of 80 and 96 informed the understanding of this experience of being very old. The findings were divided into three categories of the self, the cosmic dimension, and social and personal relationships each underpinned with eight subcategories. In the realm of the self, categories of less self-centeredness and increased acceptance of their bodies are identified. The cosmic dimension holds categories of old age being a time of reminiscence, connecting with past generations, having feelings of security and joy, and living with issues of life and death. Social and personal relationships hold experiences of change with issues of aloneness often due to the move to the nursing home. There are gains of wisdom in expression of thought and decision making. While phenomenology avoids entering explorations through a theoretical framework, the approach of Melin-

Johansson et al. (2014) offers sensitizing insight to aspects of the experience of aging for oldest-old in Sweden.

Similar to the phenomenological study of Hauge and Kirkevold (2012), Kirkevold, Moyle, Wilkinson, Meyer, and Hauge (2012) add to the exploration of the older person's experience of adapting to life characterized by losses, "aloneness," and loneliness. Using a qualitative interpretive design, they have expanded their inquiry to include participants in Australia and the UK to those in Norway. While the samples had mean ages of 79 years, 81 years, and 85 years respectively, the insight into the experience of loneliness is highly apposite to my study of loss in very old age. Through interpretation of the narrative data, researchers identify the differing experiences of those who were lonely and those who were not. The core theme is described as "adjusting to a life alone for the not lonely participants, and caught in loneliness and isolation for the lonely participants" (Kirkevold et al., 2012, p. 396). The not lonely are seen to accept losses and move on, stay committed to activities, stay connected to others, and create a meaningful life. In contrast, the lonely are overpowered by accumulating losses, are unable to carry on with activities, become isolated from others, and see life alone as empty. Most of the oldest-old have lost a spouse. This sensitivity to distinguishing the lonely and isolated from those living alone, help identify those at risk for isolation, depression, and declines of health and wellness and allow for supportive interventions.

And finally, a recent metasynthesis of qualitative research (Duggleby et al., 2012) of hope and chronic illness in the lives of persons 60 years of age and older, offers support to the notion that age matters for those suffering with chronic illness. Researchers conducted a rigorous search of qualitative literature since 1980 which

yielded 20 studies from diverse countries regarding hope and illness. Their results, while in general considering those younger than the focus of the population considered here, highlight two helpful considerations. First, hope and suffering of chronic illness are of obvious importance for the oldest-old. Their notions of hope, self-transcendence, and positive reappraisal, along with sub-processes of reaching within and without, seeking meaning and purpose, re-evaluating hope in light of illness, and finding positive possibilities, offer insight into living with the losses and gains of aging in the oldest-old years. Further, the suggestion of the researchers (Duggleby et al., 2011), that this concept of hope may be different in later stages of life compared with the early or middle years of adulthood, supports the notion held here, that the experience of the living in the oldest-old years of life holds distinctions beyond being merely “older.”

### *Quantitative Studies Addressing Aging Issues*

Moving from the qualitative to the quantitative arena of aging research provides additional and valuable insight into the experience of aging for the oldest-old. While published in 1999 (Baltes & Mayer), slightly earlier than the time frame chosen for this review, the Berlin Aging Study (BASE) must be mentioned due to its importance for the understanding of very old-age, the fourth-age, as being distinctive from younger-old or third-age.

BASE, an interdisciplinary gerontological study, focuses on a representative sample of 516 persons from 70 years of age to 100 years and over (Baltes & Mayer, 1999) in Berlin, Germany. These results discussed here were taken as a cross-sectional, but the study will be continued with longitudinal methods. Random sampling was used resulting in six equal age groups from 70 to over 100. Participants were stratified by age

and gender. The dual focus is described as being first on sample heterogeneity and local representativeness rather than convenience, and second as being on the full range of old-age, particularly the very old. Researchers sought new insights regarding aging and the influences of increasing proximity to death.

Using 14 different assessment sessions, the disciplines of internal medicine/geriatrics, psychiatry, psychology, sociology/social policy used multiple and varied instruments, observations, and medical tests in the extensive and thorough data collection (Baltes & Mayer, 1999). The results indicate manifold insights into old and very old age. For the purposes of this literature review a few important conclusions are as follows: most old people have at least one illness with 30% having at least five; the majority of very old women need assistance in bathing or showering; about one-half of those aged 90 years and over exhibit severe mental decline; memory gets worse with age; the number of social relationships decreases with old age; and the old felt lonelier. These findings testify to the myriad of losses in old age. However, the researchers state boldly that “old age is *not* foremost a negative and problem-ridden phase of life” (Baltes & Mayer, p. 506). And further, the majority of people expressed satisfaction with their lives. An interesting caveat was that the older the individual, the higher he or she perceived their health to be, compared to others of the same age. However, as mentioned previously, the very old constitute a new stage: “Very old age represents a considerable challenge to psychological resilience and coping capacities” (Baltes & Mayer, p. 509).

Using rich prospective longitudinal data in the U.S., Vaillant’s (2002) Harvard Study of Adult Development uses both qualitative and quantitative data to explore predictors of successful aging. Suggesting that this study is “arguably the longest study

of aging in the world” (Vaillant, 2002, p. 4) Vaillant, through the lenses of a psychiatrist, the concepts of adaptations or defense mechanisms, and the Positive Psychology of Martin Seligman (Shenk, 2009), seeks to provide models for living past 80 years with joy. Having acquired from prior researchers two cohorts of young men, the Harvard Grant Cohort (began in 1938) and the Inner City Cohort (began in 1939), and women from the Stanford Terman study of gifted children (began in 1922), Vaillant has carried the participants through decades more of observation, examination, and interviews to learn factors that may determine successful aging. In the spirit of Martin Seligman’s Positive Psychology, Vaillant states at the outset “whenever in this chapter I write pedantically of successful aging – think joy” (Vaillant, 2002, p. 15). Writing in an informal, highly engaging format, the research described in his book reads more like a conversation. His interpretations of significant findings that influence successful aging thus far include:

- Good people in our lives facilitate a successful old age; the bad things in our lives do not doom us.
- The ability to be grateful, to forgive, to take people inside oneself and therefore be enriched by a “loving, particular person” (p. 13) is a vital capacity.
- A good marriage predicts successful aging; low cholesterol levels do not.
- The damage caused by alcohol abuse, in part due to damaged social supports, predicted unsuccessful aging.
- More than income after retirement, the ability to create and play, and to gain younger friends to replace lost friends, adds to the joy of old age.

- The *perceptions* of good physical health is more important than the actuality of good health; not *feeling* sick is what matters.

Modifying Erickson's stage of adult development to his "empirically" based model of developmental tasks, Vaillant adds as the "pentultimate task" the task of becoming the keeper of the meaning, or passing on to the next generation the traditions of the past (Vaillant, 2002, p. 45). His final task is achieving integrity; living with a "sense of peace and unity with respect both to one's own life and to the whole world" (p. 45). With a book full of interviews, and appendices with several scales and quantitative results, Vaillant's storytelling style beautifully and very optimistically conveys a view of the positive possibilities of aging.

Vaillant's penchant for the positive is also apparent in a smaller study using the two male cohorts of the Harvard study (Vaillant, 2001). In his review of the Berlin Aging Study, he notes "Alzheimer's disease affects *only* one-half of centenarians. Social networks had declined *only* from an average of 13 individuals at age 70 to seven at age 90" (p. 840) [italics use for emphasis]. Further on, "Even after age 85, *only* one-quarter of the waking life was spent "resting" (p. 840). In discussing good health, Vaillant noted "At age 95, this level of health was *still* maintained by 30% of the subjects" (p. 840). While these observations are certainly notable, the 50% affected by Alzheimer is significant, as is the social network decline, the time necessary to "rest", and the 70% above 95 that did not experience good health. What is their everyday lived experience? What is the balance of loss and gain experienced? As Baltes and Mayer (1999) have cautioned, highlighting the positive has the potential to discount the severe challenges some are confronted with in very-old age. Vaillant's results (2001) indicated that

increased education, absence of alcohol and cigarette abuse, a happy marriage, absence of a major depressive disorder, a good physical health prior to age 50 were protective for successful aging. Individuals do have some personal control over most of these factors. Distinguishing the predictors of being “Happy-Well” from the “Sad-Sick” is an overriding concern of Vaillant (2001; 2002).

Examining the data from the Berlin Aging Study, Smith, Borchelt, Maier, and Jopp (2002) specifically explored the possible difference in subjective well-being (SWB) between the young old and the oldest-old. SWB is seen as an indicator of successful aging and thereby measures of SWB can give information on the success of social policies regarding the elderly. Recognizing the differences found between the young old or Third Age, and oldest-old or the Fourth Age in the Berlin Aging Study, Smith et al. focus specifically on the links between SWB and health in these two groups. It is not necessary to review the methods as they have been described above. The findings between these two groups and their experience of well-being are salient to this study. Using validated instruments, the Positive and Negative Affect Schedule (PANAS), and the Philadelphia Geriatric Center Morale Scale (PGCMS) both affective and cognitive components were measured. Results demonstrate that the number of impairments increased with age, leading to a time of life when multiple chronic life strains impact one’s well-being; there were no persons over 90 in the study who had no impairments, while 40% of the young-old enjoyed this. Considering positive and negative affect independently, the oldest-old reported lower positive well-being than the young old. Positive affect includes the realms of life satisfaction, satisfaction with aging, and the

experience of positive affect. Negative affect (including depressivity) however, demonstrated more stability.

The association between health and SWB has been demonstrated to be exceedingly strong. Significant sources of SWB are constructs of both functional health and subjective health. However, subjective health has proven to be the strongest predictor of SWB (Smith, et al., 2002). Likewise, physical health (number of diagnosed illnesses) “predicted the subjective evaluation of physical impairment, satisfaction with social participation, and satisfaction with social relationships” (pp. 726-727). Researchers speculated that over time, physical illness and limitations impact social participation and social contact creating an impact on positive affect. Additional implications are noteworthy. Findings noted by Smith et al. (2002) indicate that health, particularly functional health, is critical for SWB for the oldest-old. Limitations of functional health, including impairments of vision and hearing, physical mobility, and strength, negatively impact SWB for this age group. Functional health was also shown to explain most of the variance in positive SWB. For the oldest-old, there were fewer experiences of positive affect however there is no evidence that negative affect increased. In other words, there seems to be less joy, but not more sadness. It is speculated that in the oldest-old the psychological challenges of physical illnesses, frailty, social losses, and functional limitations may push adaptive abilities to their limit, impairing the capacity to feel and experience positive emotions. The authors’ argue for consideration of adaptive resources and social interventions that will support our oldest-old during this time of life in which they are experiencing the “personal ‘costs’ of aging” (Smith, et al., p. 729).



Two studies which quantitatively examine the impact of loss for older persons are considered here. The significance of these two concepts of loss of a parent and loneliness to aging is recognized although the participants included are younger than those considered as the oldest-old. Savikko, Routasalo, Tilvis, Strandberg, and Pitkälä (2006) consider the impact of the loss of parents in childhood on attitudes towards life of older people. With a high response rate of 71.8% to a mailed questionnaire, the authors were able to randomly sample individuals 75 years of age and older in Finland. The structured questionnaire, while seemingly an easy-to-answer 15-item tool, measured most constructs with just a single item. In comparing those respondents who had lost a parent(s) in childhood and those who had not, chi-square for categorical variables and an ANOVA for ordinal measures of attitudes were used. While the mean age was 81, younger than the population of interest here, the results were interesting to note. There was no significant relationship demonstrated between the loss of a parent in childhood and self-reported depression or loneliness in old age. It is possible however that a multiple item instrument measuring these constructs would yield different results. Interestingly, there was no relationship between the loss and any of the measured attitudes towards life, such as zest for life, happiness, life satisfaction, or plans for the future. However, loss of a parent(s) was associated with being unmarried, less educated, and having lifetime work that was physically heavy. What is of interest here, is the agreement with Vaillant (2002), that in older age the impact of difficult life circumstances at a young age is of little influence. Nurses should not, then, make assumptions about the impact of negative events in childhood on the experience of aging for the very old but be open to learning about the lengthy distinctive lives for which they care.

While again considering a population younger than the one considered here, van Baarsen's (2002) longitudinal study (WALS—Widowhood Adaptation Longitudinal Study in The Netherlands) focuses on the experience of loneliness after a spouse's death in old age. Participants ranged from 55 to 89 years of age, with an average age of 73 years. As the vast majority of the oldest-old that have married have lost their spouse, the results are useful in considering the experience of loss among the oldest-old. A strength of this highly theoretical study is its rigorous longitudinal design; participants were interviewed before and five times after the death of their partner. Using the theory of emotional loneliness, van Baarsen (2002) examined the impact of social support and self-esteem on loneliness over time for the elderly bereaved participants. A more rigorous study than Savikko et al. (2006), validated Dutch measures were used by van Baarsen (2002) which enabled multiple regression analysis to predict the impact of social support and self-esteem on loneliness. Results indicated that after the loss, emotional loneliness showed a strong increase and although it gradually declined, it never returned to the pre-loss level. Self-esteem also decreased after the loss of the partner and lower self-esteem increased emotional loneliness. Especially pertinent in older ages was the finding that poor general health increased the likelihood of both emotional loneliness and the perception of less social support. Studies such Savikko et al. (2006), and van Baarsen (2002), when using such a broad range of ages, lose the opportunity to examine what are quite possibly unique loss experiences of the oldest-old.

Using resilience, sense of coherence, purpose in life, and self-transcendence, another group of Swedish researchers (Nygren, et al., 2005) seek to understand forces and strengths that drive and contribute to the ability of oldest-old persons to handle adversity

and maintain or regain health. Recognizing that many varied losses are involved with becoming old, and also acknowledging that many studies have highlighted the positive aspects of old age, the authors describe four concepts in relation to the perceived physical and mental health in a sample of 125 participants who are age 85 years of age and older. Participants were part of The Umeå 85+ study. Validated and reliable instruments used were the Resilience Scale (Wagnild & Young, 1993), Antonovsky's (1993) Sense of Coherence Scale, the Purpose in Life Test (Crumbaugh, 1968), and the Self-Transcendence Scale (Reed, 1989). Multiple regression analysis was used to describe the relationship between resilience, sense of coherence, purpose in life, and self-transcendence, with the dependent variables of the physical health and mental health dimensions of the SF-36, a health related quality of life instrument.

Interestingly, in their model (Nygren, et al., 2005) which used these multiple independent variables to predict the physical and mental health aspects of quality of life, a relatively small but significant 19% of the variance of perceived mental health was demonstrated. There was however little demonstration of predictive ability for perceived physical health. The decline of the body may have less impact on well-being for this age group than on younger groups. When comparing this age group to younger age groups, the oldest-old were found to have higher mean scores of resilience and sense of coherence, whereas purpose in life and self-transcendence was comparable. Together this may indicate that frailty does not dominate all aspects of life. Strong resilience and sense of coherence may support older persons in overcoming the increasing losses and challenges of very old age. Along with this, the large gender differences in their results seem to indicate that aging is a highly individual experience and as such lends itself to

research methods, such as in this reported study, that explore the unique everyday experience of individuals.

Building on this, Lundman et al. (2012), focus on the concept of ‘inner strength’ in over 85 year old persons and how it relates to their functional status, disease, living arrangements, and social relationships. Using scales to measure resilience, sense of coherence, purpose in life, and self-transcendence, correlations between these measures and inner strength are explored in a sample of 185 Swedish men and women from the Umeå 85+ epidemiological study. Findings included that there are strong correlations between scales used, that certain progressive and debilitating chronic diseases were associated with low inner strength, that social relationships were of importance, and that women had significantly lower inner strength scores as did those diagnosed with depression and/or those using certain psychiatric medications. The authors (Lundman et al., 2012) suggest that these results can possibly be understood through the perspective of Baltes and Smith’s (2003) concept of the fourth age as a time of advanced old age when the experience is one in which life’s losses accumulate over life’s gains and limit the capacity of inner strength to prevail. Their implications include exhorting nurses to assist the oldest-old and their caregivers in identifying individual strengths and capacities when they are challenged by a period of functional decline, frailty, and weakness. This is yet another study (Lundman et al., 2012) which provides very recent evidence of the unique challenges of advanced old age.

Two recent quantitative studies from the life course perspective of Pearlin (Kahn & Pearlin, 2006; Pearlin, Nguyen, Shieman, Milkie, 2007) also offered insight for this study. Using the concept of mastery, “which refers to the understanding that people

harbor about their ability to manage the circumstances of their lives” (Pearlin et al., 2007, p. 165), Pearlin, Nguyen, Shieman, Milkie, through face-to-face structured interviews, seek to identify conditions that promote and nurture a sense of mastery for older persons. Different from the concept of resilience which is seen more as a fixed personality trait, mastery is seen as an acquired aspect of self-confidence that grows out of life experiences and is more susceptible to change brought on by “critical experience” (p. 165). As explained by their model of current mastery, Pearlin et al. (2007) see the level of current mastery impacted by both recent and past circumstances and stressors that persist despite efforts to avoid or remedy them. It is conceived that life-course mastery is nurtured by a history of status attainment (influenced by educational and occupational attainment) and the privileges and protections status affords.

Using a cross-sectional design with a random sampling of the population in the Washington D.C. area, researchers interviewed 1,167 participants, 65 years of age and older (Pearlin, 2007). Face-to-face structured interviews were used. Questions focused on ascribed and achieved statuses, past and current hardships and stressors, and life-course and current mastery. Items from the Pearlin Mastery Scale (Pearlin & Schooler, 1978) were used to assess current mastery. While rich with interesting insight on mastery for elders, of interest here are the observations that current mastery declines significantly with age, that there is an indirect effect of prior life conditions and mastery, and that there is a direct effect between exposure to current stressors and mastery. Clearly stated, “when stressors that arise in late life merge with those that earlier suppressed a sense of management over the life-course trajectory, it becomes markedly less likely that elders will enjoy a perception of control over the current conditions of their lives” (Pearlin et al.,

2007, p. 174). Current life stressors and hardship affects the sense of mastery among elders and further, current mastery demonstrated a decline with age. It is speculated that with increased age, the recognition that mortality and the end of life are eminent, and that loss of autonomy and the ability to care for oneself are very real possibilities, result in a humbling of one's sense of personal control. Mastery, in the face of adversity, according to Pearlin et al. (2007), appears to be most fragile for those in the oldest-old years.

While quantitative data such as this can be sensitizing and informative, what is lacking here in this cross-sectional study is the longitudinal perspective and more significantly, the qualitative information from the oldest-old themselves, and the ability to consider their life-course in context and listen to their stories.

The life course perspective also prompted sociologists Kahn and Pearlin (2006) to consider the impact of financial strain on the health of adults. Financial burden and its impact on life satisfaction and well-being in old age has been considered by others (Borg, Hallberg, & Blomqvist, 2006; Cummings & Cockerham, 2004; Davis & Friedrich, 2004). Using the over-65 years of age sample and data from the same face-to-face interviews as in the study above, the researchers (Kahn & Pearlin, 2006) retrospectively sought to focus on the impact of financial strain across a life course on health inequalities in later life. A stratified sample was done to increase the number of advantaged African-American participants to distinguish class effects of both African Americans and whites. Analyzed data were based on retrospective questions of the financial hardship experienced during childhood, early adulthood, early middle age, and later middle age. Data on current financial circumstances, illness symptoms frequency, functional

limitations, and mental health were also collected. Further, persistence, severity, and timing of hardship in life were also considered.

Informative findings include the following: financial hardship experienced later in life has an increased effect on the health of the elderly over hardship early in life; persistence and a longer duration of hardship has a more profound impact on health of the elderly than does timing; early hardship is significant only when it is followed by further periods of hardship; and current hardship effects are not as strong if they are preceded by a period of relative financial comfort (Kahn & Pearlin, 2006). Racial considerations indicate that impact of cumulative hardship is stronger for whites than African Americans. As the current generation of oldest-old persons in the U.S. are children of the depression and World War II eras, many would have suffered early financial hardship. Some did speak to this impact on their life experience, yet as Kahn and Pearlin related, this impact did not have significant lasting impact if financial recovery was experienced over the life course. This study (Kahn & Pearlin, 2006) demonstrates additional findings that are highly variable over the lives of individuals and have made their life stories and experiences of aging distinct and uniquely theirs, and worth hearing to more fully understand the experience of aging.

### **Conclusion**

The research and theory literature on aging is extensive. The theoretical literature has addressed the notions of continued development of individuals into advanced old age with the perspectives of lifespan and life course theories. Successful aging has sought to promote the positive potential in living into old age, countering past negative cultural aging perspectives. It has been stressed by noteworthy recent gerontology researchers,

due to findings of their studies over the last two decades, that with contemporary medical advances, people living into oldest-old ages are faced with distinct challenges to the human spirit. However studies exclusively addressing the oldest-old are rare. More often a few old-old people are included with participants in a very broad age range, with the distinctiveness of this age not being identified. An exception to this would be the cluster of qualitative studies from Sweden and Scandinavian countries (Agren, 1998; Fischer et al., 2007; Gunnarsson, 2009; Hauge & Kirkevold, 2012; Löfgvist et al., 2009; Mahler & Sarvimäki, 2012; Nilsson et al., 2000; Nilsson et al., 2003; Nygren et al., 2005; Nygren et al., 2007; Haak et al., 2007) that focus specifically on the oldest-old, those 85 years of age and older. Phenomenological studies, particularly Swedish studies, have been done to reveal some lived experiences of old-old age. However, none were found that sought to reveal the experiences of living with loss in this age group.

While many authors discuss loss involved in advanced old age in their introductions (Nygren et al., 2007; Smith, 2012; Mahler & Sarvimäki, 2011, Hauge & Kirkevold, 2012) or even discussions and conclusions (Borglin, Edberg, Hallberg, 2005; Prieto-Flores, Fernandez-Mayoralas, Rosenberg, Rojo-Perez, 2010; Gillsjö, et al. 2011), none addressed this directly in a phenomenological study. Further, although Sweden has looked extensively at this population with a qualitative focus, as has the Berlin Aging Study with multiple methods, application of and generalizability to other populations outside of these countries and cultures may be limited. While it is out of sync with the current trends to focus on “successful,” healthy, positive aging, it must be addressed. Losses of all types daily enter the lives of our oldest-old, and most deal with it in a very graceful way, striving not to give it their full attention. This study listened closely to that



experience, heard of the successful and positive that emerged in this time of life, and held the purpose of describing and gaining understanding of this phenomenon of aging and its meaning to those living it. The hermeneutic/interpretive phenomenological approach which was determined to be the most appropriate for this exploration will be discussed in the following chapter.

## CHAPTER THREE

### METHODOLOGY AND METHOD:

#### SEEKING UNDERSTANDING FROM THE OLDEST-OLD

“We explain nature,  
But human life we must understand.”

*(Wilhelm Dilthey, 1976, in van Manen, 1990, p. 4)*

Aging is experienced by every living human being. Living into very old-age is an experience that has been described since Biblical times. It is not new and is in fact, considered quite desirable compared to the alternative. It has become common knowledge that with medical and technological advances, a higher percentage of the human population than ever before is aging into oldest-old age. Becoming more common-place, as described in previous chapters, there has arisen a temptation to view advanced old age as the ordinary extension of old age. It is partly this characteristic that makes aging a phenomenon pregnant with potential understanding for nurses and others working in healthcare. Van Manen (personal communication, Oct. 24, 2011) discusses the “lure of the quotidian” or the “lure of the ordinary.” We can respond to this “lure” to understand through the method of hermeneutical phenomenology as described by van Manen (1990). With our United States populations living ever longer lives, a phenomenological inquiry can have formative consequences for nurses by increasing our perceptiveness (van Manen, 2002b) and therefore our ability to care for the oldest-old among us. With health professionals accepting the mandate to use and apply knowledge to address and resolve health and illness problems of all populations in society (Thorne, 2008) the phenomenon of aging is particularly relevant to nurses. This study has provided a way to listen to the oldest-old, to examine this most ordinary, yet extraordinary experience of growing very, very old. Phenomenology has afforded a

naturalistic inquiry, a method to examine the everyday lived experience of aging with its losses and gains, from those who are living it.

According to Heidegger (1977), “Every question is a seeking. Every seeking takes its direction beforehand from what is sought” (p. 45). This chapter explains the selection of hermeneutic phenomenology as the methodology and method used to seek understanding of the phenomenon of living with loss and gain in the ninth and tenth decades of life and beyond. The research questions are explicated; the research design and rationale are provided. Sampling strategies and data collection issues of settings, methods of collection, and procedures for recruitment, consenting, and protection of data are described. Methods of phenomenological data analysis that were used and were oriented to seeking understanding of the lived experience of aging is set forth. Elements of phenomenology that has an impact on this study, such as the concept of fore-structure (Dreyfus, 1991; Johnson, 2000; Moran, 2000; Plager, 1994), and the hermeneutic circle (Johnson, 2000; Moran, 2000; Plager, 1994; Weiss, 1996) are also addressed.

### **Seeking Understanding: The Research Questions**

As described in chapter one, the prevailing question that had developed after years of work with persons living in the oldest-old years of life is the following: What is this experience of living with losses, and likewise gains or rewards, in advanced old age, when longevity is diminished and death moves ever closer? This is the “lure” of which van Manen spoke, the ‘what?’ that is behind the drive to understand. Understanding was also sought for these additional and similar questions:

- What counts as loss and what counts as gain for the oldest-old?
- What is the meaning found in loss/gain experiences for the oldest-old?

- How do we understand maintaining a meaningful “life world” while managing life in the oldest-old years of life?

Wrubel, Acree, Goodman, and Folkman (2009) have explored this notion of “lifeworld” with people living with a terminal illness; it has particular relevance for this study. Lifeworld, originating from the German word “lebenswelt” as originally used by Edmund Husserl (1859-1938), refers to “what individuals experience pre-reflectively, without resorting to interpretations (Dowling, 2007, p. 132). For Wrubel et al. (2009), lifeworld holds the definition offered by Agre and Horswill (1997) and refers to “the familiar world of everyday life, and specifically to that world as described in the terms that make a difference for a given way of life” (p. 64); in other words, that which provides context for aging. In exploring the lifeworld of the oldest-old, similar to Wrubel et al.’s (2009) perspective, effort was made to capture their meaning *in* life as they are experiencing the losses and gains of advanced old age in everyday life, not the meaning of life in a more existential way. Max van Manen (1990) also has much to say about this understanding of lifeworld. His perspective will be presented more thoroughly in the following section which will also describe why hermeneutic or interpretive phenomenology was deemed as well suited as the qualitative methodology for this exploratory study.

### **Methodology: Why Hermeneutical or Interpretive Phenomenology?**

The popularity of using phenomenology to understand nursing phenomena has been mounting over recent years (McConnell-Henry, Chapman, & Francis, 2009). As discussed by Dowling (2007), phenomenology has become a popular and appropriate means of pursuing credible and living nursing knowledge. However, phenomenological

approaches used are as diverse as are the phenomenologists who have explored and developed them. Husserl, Heidegger, Merleau-Ponty, Gadamer, Giorgi, and Ricoeur are a few of the phenomenologists who have developed various philosophies of inquiry.

### ***Research Design and Underlying Assumptions***

Heidegger, Gadamer, and Ricoeur, in particular have developed and expanded the movement of hermeneutic phenomenology (van Manen, 2011). Heidegger (1977) explains that generally “The expression ‘phenomenology’ signifies primarily a concept of method. This expression does not characterize the ‘what’ of the objects of philosophical research as subject-matter, but rather the how of the research” (p. 73). This “how” has taken on various forms. Crotty (1996), Caelli (2000), and Dowling (2007) discuss the contemporary distinction between European phenomenology and American “new” or “Continental” phenomenology, and their differing processes, concerns, and goals. The work of van Manen (1990), (which follows Heidegger, Gadamer, Ricoeur, Merleau-Ponty, and others), through his hermeneutic phenomenological approach to human science research and writing, guided this study which sought to understand the nature of living with aging in old-old age. As seen by Cohen and Omery (1994), van Manen’s writings use a combination of descriptive and interpretive phenomenology.

Phenomenology is described as hermeneutical when its method is interpretive rather than purely descriptive (van Manen, 2011). According to van Manen (1990), phenomenology is a human science which studies persons (p. 6.) and holds the task of constructing “a possible interpretation of the nature of a certain human experience” (p. 41). “A good phenomenological description is an adequate elucidation of some aspect of the

lifeworld—it resonates with our sense of lived life” (van Manen, 1990, p. 27). The experience explored here is that of living in oldest-old age.

For van Manen (1990), a primary characterization of phenomenological research is that “it always begins in the lifeworld” (p. 7) or the world of lived experience. Life world, the world of the natural attitude of everyday life also called the pre-reflective or pre-theoretical attitude (p. 7), is both the source of phenomenological research and the object of phenomenological research (p. 53). As stated another way by van Manen (1990), “phenomenology is the study of the lifeworld – the world as we immediately experience it pre-reflectively rather than as we conceptualize, categorize, or reflect on it” (p. 9). It succinctly asks the question of “what is this experience like?” from the view of the participants. Dowling (2007) points out that van Manen uses ‘Experience’ and ‘Phenomenon’ to mean the same things; this usage was held for this study as well.

Phenomenology also explores the tension between the universal aspects of an experience or phenomenon and the individual living out this experience of the phenomenon. On one hand, consistent with Husserl, phenomenology is the study of essences—a theory of the unique, a study of the essential nature of a thing, or of what this “thing” is and without it, it would not be (van Manen, 1990). On the other hand, hermeneutic phenomenology is also a study of the personal, the individual experience of a phenomenon. This is however pursued “against the background of an understanding of the evasive character of the logos, of other, the whole, the communal, or the social (van Manen, 1990, p. 7). What is this thing? And what is the everyday lifeworld experience of this thing for the individual? This tension creates a realm of possibilities for living out a phenomenon that may be common to the human lifeworld. In this study, essences of

losses and gains in the aging experience for the oldest-old were explored as the backdrop for understanding the nature or meaning of the everyday experiences of the individual.

An additional aspect of the lifeworld needs mentioning. Van Manen (1990) sees the exploration of the human lifeworld, the lived everyday situations, as the focus of all phenomenological research efforts. These thematic situations are seen to pervade the lifeworld of most if not all human beings regardless of how they are situated in terms of social, cultural, or historical influences. Although there are others suggested, van Manen (1990) identifies four of these “fundamental existential themes” as guides for phenomenological reflection and exploration: lived space (spatiality); lived body (corporeality); lived time (temporality); lived human relation (relationality or communality). Others have also seen these as significant to understanding in a phenomenological perspective. Temporality, corporality, and spatiality, are themes addressed by Heidegger, in his dense and complex works addressing what it means to be a person (Dreyfus, 1991; Fjelland & Gjengedal, 1994; Johnson, 2000; Leonard, 1994). As van Manen describes relationality (1990), it is similar to Heidegger’s conception of the person in the world as described by Leonard (1996). Hans Georg Gadamer’s (1900-2002) exploration of the role of language, human conversation, prejudice, historicity, and tradition in human understanding (van Manen, 2011) fits with van Manen’s theme of lived human relations. For Paul Ricoeur (1913-2005), hermeneutic phenomenology explores how language, storytelling, and narrativity, along with temporality impact meaning and self-identity (van Manen, 2011), also addressing issues of relationality. Phenomenologist Maurice Merleau-Ponty (1908-1961) has been a noted influence in the realm of corporeality, or using his terms, embodiment and bodily intelligence (Benner &

Wrubel, 1989; Dreyfus, 1996; Leonard, 1996; Moran & Mooney, 2002). It is not difficult to imagine the intricate manner in which these four themes are woven together to form the grounding from which we live our lives. And so for the oldest-old in this study, what did these existential themes “look” like from the end of life, in a frail body, and possibly from diminished space and community?

While each of these four themes clearly hold potential for discovery and understanding, the theme of temporality, particularly Heidegger’s temporality, helped to frame this study. Time is seen as a fundamental and unified whole, not as a series of ‘nows’ or events. It is this whole that needs to be considered when seeking to understand what gives a human being meaning in its being— the horizon from which a being is understandable (Johnson, 2000). Further, as explained by Johnson (2000), this dynamic structure provides the answer to Heidegger’s question of the meaning of being. As time has movement towards the future, human beings are always becoming and are “constituted by their movement into varied possibilities of what they could become” (Johnson, 2000, p. 138). Humans live in the now, the present, as influenced by our past, and projecting ourselves into the future; “time creates a story” (Benner, & Wrubel, 1989, p. 64). This basic structure of living-into-possibility is what is seen to create a story of meaning and significance for the individual, whether one has a full life ahead, or recognizes that one’s life is nearing its end. ‘Lived-time’ is the context through which one creates meaning for one’s life and chooses one’s own possibilities. As further asserted by Heidegger, future purpose is what gives present things their meaning (Johnson, 2000). For this study, knowing a participant’s personal life history and where they feel they are going (van Manen, 1990, p. 104) even in late life, created a context for understanding



their meaning and lived experience as it relates to living in advanced old age. The oldest-old have extensive personal histories and memories giving context to the now of their lives and the possibilities of their future, no matter how much future remains.

Three basic assumptions that are presented by Benner, Tanner, & Chesla (2009) in their interpretive phenomenological study also informed this research design. The first is the understanding that “human lives are situated within meaningful activities, relationships, commitments, and involvements that set up both possibilities and constraints for living” (p. 436). This study’s participants were of a specific generation that has commonalities different from younger generations. Opportunities, choices, and possibilities for life can vary simply due to when and where one is living their life. This notion of ‘situatedness’ reflects this understanding that one is never totally free or totally constrained in choices of how one sees and responds, acts and thinks. Dreyfus (1991) also relates Heidegger’s view that “human beings are never directly in the world; we are always in the world by way of being in some specific circumstances” (p. 163).

The second understanding or basic assumption, originally described by Heidegger, is that humans live in the world in an engaged, even practical way of daily activity. This ‘way’ of involvement is described through three modes of existence (Benner et al., 2009; Dreyfus, 1991; Plager, 1994). The ‘ready-to-hand’ mode is the full and unreflective, taken-for-granted engagement in everyday activity. This mode is where most everyday human activity is focused (Plager, 1994). A second mode is identified as the ‘un-ready-to-hand’ mode and refers to the times when taken-for-grantedness is disrupted by something unexpected; when there is a breakdown in the normal way things should go that requires one to consider alternative possibilities (Benner et al., 2009).

Things are disrupted, but one is still involved in activity. It is in the 'present-at-hand,' or the third mode, where the flow of everyday activity stops, and when the real breakdown occurs. Here one stands removed from the situation to theoretically and objectively reflect, and rework an understanding or an explanation. Scientists typically view understanding through this third mode, seen by Heidegger as a deficient approach (Plager, 1994). Hermeneutic phenomenology sees the 'ready to hand' mode as offering the most direct access to human phenomena, focusing on the practical everyday life of human activity that is basic and more difficult to describe (Benner, 2009; Plager, 1994). The 'unready-to-hand, or more reflective mode is also seen as helpful to understanding (Plager, 1994).

The notion that humans engage in their world in a way that is "set up and bounded by what matters to them" (Benner et al., 2009, p. 437) is addressed in the third assumption that helped inform this research design. What one sees or doesn't, how one acts or doesn't, is set up by the things that concern the person or matter in one's lifeworld. Together these phenomenological assumptions, as part of the fundamental consideration of Heidegger's 'being-in-the world' (McConnell-Henry et al., 2009, p. 9), support the consideration of what it means to be. Johnson (2000) reminds us that for Heidegger, "death is the ultimate and most fundamental meaning-giving possibility" (p. 138). This idea is highly apposite to this study. Meaning for the oldest-old, whether reflected upon or not, is considerably influenced by finitude and the approach of death.

As contemporary research and theorizing are focusing on the successes of aging, and medicine and technology are prolonging lives, it is a time (as originally stated by Husserl) "to go back to the things themselves" (van Manen, 1990, p. 45) and see if these

constructed frameworks are true to the lived experience of our oldest-old. It is time to return to the oldest-old themselves to inform our understandings of advanced aging and its meaning from those actually living it. Collecting narratives and stories as text and data, is one way to contextualize and reveal the meaning and significance of lived experiences of those in their very late years of life.

### *The Hermeneutic Circle*

According to Heidegger, all questioning or inquiring develops from and carries with it certain assumptions and presuppositions that guide the inquiry, predetermine what questions are asked, and govern “to a certain extent, what can be discovered” (Moran, 2000, p. 237). What is termed the “hermeneutic circle” describes the manner in which we interpret our world through presupposed understandings of shared practices, cultural and personal histories, and current personal and social insight that both shape the questions we ask and the interpretations we offer (Moran, 2000; Plager, 1994). As explained by Weiss (1996), interpretation is central to human understanding of human concerns and further, interpretation is always situated in our point of view, not completely detached and objective. This hermeneutic circle is not to be seen as a vicious circle of circular reasoning, but a back and forth movement between questioning, phenomenon, and further questioning. Our questioning is seen as a type of light that casts a pattern on a phenomenon, or lived experience, that fills in our presuppositions in a way that stimulates further questions, which results in further understanding (Johnson, 2000; Moran, 2000). There is however, according to Heidegger, a right way to ‘leap’ into the hermeneutic circle of interpretation and understanding. The right way for the researcher to leap in is to lay out beforehand assumptions, preconceptions, biases, and

current understandings that make the study significant to the researcher and that may impact the conceived understandings and shape interpretations that result from the investigation (Plager, 1994). We must be alert to that within us that gives rise to the question and interpretation or likewise, covers them up (Moran, 2000).

### ***Entering the Circle: The Fore-Structure***

To enter into an interpretive study influenced by Heidegger and those that base their methods on his philosophy, one must first reflectively examine the pre-understandings with which one approaches the inquiry. Moran (2000) explains Heidegger's thinking, "every seeking gets guided beforehand by what is sought" and further, "the kind of answer we get depends on our way of posing the question" (p. 236). In light of this, entering the circle requires the investigator to lay the foundation by examination of his or her fore-structure. It is this fore-structure that connects understanding to interpretation (Plager, 1994).

There are three aspects of this fore-structure (Dreyfus, 1991; Johnson, 2000; Moran, 2000; Plager, 1994): The first is the *fore-having*, the practical familiarity that one brings to the phenomenon or lived experience that makes interpretation possible. *Fore-sight*, the second aspect, is the point of view from which one develops an interpretation. The third, *fore-conception*, is the expectation of what to anticipate in the interpretation because of one's background with the phenomenon or experience (Plager, 1994).

### ***Laying out My Fore-Structure***

As an Anglo-American middle-aged wife, mother, daughter, sister, granddaughter, nurse-in-practice, Christian, academic professional, I had a many-chaptered story that I brought to this inquiry of the experience of aging. Although how I

became “lured” to this exploration of advanced old age was briefly related in chapter one, I describe it more fully here in this description, even confession, of the fore-structure I brought to this interpretive project. Being English speaking, third-generation white-American, creates in me a certain worldview endowed with a western, middle-class perspective on life and living that provides a background of experiences and understandings with those that share this tradition and the common meanings this provides. In Heideggerian language, this is how I was “situated” for this study and what I brought to those that became participants for this hermeneutic, interpretive study.

As my mother died when I was 30, I have had a closer relationship with my father than I otherwise might have, observing and participating in his journey into the oldest-years. He is currently 89 years of age. His mother, and my mother’s mother both lived long lives of considerable health until their early eighties when they both developed chronic diseases that led to difficult and debilitated lives; one by stroke, the other by Alzheimer’s disease and type 2 diabetes. My father has said many, many times that life changed for him at age 80. He was in excellent health prior to that. Having been an avid runner for much of his mid-life and early old-age he maintained excellent health. Arthritis and one knee replacement slowed things down at 82; as atrial fibrillation and a pacemaker continued to do at 84. A second knee replacement and osteoporosis related fractures further impacted his physical abilities at 85 and beyond. In spite of this, my father has remained very positive. He is by nature an optimist and focuses on his relative good fortune, seldom talking about his pain, or disability.

Two recent “incidents” made a significant impression on my thinking about him and his experience of these very late years. When he was hospitalized for his second

knee replacement, he had a relatively pain-free post-operative experience. He was jovial, expressing appreciation for all of his caregivers which resulted in reciprocal appreciation of him by them. It was a pleasure to see. If he had to be there, this was the ideal situation. Sitting by his bedside one of those afternoons, I decided to try out an interview question I was pondering. “So dad, can you tell me something positive about being your age?” “Pppphhh! No!” he immediately and jovially replied, laughing as he said it. Of course, being ever-optimistic, he then related how fortunate he was to have relative good health, own his own home, and be financially secure. However, I took his spontaneous and quick initial reply as very telling. But he would not allow himself to stay in that frame of mind.

A second very recent incident was a much simpler, but equally telling moment. Getting into his car to drive home from my house, he had some difficulty fastening the seat belt. He sighed and said “Boy Julie, I tell ya. . . .” Sensing his frustration, I said “Dad, it looks hard.” “No, it’s not hard . . .” was his initial reply, followed by “it’s just . . . [long pause] . . . hard.” This of course was followed by laughter for us both, but again this was telling. It *is* hard. I approached this study of the lived experiences of oldest-old age with the perspective of aging being hard.

Being fourth in a large family of 11 children, my father has also experienced the deaths of his two older brothers. One of them, just 18 months older than my dad, who could also have been considered his best friend, died four years ago. Most recently a sister, the oldest in the family, the matriarch who was an inspiration to all who knew her, died at age 93. While recognized as significant losses, there has been resistance to having much conversation about how these experiences have been for him. Of course by

the age of 89, there have been other losses of friends, not to mention the loss of his wife, my mother, 30 years ago. Losses of hearing, a diminished social life, and losses of the pleasures of running, fishing, swimming, and gardening that have become minimized or nonexistent add to the list of changes in his life. Recently, this former avid runner met my son at the finish line of a marathon, resting on a walker. The photo I took reflects much about the process of aging for a very resilient man.

A parallel journey of mine has been the years spent at the Neighborhood Wellness Center run by the School of Nursing where I teach. First as a clinical nursing instructor on site, and then as the director, I have spent almost 16 years working with nursing students and our visitors there. Over these years there have been several older persons that I have come to know well and visit with often. Like my father, these individuals have also experienced various bodily changes and challenges. These include losses of physical abilities, family and friends, and losses of various significance and meaning such as independence, ability to see and hear, to drive, to go for a walk, and to have a pain free day. Their worlds seemed to have gotten smaller, many of them seeing their daily lunch at the senior center as being the only thing that enables them to get out of their home. And even there, losses of course occurred often. The chair next to them at the lunch table may be empty the next day.

Recently, a beautiful 86 year old woman whom I have known for over 12 years had stopped taking some newly prescribed medications for her newly diagnosed heart failure because "I'm not feeling any better." After I took her blood pressure and pulse, we discussed her condition, the purpose of the medications, and some symptoms she was feeling, particularly her shortness of breath. When I very strongly encouraged her to take

her medication and make an appointment to see her doctor, she stated these beautiful words: “I am sorry, but I’ve never been this age before.” We both laughed, but recognized that she had no experience being this old and this unhealthy. She just didn’t know how to “be” that, how to behave as an “old, sick person” as she stated.

So as my fore-having, I came situated in a world where people live long, but are eventually confronted with very difficult obstacles to wellness, health, and even dignity. I came very familiar with the journey into what is considered oldest-old age. My fore-sight is admittedly from the western American perspective that activity, productivity, independence, and mobility are highly valued and life without them is difficult and possibly depressing. Self-worth and hope can be challenged. Further, I wondered if the successful aging people are just trying to protect us all from the eventuality that life takes a course that we cannot control, and the possibility of a time in oldest-old age when our hope, purpose, and even human dignity are relentlessly overwhelmed. A fore-conception, perhaps in the form of a confession, was my expectation of what I might find in an interpretation of the lived experienced of oldest-old age is that losses do outweigh the gains of advanced old-age. This all then, was my fore-structure. I wondered how they do it. How do they live with these mounting and frequent losses? What is it like? What is this experience of losses like when one is near the end of one’s life? Are they seen as losses?

While the formal research questions for this study are addressed below, these questions floated around in my mind waiting for a time to talk with informants that are living this aging experience every day. I sought to listen and interpret what they conveyed in a manner that is clear and truthful in representing their experiences, not my



perceptions. By laying out these fore-structures, I hoped to recognize my own assumptions and understandings of aging and make way for those that are revealed to me. As stated by van Manen (1990), “The problem of phenomenological inquiry is not that we know too little about the phenomenon we wish to investigate, but that we know too much” (p. 47), or at least we think we do. If we try to ignore, or pretend we can forget what we know, our assumptions, pre-understandings, constructed theories, beliefs, biases, suppositions, etc., may persistently “creep back into our reflections” (p. 47). The hope still is that I came to terms with them, held them at bay, and used these questions to enter the hermeneutic circle that took me from these questions to the lived experience, to further questions, to further lived experience, and ultimately to understanding and interpretation of meaning as revealed by those living in oldest-old age.

### *To Summarize*

To summarize succinctly, hermeneutic phenomenology was used here to answer questions of meaning and to seek understanding of the aging experience by those living it. According to van Manen (1990) phenomenology conveys how one orients to everyday lived experiences. Hermeneutics describes how one interprets these life relating texts; it is the theory and practice of interpretation (van Manen, 1990, p. 178). It is further suggested (Cohen, Kahn, & Steeves, 2000) that phenomenology be used when beginning to study a new area of interest or one in which a ‘fresh perspective’ is needed (p. 3). With lives being extended, with a recent preoccupation with successful aging at younger old ages, and with a neglect of an exclusive understanding of the oldest-old, a fresh perspective and ‘a return to the things themselves’ was seen as needed. This new qualitative exploration of the process of aging, with its potential for accumulated loss and

gain in this time of very late life, offered rich and fruitful insight into the lives of the very old among us. In the inspirational words of van Manen (1990) “To the things themselves” and “let’s get down to what matters!” (p. 184).

## **Method**

### *Sample*

This study sample consisted of 13 oldest-old participants, who are community dwelling individuals, 85 years of age and older. Purposive sampling ensured that the individuals selected were able to inform an understanding of the phenomenon of aging under study. Inclusion criteria other than age included the ability to participate in a narrative interview and communicate in the English language. There was an attempt made to have an even number of men and woman, with various races and ethnicities. These persons lived in the broad Southern California area. Participants were identified through word of mouth to known qualified individuals.

Each of the 13 individuals were interviewed three times, as planned. This resulted in a total of 39 interviews for narrative data. The final sample involved eight females and 5 males, the youngest being 87 and the oldest being 100. Eight participants were Caucasian. Three Hispanic women and two African-American woman were purposefully sought, to bring ethnic and cultural diversity to the sample.

Nine participants lived alone; Five of these in either senior apartment complexes, retirement communities, or residential/independent living communities. Eight lived in private homes. Only four participants lived with family members. All participants had at least a high school education; seven had college degrees, with three having advanced

degrees. The financial situations of the participants ranged from having much more money than was needed to just barely making financial obligations.

### *Setting*

Interviews were conducted in the setting that was preferred by the participant. Home visits or visits at a relative's house were suggested as these are usually locations where older persons feel most comfortable, unreserved, and at ease. This supported their ability to relate their lived experiences of aging. It is recognized that these participants are part of a generation born in 1927 or earlier who were Great Depression era children and World War II young adults that bring a historical context to their lives. In the U. S. this is a group that also experienced the discovery of penicillin, struggles toward racial equality, the eradication of small pox, landing on the moon, the explosion of computer technology, and the mapping of the human genome. Different from other age groups, this cohort now consists of more woman than men, have high numbers that are institutionalized, most likely have some form of chronic disease, and consume more health-care dollars and medical services than other age-cohorts. They are admittedly the survivors, out-living most of their fellow sojourners. For many this includes spouses and children; they are growing old and frail as widows or widowers.

### *Method of Data Collection*

The world of the lived experience is “the source and the object” of phenomenological research” (van Manen, 1990, p. 53). As such, this lived experience of aging was seen as the source of the data, object of the method, and focus of the data collection. The stories of narratives elicited enabled the meaning and significance of the aging experience to be revealed (Benner & Wrubel, 1989). Johnson (2000) supplies the

reminder that Heidegger's notions of *being-in-the-world* and *temporality* see our lives as unified wholes within involvements that matter to us and create meaning. Therefore, the narrated experiences and meanings of the participants' experiences were not viewed separately but from the whole of the participants' world. A practical understanding of this notion is that "a single experience is inseparable from its context of involvement" (Johnson, 2000, p. 139) and therefore in this study, meaning was not understood as an isolated entity. Thus the context of the interviewee's experience, the life story, was explored in an effort to understand the whole and the parts. The interest was in the interviewee's understanding of the experience and the meaning of it within the context of his or her world.

Using semi-structured interviews to keep the interview focused on the phenomenon of aging, participants were asked questions in three separate interview sessions in order to gain insight first into the context and story of the participant's life and second to stimulate the telling of instances of living with loss and gain in oldest-old age. Interviews were spaced approximately 3 to 4 weeks apart and sought to gain multiple stories relating instances of loss, gain etc. Questions on the first visit focused on gaining context and understanding the individual's history as well as initial stories and instances that reflected experiences of aging in their current everyday life. The second visit focused first on questions regarding the current typical daily routine of the participant and second on gaining additional stories of aging experiences. Given the importance of the narrative stories, the third visit provided opportunity for additional narratives, reflection with the participant, and final closure. It was recognized that with interviewees of very old age, there needed to be sensitivity to issues of stamina, fatigue, and memory. On a

couple occasions, shorter interviews were chosen to ensure that the interview not be a burden nor cause undue fatigue.

### **Nature of the Interview.**

As explained by van Manen (1990) the point of phenomenological research, and therefore the interviews and interview questions, is to “borrow” from the participants their experiences, reflections, and stories in order to gain understanding “of the deeper meaning or significance of an aspect of human experience, in the context of the whole of the human experience” (p. 62). The goal then to become and remain oriented to asking the question of what is the nature of this phenomenon of aging as an essentially human experience (van Manen, 1990). In a hermeneutic phenomenological study the interview serves two specific purposes. The first being a means to explore and gather experiential narrative text which offers a resource for interpretation that enables one to develop a deep and rich understanding of the phenomena of interest, for this study that of aging. The second purpose is to develop a conversational relationship with one living the experience, the interviewee, about the meaning of their experience. Van Manen (1990) points out that this interview process needs to be a process with discipline, one that remains oriented to the research question and the purpose of the interview. As succinctly stated by Smith, Flowers, and Larkin (2009), it is ‘a conversation with a purpose’ (p. 57). It was therefore recognized that the interviews needed to have enough structure or concreteness, to support the objective of gathering narrative about specific instances, situations, or events. These instances were explored to the fullest.

### **The Initial Interview.**

In seeking to gain a context for the participant's current aging experience, an interview format was used during the initial interview that first focused on eliciting general demographic information and a brief narrative about his or her life story in a historical sense. I learned what stands out for them as significant in their life in years past, and what stands out as significant in everyday life in the now. A demographic tool was developed to get initial facts about the participant's life circumstances (see Appendix A). The second interview guide was designed to guide the participant in relating a brief life history, or story (see Appendix B). Instances of the experience of aging that were of interest were actually discovered during the first section. Probing questions that are described below were used to gain access to the experience and not lose the spontaneity of response and the particularly relevant and rich data that was revealed.

When time and participant energy allowed, the Experience of Aging interview was also initiated (See Appendix D). Personal life stories in the form of instances, anecdotes, and specific experiences are the valuable data and goal of the narrative interview of phenomenological research. This semi-structured interview, with the goal of eliciting specific instances of the losses and gains experienced by the oldest-old and the meaning of these experiences, was developed. Due to the nature of the unfolding qualitative interview, and each individual's distinctives, comfort, and penchant for sharing life stories, each interview evolved in a natural and unique manner created by the interviewee and me.

Every effort was made to stay close to the experience as lived by the participant and to encourage a description of each shared instance to the fullest. Concrete questions

were asked as follow up to responses to the interview guide questions. Questions such as “How did you feel about that?”; “How did you handle that?”; “Who did you share that with?”; “What were your thoughts at the time?”; “How did you talk about it with your daughter/son?”; “What was the hardest/best part about that?” were asked to elicit rich and full narratives. While it is impossible to list all exploratory questions that developed, the goal was to keep close to the experience as it was lived and away from generalizations.

### **The Second Interview.**

The focus of the second interview was to explore the current daily life of the participant and what stands out to them as significant in life now, and to again encourage descriptions of specific instances of the lived experiences of aging. A third tool was developed to assist in gaining an understanding of the everyday life as it is currently experienced by the participant (see Appendix C). This was designed to reveal what remains salient and meaningful in the participant’s life as they daily experience aging at this late time of life. As previously discussed, rich data was revealed through this portion of the interview therefore the probing questions described above were also used when helpful.

The Experience of Aging interview (Appendix D) was used again and either resumed from where we left off at the end of the first interview, or re-introduced to prompt thinking of additional and/or new experiences from the previous 3 to 4 weeks. Any questions of confusion about text from the previous interview was reviewed and explored again with the participant.

### **The Third Interview.**

This final interview provided opportunity to hear additional responses to the Experiences of Aging questions, and allowed for reflection and closure with the participant. More stories offered more text and added narratives to support fuller recognition of patterns of meaning and more informed interpretive analysis. Summary questions (see bottom of Appendix D) were asked to provide one final opportunity to listen to what the oldest-old wanted me and others to know and understand about aging and being very old. Through these interviews the experiences of very old persons were “borrowed” to enable me to become more experienced with aging and come to an understanding of the significance or deeper meaning of aspects of aging within the context of the whole of one’s life. And further, these experiences allowed me to suggest an answer to the question of what is the nature of the phenomenon of aging while very old, as an essentially human experience.

## **Procedures**

### ***Recruitment and Consent***

IRB approval was obtained from Loma Linda University prior to all recruitment efforts. Participants were identified through word of mouth to known qualified individuals. Local senior center personnel, professional acquaintances, and other participants were asked to consider referring acquaintances, friends, and relatives to the researcher. They were given the contact information of the researcher and encouraged to initiate the first conversation. Each participant was asked to give verbal consent allowing me to visit them in their home or other preferred location. At the first meeting, the study purpose and methods of the study were explained, and the participant was encouraged to



ask questions and seek clarification. The consent form was read aloud to each participant. Signed informed consent, including permission to be audiorecorded, was obtained from all participants. They were made aware that their participation was completely voluntary and that they had every right to not respond to any questions and/or to withdraw from the interview and/or the study at any time without penalty.

Return visits were also conducted at a time and place convenient for the participant, and were scheduled for the second and third interviews. All consenting participants were interviewed by the author. Participants were reminded that they could withdraw from the study without consequences and refuse to answer any of the interview questions. Each interview was recorded with a digital recorder, and later transcribed and analyzed according to the phenomenological approach described below.

### ***Protection of Data***

All identifying information was kept separate from the audio recordings, field notes, and transcriptions and locked when stored. Recordings were transcribed with no names or other identifying information included. After each transcription was completed, the transcript was reviewed for completeness and to ensure that any identifying information was removed.

### **Method of Data Analysis: The Interpretive Task**

Guidance for data analysis in this study was sought in the hermeneutic and interpretive phenomenology methods of van Manen (1990), and Benner (Benner, 1994; Benner et al., 2009) and the interpretive phenomenological analysis (IPA) of Smith, Flowers, and Larkin (2009). The data for this study consisted of the narrative texts that resulted from the participant responses to the questions and prompts from the interviews

described above, as well as field notes, observations, and reflections. Van Manen (1990) posits that there are not formalized techniques or procedures for phenomenological inquiry methods; it is not a “rule-bound process but a free act of ‘seeing’ meaning” (p. 79). Smith et al. (2009), also relate that there is a “healthy flexibility in matters of analytic development” and no clear right or wrong in matters of phenomenological data analysis. While encouraging creativity and innovation, they also seek to provide the novice with a starting framework for data analysis.

The work of hermeneutic phenomenology is interpretation with the goal of understanding human concerns and experiences. Narrative texts that were elicited in these interviews have captured the human experience of aging, and the everyday involvement with the losses and gains in very old age. The analysis of the text through reflection and writing sought to grasp and explicate the meaning of this experience. Van Manen (1990) calls this crafting of text by the researcher “textual labor” (p. 78). Thematic analysis was the primary strategy for this reflection and interpretation. Two additional strategies, identification of exemplars and paradigm cases, suggested by Benner (Benner, 1994; Benner et al. 2009) support the interpretive process.

### *Thematic Analysis*

Thematic analysis is “the process of recovering the theme or themes that are embodied and dramatized in the evolving meanings and imagery of the work” (van Manen, 1990, p.78). Themes are viewed here as structures to the experience of aging through which meaning can be found. Further, a theme is seen as the experience in our focus that captures some aspect of understanding being sought. Identifying themes comes from the desire to make sense of some experience, by being open to what is

embedded in the narrative, and the processes of insightful discovery, invention, and disclosure. Themes are useful ways of getting to the meaning of an experience and giving shape and content to a 'shapeless' notion (van Manen, 1990). An apt description offered by van Manen is that themes are "like knots in the webs of our experience, around which certain lived experiences are spun and thus lived through as meaningful wholes" (p. 90) that allow for phenomenological descriptions.

Steps for thematic analysis suggested by Smith et al. (2009, pp. 82-107) that guided this analysis involved the following:

1. Reading and re-reading: Immersing myself in the narratives starting with the first written transcript facilitated the process of entering the world of the participants and ensured that they were the focus of analysis.
2. Initial noting: Being very close to free textual analysis, initial noting familiarized me with the text as I examined the semantics, language, and anything of interest. The goals were to make a detailed, thorough, and comprehensive set of notes on the narrative texts and to engage with the data. This process yielded descriptive, linguistic, and conceptual comments that focused on meaning and things that mattered to the participants.
3. Developing emergent themes: This phase was conducted using both the interview narratives and the notes gleaned from above and the continuous back and forth process between the whole of the parts within interviews, between interviews, and my notes. This process was one that moved me toward themes and interpretation and away from the actual text while staying true to experiences related in the text by the participants.

4. Searching for connections across emergent themes: Drawing together emergent themes and looking for a “structure” allowed for identification of those aspects of the narratives that provide for understanding of the experiences and meaningful patterns lived by the participants. Methods of abstraction, subsumption, identification of polarized themes, and attending to the contextual influences, are approaches that were used as connections across themes were considered.
5. Moving to the next case: Considering each interview on its own terms and repeating this process was important in order to hold on to the individuality of each narrative. Recognition that my fore-structure was changing from the influences of each interview was important and was identified in my notes. New questions or lines of inquiry developed from previous interviews and were explored in subsequent interviews.
6. Looking for patterns across cases: Examining how themes surface and illuminate or distort across cases was a vital process towards understanding. Identifying themes with higher and lesser importance, reconfiguring, relabeling, and re-describing themes was done. A back and forth movement from the parts to the whole, and the whole to the parts informed interpretation. The parallel movement into the hermeneutic circle of fore-structure to text and back, was another ongoing process of informing interpretation.

To this process, I added the notion of incidental versus essential themes as described by van Manen (1990). In determining the themes around which my phenomenological description and interpretation will be woven, some were deemed more significant and/or universal than others. This differentiation is seen by van Manen as the

most difficult and controversial element of phenomenological study. The concern is to discover or uncover the qualities or aspects of the phenomenon that makes it what it is, and without them it could not be what it is. This seventh step was added to my “process” which involves the method of free imagination (van Manen, 1990). The researcher asks the question: “Is this phenomenon still the same if we imaginatively change or delete this theme from the phenomenon?” Or, does it lose its “fundamental meaning?” (van Manen, 1990, p. 107). In this manner, essential themes and meanings of the losses and gains of the aging experience were identified.

Van Manen (1990) also speaks to three approaches that assist with uncovering thematic statements and isolating thematic aspects of the phenomenon. In reading the text as a whole, the question asked was “What phrase may capture the fundamental meaning, salient aspects, or main significance of the text as a whole?” (p. 93). When reading selectively over particular sections, the question was “What statements or phrases seem essential or particularly revealing about the experience being described?” And thirdly, when reading line-by-line and sentence by sentence, the question of “What does this sentence or sentence cluster reveal about the phenomenon or experience being described?” was asked. Through these approaches, certain experiential themes recurred and commonalities were discovered. “The task is to hold on to these themes by lifting appropriate phrases or by capturing in singular statements the main thrust of the meaning of the themes” (van Manen, 1990, p. 93).

This order is explicated in a sequence that appears much more orderly than the process of thematic analysis actually was. However, being a novice in phenomenological research, the structure of the Smith et al. approach (2009), the strong interpretive

approach of van Manen (1990), and the use of exemplars and paradigm cases of Benner et al. (2009) described below, provided a strategy for the interpretive process that led to a meaningful and truthful understanding of the text and lived experiences as related by the oldest-old participants.

### *Paradigm Cases*

Identifying paradigm cases (Benner, 1994; Benner et al., 2009) was an additional strategy that was used to gain understanding of textual meaning from the participant's concerns, meanings and experiences. Paradigm cases for this study were those that offered vibrant examples of the aging experience, revealed different ways that one can live out being old (L. SmithBattle, personal communication, May 29, 2013), and provided strong instances of losses, gains, and other experiences described by the narrators. In studying these cases, the aim was to understand these aging situations within the practical, everyday world of the oldest-old participants with all the possibilities, constraints, and realities involved. Each text of the identified cases were examined first as a whole then further analyzed in a line by line manner, or instance by instance manner. The movement back and forth from parts to the whole of the narrative allowed me to enter further into dialogue with the text and gain an in-depth understanding of the concerns, actions, and meanings of the participant (Benner et al., 2009).

### *Exemplars*

Throughout the reading, analysis, and interpretation of the narratives there was an examination of the text for exemplars. Exemplars are short stories or small vignettes which capture or demonstrate meaning or understanding revealed through thematic analysis or the paradigm case (Benner, 1994; Weiss, 1996). They can be seen as

substitutes for operational definitions in interpretive research, present a range of attributes of a particular concern, meaning, or theme, and emphasize similarities and distinctions (Benner, 1994). In this way they provided deeper understanding of the narratives offered by the oldest-old and help fill in the story of aging.

### ***Field Notes***

Field notes, written before and after each interview consisted of researcher reflections, reactions, thoughts, and analyses and contributed to the collected data. Observations made during participant interviews were entered as well. These notes aided in identifying aspects of the fore-structure that influenced description, understanding, and interpretation.

### ***Data Analysis Tools***

While use of data management software is popular, the importance of knowing the data inside and out was of primary importance. Software is not needed for that and was deemed unnecessary. Printouts of the transcribed narratives allowed for uses of color coding, and post-it labeling to allow for identifying similar themes. SmithBattle (2010) describes the creation of “Interpretive Profiles” that consist of electronically copied & pasted pieces of text that address the research questions and identified themes, along with the researcher interpretive commentary. These profiles were compiled for each participant.

### **Evaluation of the Interpretive/Hermeneutic Phenomenological Inquiry**

For van Manen, “A good phenomenological description is an adequate elucidation of some aspect of the lifeworld – it resonates with our sense of lived life” (1990, p. 27). The term ‘phenomenological nod’ is used to describe an interpretation that is a

recognizable experience we either have had or can imagine having. The ‘validating circle of inquiry’ indicates a “good phenomenological description that is collected by lived experience and recollects lived experience—is validated by lived experience and it validates lived experience” (van Manen, 1990, p. 27). In this spirit, the final evaluation is to be known by my interpretive writing. Does it “ring true” to the sensibilities of the reader? Do I demonstrate the interpretive flow from phenomenon to questions, to interview, to analysis, to conveyance of this process in my interpretive writing? That remains my hope.

There is relative consensus among qualitative commentators that a clear standard for evaluating qualitative research in a manner that is appropriate to the method, as reliability and validity are for quantitative methods, is not universally established (Angen, 2000; Benner et al., 2009; Corbin & Strauss, 2008; Creswell, 2007; Leonard, 1994; Smith et al., 2009). Angen (2000) contributes to this ongoing discussion by offering the concept of validation over validity, with the dual aspects of ethical validation and substantive validation. The former requires that the aim of interpretive inquiry is to offer thoughtful, caring, practical, generative and even transformative answers to the questions posed and insight pursued. The latter requires that the researcher provides a chain of interpretations that is described and documented in such a way that others may “judge the trustworthiness of the meanings arrived at in the end” (p. 390). Angen sees that validation ultimately depends on not only the abilities of the researcher but the characteristics of him or her as well (2000, p. 391). In short:

In interpretive inquiry there is no choice but to be responsible for choosing, and much of the craft of the inquiry process lies on the shoulders of the person conducting the investigation. As investigators, we



are responsible for choosing topics that have practical value; our research should be both relevant and beneficial to those concerned (Angen, 2000, p. 392).

It is hoped that these criteria for validation were met. I see this pursuit of an understanding of the losses and gains, disappointments and surprises, in the lives of the oldest-old through interpretation of their narratives and stories as offering enhanced understanding of their aging experience. The result is, for nurses and others that serve them, to offer more insightful and meaningful care and support as they live out their lives in dignity.

More recently, Smith et al. (2009) have promoted four broad principles proposed by Lucy Yardley (2000) for evaluating the quality of qualitative research. These principles along with those suggested by Angen provided guidance for conducting a high quality interpretive study:

1. Sensitivity to context: This sensitivity was demonstrated to cultural context of the current generation of oldest-old, to awareness of the current literature, and to the appreciation of what the interactional nature of the interview process meant to the participants and how they made sense of their experience. Sensitivity to the data was respected through the use of verbatim narrative extracts to demonstrate the interpretive conclusions.
2. Commitment and rigour: Commitment was demonstrated by staying attentive to the participants during data collection and remaining attentive through the analysis of each narrative. Rigour addresses both the “goodness” of the interview, the ‘thoroughness’, and the ‘in-depthness’ of the interpretation;

pushing beyond a mere description of aging to the interpretation of meaning to the participants.

3. Transparency and coherence: A clear and careful description of the stages of my research process is presented and described in this final write-up. Every effort has been made to present coherent arguments and themes that ‘hang together’ logically. The study approach also demonstrates fit with hermeneutical phenomenological assumptions and sensibilities, particularly through staying close to ‘the thing itself’.
4. Impact and importance: Every effort has been made to relate to the readers something that is “interesting, important or useful” to the understanding and care of the oldest-old among us (Smith et al., 2009, pp. 180-183).

Van Manen (1990) also offers a clear exhortation to commitment through his artful words:

Human science research is rigorous when it is “strong” or “hard” in a moral and spirited sense. A strong and rigorous human science text distinguishes itself by its courage and resolve to stand up for the uniqueness and significance of the notion to which it has dedicated itself (p. 18).

### **Conclusion**

Experiences of loss and gain, and of disappointment and surprise during oldest-old age are seen not as isolated and singular experiences but also part of a unified whole of a very long and continuing life. These experiences continue to shape and influence as well as be shaped and influenced by the participant’s past and ongoing interests and concerns. Thus meaning can continue to evolve as something present to the participant. The methodology and methods described in this chapter are seen as an appropriate, even

necessary approach, to bring us into more direct contact with the world of our oldest-old. Through this attentive listening, and the resulting interpretations, greater awareness of the range of meanings in this phenomenon of aging, as it is lived by the aged in their everyday life, can be offered. Heidegger (2002) reminds us “we must *keep in mind* that the expression ‘*phenomenon*’ signifies *that which shows itself in itself*, the manifest” (p. 279). There is the potential to impact the way nurses, and our society as a whole, seek to support and care for our oldest-old in their final years through that phenomenon of aging that manifests here.

### **The Method as Lived**

As this experience of seeking to understand the experience of aging through this method unfolded, it revealed itself to be a tremendously challenging yet fulfilling process. Participants were found rather quickly. After the first seven participants were enrolled, it was realized that a purposive effort needed to be made to create a more diverse sample. Not surprisingly, the only two refusals were from persons of color. The five non-white participants proved to be diverse among themselves with profound stories to tell.

Interviews began in September of 2013 and ended in May 2014. All recording and transcribing went smoothly. Notes were taken before, and after each interview to capture researcher thoughts and emotions in the moment. With each participant’s interview process, the first interview was listened to immediately before the second, and likewise the second immediately before the third. Notes were taken of any questions that arose in the review and any clarification that was needed about interview content. In addition, this allowed for a re-emersion in each participant’s specific life and stories as

the researcher was involved in multiple interviews throughout the data collection time period. All but one participant was able to follow the time frame of three to five weeks between. The one exception had a serious illness that resulted in two and one-half months between the first and second interviews. Re-listening to the interviews and reviewing the notes taken were essential to stay “in touch” with the uniqueness of each participant’s life and experience.

Highlighting and post-it tabs were used to color code topics and themes across all interviews, as well as to tag potential exemplars and themes singularly unique to individuals. The second review of the interviews involved listening to the audio-recordings while simultaneously reviewing the typed transcripts and highlighting and tagging with a pre-determined color coding technique. The third review of the written transcripts involved using the template of Smith, Flowers, and Larkin (2009) to identify emergent and recurrent themes as well as documenting ongoing researcher exploratory comments and questions. This proved to be a time-consuming and tedious process. However, it was valuable to have some initial structure to provide direction and consistency.

Some interviews proved to be very dense and rich with data, other interviews less so. All interviews however were honest and revealing of the experiences of those living very long lives. The attempt here is to convey the lived experiences discovered through the interviews in a manner that is illustrative and true to the words and lives of each participant. Aging has presented itself in a similar manner to all of the participants, yet each responds uniquely. In their “situatedness”, their long lives have fashioned

responses, possibilities, constraints, and decisions that are theirs alone; their created life habits continue to guide their days.

As was suggested by Schuster (2013), the concern in this interpretive study was not to see what is hoped to be seen and ignore other possibilities that are offered through the narrative texts as told by the participants (p.12). After completion of the interviews, the importance of sustaining the integrity of the words of these oldest-old individuals and of avoiding arbitrary interpretations influenced by preconceptions was heightened. The honesty, trust, and transparency of these remarkable participants created a heavy desire to be a good steward of their integrity and truth.

Much of what was conveyed was done so with words. However, as hermeneutic phenomenology is an interpretive journey not only descriptive, the lives and ‘findings’ are also interpreted and presented through the eyes, mind, experience, and heart of the researcher. What could be found in this rich and dense data of narrative, is seemingly endless. The work presented focuses on addressing the research questions posed earlier.

In organizing the remaining chapters, the hope was to follow the guidance of Lee Smith Battle. Her encouragement was to present in a manner that is creative and allows for “letting the various voices shine through” (Personal Communication, December 12, 2014). In response to this direction, an additional step was added. An additional review of the emergent themes was conducted to complete a “Where is their voice?” template. This was designed to identify which research question each participant’s life experience most spoke to, who were the paradigm cases and how we could best learn from each unique life. Voices shine!

## CHAPTER FOUR

### WHEN THE BODY SPEAKS

“At ninety we woke up in foreign territory.  
Whatever premonitions we may have encountered earlier  
and tossed off as odd and even funny,  
we soon began to face unavoidable—  
and certainly not amusing—realities.”

*(Joan M. Erikson, 1997, p. 4)*

These words, in the preface of their last work written after Erik Erikson’s death, poignantly express the reflections of his 93 year-old widow and partner in research. There she explains the addition of a ninth stage of development to their original eight. Her entire preface discloses their realities, their painful surprises of all that oldest-old age revealed to them. So intense and unique was this time, they recognized the necessity of adding the Ninth Stage, beyond Old Age with its task of ‘Integrity vs. Despair.’ Through her own experience with aging, Joan Erikson determined that “we must now see and understand the final life cycle stages through late-eighty- and ninety-year-old eyes” (Erikson, 1997). Even now, those 100 years of age and older should be added.

The 13 participants in this study have offered their eyes and voices, their honest and transparent narratives of experiencing loss and gain, happiness and sadness, reward and disappointment, purpose and meaning. How they experience this ‘moment in time,’ this ‘moment’ of living in advanced old age, relates to their ‘situatedness.’ This notion conveys their way of being in their specific circumstances, at the end of a long lifetime of meaningful circumstances, activities, relationships, commitments, and involvements which have set up both possibilities and constraints for living throughout their lives (Benner et al., 2009). It is the very impact of this long stretch of time that allows each to be uniquely them, having become increasingly distinct over time through accumulated

idiosyncratic experiences with commitments and responses to a unique set of people, interests, values, beliefs, events, and activities (Neugarten, 1971). As stated by Florida Scott Maxwell (1968) “It is the long stretch of time that gives us our viewpoint” (p. 38). Here we see them situated in their now, this “moment,” this time of oldest-old age.

Growing old looks ominous, challenging, and at times frightening. Changes can come quickly, or so slowly they are almost not acknowledged. This chapter will begin to convey and interpret this ‘moment’ of aging, this late season of life, from both the inside, through the voices of those who volunteered their intimate lives for our learning, and from the outside, as it reveals itself to me. This journey will begin with the experience of loss, with a particular exploration of what has been revealed about body concerns, changes, required care, and strategies for coping with these ever-present encounters with bodily aging. Additional chapters will relate experiences of challenge to independence and autonomy; of the losses of spouses and loved ones and the rewards and gains of relationships; of attitudes and habits of the mind that allows for coping and even thriving in these late years; and where meaning and purpose are experienced in this time of waning ability.

### **Living in the Aging Body**

“I really don’t find too many people near my age that are just gonna say  
‘Oh, good! Isn’t this great!’  
I try to not let it overwhelm me, you know,  
I guess because any day could be my last one.”

*(Alma, age 90)*

### ***Paradigm of Alma***

At 90 years old, Alma currently lives in a rented home with her oldest of four children. Her husband died of a long debilitating course of chronic disease. Alma is a determined, articulate, woman with clear, thought-out ideas and beliefs. As a woman of

her time, her adult life is marked by the births of her children, and events in their lives. She followed her husband's career, which led to many moves for advanced education and professional development. Growing up in a rural farming community, her childhood and adolescence was imprinted with multiple tragedies and loss of family. She comes to this time of life experienced with both burden and healing, and comments "I think I'm coping better now than I did earlier in life."

Every interview with Alma, proved to be rich with revelations of her life experiences during this time of oldest-old age. Glaucoma and macular degeneration have created an increasing impact on her life; falls and prevention of falls yet more. It was however, in the third interview with Alma, that interesting challenges and her insight in identifying them, revealed impressive observations of her aging self as she talked about life at 90 years of age:

A: Well, I thought about this, and I wrote down some things. One thing I don't like, I'm finding myself like when I eat, if I chewed tobacco, it'd just be running down like this (laughs). I'm slobbering . . . and I need to be sure to wash my face before I leave this house (laughs). . . . It's just plain slobbering. . . . Then, my eyesight is not able to check whether my clothes are soiled you know. . . . For a long time, I felt I'm very much in sympathy with people who have dirty fronts. They may not have the eyesight to differentiate, you know? (Laughs). . . . You know, I have a very difficult time like in the mirror even, because of my vision . . . .

I: Anything else?

A: Well, I could get the toe pads out . . . when your feet get tired, you know you've lost fat pads. And if I have pain, it's probably gonna be my feet, even though I'm wearing these are diabetic shoes. . . . I've been recently sorting my thinner socks. I'm gonna get rid of 'em because I have to wear at least two pairs, and that's a nuisance. If you're gonna be on your feet you've gotta be comfortable . . . .

In the second interview in the middle of describing her day, Alma illustrates another way her body speaks and requires more of her.



And then I finally brush my teeth, and that's a challenge because of my vision . . . I can't really see clearly . . . we found, they're little, well they're kinda like toothpicks, but I use them better than floss, I can with my arthritic hands and stuff. Floss is not good for me.

At the end of our final interview, she was asked what she would take a picture of that symbolizes this time of her life. With a deep sigh, she arrived at this: "The walker . . . and I could go into the bathroom and photograph the commode, (laughs) you know, and the bath bench, and the grab bars."

Assistive and fall prevention devices, slowly take up residence in the homes and living spaces of the oldest-old. Alma's spontaneous response and her deep sigh show an awareness of how this has happened in her home. Her eyes start by looking at her walker, and then her mind's eye is drawn to view her bathroom. It is unmistakable; it is the bathroom of an old person.

Alma's body is presenting her with reminders of her age and is calling for adaptations and precautions needed for this time of life. Her stories also convey the challenges of living in this aging body and at times experiencing embarrassment as a result.

There is a lot to pay attention to. Several other participants note these undeniable changes and challenges through which the body speaks, notifying its occupants that old age is moving in. It should be noted that these physical losses, these body changes, are not to be regained. Alma's vision will not return, her hands will never be able to floss again, and her walking will not be restored to a pain free, walker-free state. As will be seen in chapters ahead, the resilience, attitudes, and perspectives of these informants help them navigate these ever-changing waters. However, short exemplars presented here will further convey the nature of this aging, loud-speaking old body.

*Noticing the Body's Changes: When it is Hard to Grow Old Gracefully*

Alma's discovery of drooling was "noticed" by another participant. Betty, at age 87, is the youngest of the participants. She was widowed in 2003, has three children and four grandchildren, and lives alone in her own home. Replying to a question about changes that she has experienced as she has gotten older she tells of what she's noticed.

Well, you know, little by little I've noticed that my dentures . . . it's just my teeth . . . I noticed it. . . . Since I got my dentures I noticed that on my cheek, there it is [drooling when eating]. I have to be careful.

"I noticed it." Betty, like Alma, has to be careful about the drooling. Changes sometimes happen little by little. Imagine dabbing the napkin to the face and finding more than was thought to be there. Or maybe feeling that dampness at the corner of one's mouth, wiping it and realizing there had been drooling. This body cannot be ignored. There is a lot to pay attention to.

William brings a different experience to the narrative of living in the aging body. A 92 year old highly educated engineer, William has been widowed for three years. He has lived with neurological complications of disease since his twenties; he gets around with an electric cart and multiple wheelchairs. However, in talking with William one is left thinking that it can't be all that hard to grow older. His wit and humor mask his daily challenges. But his keen, observant nature tells another story.

I always have swallowing problems. After my heart attack and bypass I lost muscular strength all over my body including the muscles that determine whether you are breathing or taking food in. And so, actually I had therapy on that for close to two months, so I have to be a little bit careful on that. And well, I won't go into detail, but all of my bodily functions are a little askew and I just have to be careful. You know the phrase "it's hard to grow old gracefully?" . . . Well, it is hard . . . and if you're a survivor, you have to survive.

“It *is* hard.” Whether it is a side effect of an illness, or change that comes on little by little, the aging body’s functioning shifts or even declines. Alma, Betty, and William have noticed these changes, and while they are not complaining, they make it very clear that it is hard, very hard, to grow old gracefully.

Barbara, a 98 year old widower of 11 years, who remains very active and lives alone, describes a change involving her arthritic hands that she just noticed.

The funniest thing was I had on a different blouse that had those rounded buttons that are rather big . . . with the left hand I was able to button it rather quickly, but the right hand didn’t seem to want to button it and I said, “Now, you’ve got to do this,” and then grabbed hold of a button and I said, “Now, this has to go in there” (laughs).

It finally did go in, “but it took me a long time. It seemed so ridiculous. My right is supposed to be better than my left.” When asked if she became frustrated, her reply indicates her patience with such things, “Well, I suppose, but my feeling is that life goes on, there’s nothing much you can do to change some things. . . . Why let it bother you?” It is this very attitude that has helped make oldest-old age so manageable for her.

Having excellent health, Barbara enjoys the amenities of a very large upscale retirement community. Living in her own home for over 20 years, she thrives in the availability of many social engagements, friends, and nearby neighbors. None of her children live locally, but all are engaged in her life. During our third interview she remarks “You probably realize that I did not take a class in philosophy. In thinking what you think about things, I never thought about thinking about (laughs).” Barbara’s humor is evident. When I asked how she would describe her life right now, her response is casual. “Oh, it’s been good. I’ve enjoyed life. I’m not sorry that it’s coming to an end but who knows, I may live another few years.” Time together spent with Barbara causes

one to wonder about the wisdom of the old adage of the unexamined life not being worth living. While experiencing the deaths of two husbands, and her father at an early age, she marches on, enjoying what comes her way.

Walt, an accomplished health professional who is still working and playing 18 holes of golf each week at age 92, poignantly describes a day his body talked to him.

But my body began to talk to me. Almost one morning my knees were stiff. Not like immovable, yeah. Just like I'd run out of fluid down there or something. So, it was mobile and it wasn't. I also noticed that proprioceptively, I'd be standing and I'd find myself kind of falling back.

He describes this as a sudden realization, an almost startling reminder of his age. As quickly as he interjects it into the conversation, he quickly returns to describing his demanding and varied work days. Walt doesn't allow this revelation much space in our interview, but he aptly describes the suddenness in which the aging body speaks.

Norma, the daughter of immigrant dairy workers, at age 93 still lives in the home her husband built 60 years ago. Remarkably, she has no illnesses and is on no medications. Her physical needs are few, as are her personal needs and expectations. When asked how she describes her life to others, her response was "Well, life is good . . . I'm in good health. I can still go to the bathroom by myself and I can still take care of myself: take my shower, cook my meals and whatever." Her measuring stick is simple. She is content in her home by herself, yet grateful for her very attentive daughter who lives close by. She noticed a change she seems to take in stride and relates this when asked about hobbies of interests:

I used to knit and crochet, but my hands just won't go anymore (laughs). I tried to. I gave it up, when I was working. I used to knit and crochet on my breaks, but then I quit for a while. My daughter-in-law came and she likes to go to this thrift shop over here. So, I went with her and I saw some yarn there and I thought, "I'm gonna take some yarn and see," and

you know, I just couldn't make my fingers work. They just wouldn't go (laughs). I lost whatever it takes to make it go! It was just awkward. I couldn't seem to turn the yarn the right way (laughs). No more knitting!

Barbara, Walt and Norma, take a nonchalant untroubled response to these body changes they have noticed. Their observations seem to have minimal impact on their daily lives. This, combined with their general approaches to life, helps them take these bodily malfunctions with humor and an attitude of acceptance. These attitudes and habits with their impact on coping and thriving will be explored in a later chapter.

***“The Shocker”: “I Am Old”—Rebekah’s Exemplar***

Rebekah, a 90 year old divorcee who moved into a residential facility two years prior to our interviews, described when her body began speaking to her about aging. She aptly names this unwanted revelation as “The Shocker.” Due to concerns about falling in her own home, Rebekah was encouraged by her daughter to look for a residential community in which to live. During her visits to possible communities, she has an inner dialogue. “. . . First comes this thing of anguish. ‘Why am I here’? Especially when you come in and you see people in wheelchairs or walkers.” Rebekah uses a strong and emotive word—anguish. “This thing of anguish” bears notions of suffering, of despair, of sorrow; words of trauma. She was indeed traumatized by realities that were not previously recognized. Although her physical health was compromised due to diabetes, hypertension, and high cholesterol, Rebekah had managed her life well while actually feeling very few complications of these conditions. She had in fact slowly accommodated her medications and modifications into her life. With the decision to move to an assisted and safer living situation, she confronted her new reality.

A second startling observation was similar to the first. “So what happened was when I first went to the dining room and I had never thought about having gray hair. It had never bothered me.” Gray hair doesn’t lie. She emphasizes the shock of this in the next interview. “I didn’t know I was old until I moved in here with all these gray-haired folks! Gray-haired OLD folks [stated with emphasis]! It just didn’t dawn on me. You’re old just like they are.” A few months after she moved in, she had another knock on the door from old age.

That morning that I got up, and I couldn’t hardly get up, and I had to go to the doctor in a wheel chair. I couldn’t believe it. This is not me! What has happened to me? I was upset to be in this wheelchair. So he [massage therapist] worked on me for about an hour, and so I walked back out. But in my head, I am older. I’m old.

“This is not me!” The incredulity of this type of recognition is common to many who encounter blindsiding realities of life. Rebekah was blindsided. This old-ness, this being “old,” felt foreign and frightening. She was in what, for her, was unknown territory. Not only is Rebekah seeing she is old, she is also seeing that the young Rebekah is no more. This narrative of realizing and accepting being old is intertwined with her struggle with independence and autonomy that will be chronicled in the next chapter. These two strands of her story, depicting her awakening to old age, and struggle with independence, are woven into two years of depression, and personal and spiritual growth. As with most participants, Rebekah’s journey was a difficult one.

### **When Losses of Health are Devastating**

“I keep thinking I’m gonna feel better (laughs).  
And like today, it’s not materializing.”

*(Madeline, 91 years)*

While some losses develop slowly, gradually becoming noticed and growing to demand attention, other losses enter suddenly. Often these sudden entrances are made on

top of previous losses and adjustments that already have gathered to require much attention. The impact can be quite devastating, as heard in the following narrative.

*Paradigm of Madeline: Sadness Comes When the Body Disappoints*

On our first interview, Madeline appears as a small, frail, bent, silver haired woman of 91. She talks quietly, even weakly. Although cautious about sounding like she's complaining, Madeline feels like her life "is for the birds." After 20 years of around-the-world adventure, she still thinks about her bucket list, two more countries and two more penguins. Madeline is the only married woman in the study. A very independent, intelligent woman, she is struggling with feeling tired, catching her breath, and hearing. When asked how she would rate her own health, her reply of "It's the pits," speaks of her discouragement. Aging has made itself known in Madeline's body in multiple ways; diagnoses include atrial fibrillation, hypertension, vertigo, spinal stenosis, arthritis, and macular degeneration. Her hearing cannot be completely corrected. Doctors can't seem to solve her problem of fatigue. She has dreaded the frailties of old age and she is now experiencing them.

Just a week before our second interview, Madeline had a serious fall. She had an extensive butterfly mask bruising on her face. Her legs were also bruised with deep healing wounds on her shins. The right ankle was bruised and swollen. It is clear that Madeline's bruising is not only physical, but also deeply emotional. Speaking in a very quiet and slow voice, and again concerned about sounding like she is complaining, she relates the following:

Well, I just sit around and mope, and I'm not usually that kind of a person. If I could just get out and walk or do something, you know, on my own. . . . But, I don't feel up to walking for the one thing . . . .

Although she has had multiple previous falls, Madeline is very discouraged about this one and speaks very openly about the impact it has had. “My eyesight has gone crazy.” It has gotten harder to read and watch TV. Although she is getting shots in her eye to treat the macular degeneration, it’s only gotten worse. The distortion is much greater; she can no longer read with both eyes open. “They’re not mates.” She also has glaucoma and uses hearing aids. “I hate to complain.” Madeline’s struggle with her injury and poor health is painfully apparent. While trying to be hopeful, she still candidly admits, she would rather not live if this is how it would be. When asked how it is to be 91, she replies:

It’s the pits . . . it just seems like the last month or month and a half, it’s just going downhill all of a sudden. Especially now that I have a head injury and all that. But before that I thought, I’m gonna exercise, and I’m gonna stay fit. And it won’t be too bad . . . I thought, you know, if I keep up a routine, I’m gonna be fine. I could live to be 100, but (laughs) my mind has changed about that now. I don’t wanna live to be 100 if I’m feeling this way. . . . It’s not worth it.

*I hate to complain; but it’s not worth it.* At this moment Madeline’s experience reveals her deep discouragement. Everything is taking effort. Hope of feeling better is waning. It just doesn’t seem worth the effort. *I hate to complain; but I can’t help it . . . this is awful, and I’m struggling.* Despite a life with practice at living through hard times, Madeline may have met her match in old age. Even so, she needs assurance that complaining is both appropriate and acceptable. I leave this interview feeling saddened.

When a new disability arrives I look about to see if death has come, and I call quietly, “Death, is that you? Are you there?” So far the disability has answered, “Don’t be silly, it’s me” (Scott-Maxwell, 1968, p. 36).

These words are recalled as I approach the third interview and am relieved to see Madeline’s improvement. So far, it appears it is disability of a very old body that has



again, knocked at her door. After I comment on how wonderful her face looks, Madeline responds with “Yeah, I was kinda worried at first. How long am I gonna look like this?” Relief is in her eyes. Her voice is stronger. However, she is unable to stay positive for long. Responding again to the question of what life is like at 91, discouragement is heard.

M: Well, my biggest problem is being I guess, too lazy. I know I need to exercise, and I’m not gonna get any better or sustain myself if I don’t get out and walk and do some exercise. But I can’t seem to budge myself. . . . Now, this morning I did 15 minutes on the treadmill, but “Should you do that with your leg?” They don’t know about my leg, but my knee hurts, arthritis, and if I don’t walk, it’s gonna get worse. Anyway, I did that. I did push myself this morning a little bit.

I: Tell me how you talk to yourself to get yourself on the treadmill.

M: Well, I just feel . . . well, I don’t know. I don’t hurt, I just don’t feel good really. But I don’t like myself the way it is, and I know, even if I’m 91, they say if you get enough exercise, everything’ll do better. And I (laughs) scold myself about eight o’clock at night. I said, “I should get in there and do the treadmill,” and then, something happens and I don’t do it. So, I’ll do it in the morning. (Laughs) I just keep putting it off and putting it off, and my husband said, at one time he said, “We’re going to walk every morning. When we get up, we’ll go out and walk.” But that hasn’t realized.

Madeline’s physical challenges and her fight against discouragement are striking. Sadness comes when the body disappoints. While seeming a bit depressed, she hasn’t lost sight of what she ‘should be doing.’ Doing is a strong drive. No one is content to sit, even though sitting is what is done much of the day. The self-scolding, the admission that one cannot do what the mind wants to, lingers in her thoughts. The Western cultural ethic of doing, being productive, move . . . do . . . be productive. And when one can’t keep it up? It must be laziness. Or could it be old-age making itself the victor? Has the healthy, younger self been lost?

### **Slowing Down: When Everything Goes Slower**

“I’m up at 6:30 because getting on a dress shirt, and the tie, and the trousers and coat, and everything is a little more time consuming than it used to be.”

*(Louis, age 93)*

One of the ways we experience ourselves in the world, in our lifeworld, is through the sense of lived time or temporality (van Manen, 1990). Time, as this notion of temporality, is seen as a unified whole, not a series of moments in time. We do live in the now, in this moment, yet it is influenced by our past, and projected into our future. This notion of “slowing down” is based on the inner sense of how much time tasks, projects, movements, thoughts, etc., should take; perhaps how much time they used to take “when I was young.” Yet this is also set in a larger context of how fast time is moving generally. Most people in late life have the sense that time is moving very quickly. And here, participants are saying *they* are moving very slowly. At some level, this is very unsatisfying for them. Or perhaps it is indicative of being old, and being a reminder that one’s life is nearing the end.

#### ***Slowing Down: A Common Experience***

While all participants could probably attest to this notion of slowing down, some spoke specifically of this being one of the main ways their aging body has “spoken” to them. Each puts their own twist to the experience. Barbara uses humor to cope and told this story twice during our three interviews.

I’m not as quick as I used to be. I told my son that I was getting slow and he looked at me funny and said, you’re complaining about being slow and how old are you? I thought that was so funny (laughs).

At another point when describing changes she has experienced Barbara simply stated “Well, it’s mostly being slower.” When asked about any abilities that have become difficult or annoying she replies:

No, you just know that you can't do some things, it's like running (laughs). I used to run, did I tell you about that? My son called me one day and he said, "thank you for running to the phone (laughs)." Because I always ran if I was out in the garden . . . and I'd hear the phone and so I'd run to catch the phone . . . (laughs) I always loved to run. But I don't need to run . . . I can get where I'm going without running.

These bodily changes have not escaped her notice, but Barbara's stated "Go with the flow" approach to life is evident. She has noticed the change, she sees the humor, but she is not too distressed.

Likewise, Norma has observed this same slowness. Yet, she approaches it as something to be expected. When asked what recent changes she has experienced, she replies: "Well, I don't get around as fast as I used to, you know. I'm just going down, I guess, little by little. No sudden change."

In her last interview, Norma again comments that at 93 "I can't move around as fast as I use to." And, "I don't get up as fast as I used to." She demonstrated how she gets herself off the couch in a slow methodical way. "It takes me a little longer, and I make sure my feet are down, you know . . . and then I brace myself like this, and sometimes I grab ahold of there, you know."

I am struck by two things about Norma. First, at 93, her slowness is one of the main things that comes to mind about her changing body; she is remarkably healthy. Although memory and hearing issues are impacting her quality of life somewhat, the second noticeable trait of Norma's is her relaxed calm, untroubled spirit. She just "takes it a day at a time."

For two other participants, this slowness shows up as everything taking so much longer, as being inefficient. After describing her morning routine, Alma (age 90) relates

“at this age you’re so inefficient that the day is practically (laughs) over! It’s practically time to start getting ready for lunch.” Every task requires more time to be accomplished.

Betsy, at age 87 is a small and frail woman who speaks in a very quiet voice. Between our first and second interview, Betsy was hospitalized with a serious urinary tract infection that progressed to life-threatening septicemia. This left her even frailer, with an even quieter voice. By the third and final interview, her recovery had progressed but her increased weakness continued to be evident. Betsy’s primary characteristic is her spirituality. Her faith in her Lord sustains her. Regarding what life is like for her at 87, Betsy offered this insight during our final interview: “It’s having to get used to a lot of things that are different. So different because I have to do things, think of what I’m doing, and so it’s slower, a lot slower.”

Similar to Alma, this slowness is related to mental slowness combined with body slowness that causes “things” to go slower, to take more time. This notion of time in one’s day, particularly this concern of “doing” taking so much time, is reflective of another significant change. This change points to another aspect of time, the reality of having moved closer to the end of one’s time, one’s life. Slowness of movement and thought reflect an aging body and mind. That this has been noticed by these women, indicates that this slowness matters to them, concerns them, most likely for what it represents—old-age.

For Madeline (age 91), a former engineer, this slowness appears as mental slowness, which clearly is disturbing for her. In our last interview she related an incident that had occurred during a visit from her grandson and his family, including a daughter

who is a young adult. She was offering an example of a recent loss of something important.

M: There's something the other day that I was thinking about. Oh, this is (laughs) this jigsaw puzzle (laughs). . . . I put it out there when the kids were here last week. The girl, who's I think 21 or 22, brought her violin and she played a nice little concert for us, but I had a jigsaw puzzle in process, and I said "Go ahead." She finished it in just a few hours. And then, I put that away and had started another one, put the stuff out there, and she had it done by mid-afternoon. And (laughs) the third one, she finished, too. So, which, when they left, I put this other one out, and I've been working on it, and working on it, and working on it (laughs). I can't even get the frame around it. . . . I got a little part down here, that's all. But I spent hours and hours.

I: Putting together a puzzle that this young girl put together really fast. . . .

M: . . . And, I taught her a card game called Nertz . . . first time she'd ever played, and she beat me bad (laughs). I did it once to see if she was doing everything right, but whatever it was, she beat me. And I have a reputation of being the best Nertz player in the family. Not any more (laughs).

Madeline has enjoyed her puzzles and this card game that is based on speed. She was confronted by the speed, in both her beloved puzzles and her Nertz prowess, of her granddaughter. Even more significantly, she was confronted by her slowness in the puzzles and the game. Slowness, in this case as time, reflects Madeline's aging brain. Her slower thinking and awareness reflect her old age; this old age indicates her movement closer to the end of life. This encounter has deep meaning for Madeline.

### *"I'm Lethargic"*

A final yet distinct example of slowness appears as lethargy to John, who was widowed three years ago, and currently lives alone in a small apartment. In two separate interviews, in response to the question about what life is like at age 88, John brings up his "lethargy."

I'm lethargic. I have things to do, I've got lots of things to do, but I can't make myself do them and that's the biggest problem. In other words, there's plenty of things to be done but I have problems making myself do them.

Bringing up this lethargy in two different interviews indicates how disturbing and significant this is to John. This sluggishness may be a symptom of depression. It is full of meaning and reflective of this time of his life. He is not accomplishing anything. He is slow to get things done; he is slow to get out of his apartment. Time is being wasted.

### **When Vision and Hearing are Diminishing**

“Now, I occasionally think, I don't dwell on it, what would happen if the other one [eye] did that. . . .  
So you do think about that once in a while.”

*(Douglas, age 100)*

Two bodily senses that are notorious for giving out in old-age are vision and hearing. How we move our bodies in and come to know our surrounding world is profoundly impacted by our vision. How we interact with our world and those around us is greatly influenced and informed by our hearing. The narratives of over half of these participants tell of lives profoundly altered and impacted by the loss of vision and/or hearing. These losses speak loudly.

### ***Living With “What If?”***

In our first interview, Douglas (age 100) responds to my question about what it was like to have lost something that was important to him.

The loss of the sight in the eye would be one, yeah. It hasn't bothered me, at least, it frightened me at the start because he [the doctor] checked very closely on the other eye and said it's possible it could happen there. And that frightened me. But I go in every six months, he checks that regularly. That was the biggest fright I had.

This occurred ten years ago, when he was 90 years of age. In our third interview Douglas describes his diagnosis:

When I first noticed it was happening, I was driving to Montana and the middle lane looked like it was crooked . . . So, I went to see my eye doctor and he said “You have macular degeneration.” So, he said, “We’ve lost that one. Now, you can see out the side,” that peripheral vision I can see very well. . . . And I thought, “Well, what’re you gonna do about it?” That’s all there is to it (laughs). Now, I occasionally think, I don’t dwell on it, what would happen if the other one did that. . . So you do think about that once in a while. . . .

Douglas’s use of the word “frightened” discloses just how meaningful this potential loss of vision in his other eye is to him. He uses frightened only one other time. That was when he related his history of two significant heart attacks. For Douglas, fear of dying during a heart attack is similar in intensity to fear of essentially going blind. His life would be radically altered. Yet he chooses not to dwell on it, although the possibility still looms in his mind “once in a while.”

### **Eyesight Gone Crazy**

Madeline’s vision loss is more disruptive to her life at this point. Walt, her husband clarifies that she started having bleeding in her eye when her blood pressure began going up. Laser work was done which has left a lot of scar tissue with a “build-up of fluid.” She has moderate macular degeneration in one eye and glaucoma in both.

Especially since my fall, my eyesight has gone crazy . . . just my left eye has a bleeding whatchallit, and I’ve been having shots in it to stop the bleeding and everything. And the last two shots have made the distortion between the left and right much, much greater so that it’s hard for me to read with both eyes open. . . . I just close it. But like the watching the preachers . . . on the TV, they have two sets of arms. So, my eyes are not mates. . . . Ever since my bump, it seems like it gets harder to read.

Clearly this loss of vision has interfered with much of Madeline’s daily life. Reading and watching TV are frustrating and unenjoyable; without question this interferes with her quality of life. Sadness is evident in her voice as she talks through her vision struggles.

## Using Your Vision for Only Necessary Things

Alma's (age 91) eyesight is deteriorating. She has glaucoma in one eye and macular degeneration in both. Talking about falls, she describes why extra caution is needed:

And I especially need to be very careful of that because of one eye vision and an eye that tends to be a little bit blurry in itself. So I am very much aware of the fact that I've got to be very careful and I try to be. . . . I used to collect stamps . . . and they were kind of fun, but I don't have the vision for that kind of stuff now . . . at this stage you just use your vision for the necessary things and to try to keep as safe as you can. After this fall, vision is a little more blurry or something. Now that could be imagination or suggestion or something like that. If I have real good light, I can read, but I'm not supposed to use it too much (laughs).

Her failing eyes also slow her down. Alma admits that it is hard for her to limit her reading. She then describes a collection of audio recordings, "So, if I ever get to the place where it's almost impossible to read, I do have a lot of stuff I can listen to." She is preparing for the day when her vision ultimately steals the ability to read. In the meantime, her strategy is to be careful and "I'm not gonna worry about it." In our final interview, Alma relates a string of difficulties that are a result of her poor vision.

I do have to continue making my lists and stuff. It's kinda hard sometimes to get organized at 90. And if I lose something, it takes me a ton of time to find it because of the vision . . . . Because I don't necessarily instantly recognize stuff . . . . I think it's my depth of focus is screwed up with just one eye and stuff. . . . Like for example, when I'm getting strawberries ready for breakfast, and the dark green little cap around it, and the dark red strawberry, there's just not enough contrast there, you know? And so, it takes me a little while longer to find it. . . . I've very much slowed down, I guess. . . . And I have tons of stuff to do (laughs).

It is easy to imagine Alma with a small knife in one hand, a strawberry in the other. She brings the strawberry up close to her right eye, her "good" eye, and stares intently, examining it, trying to make out the change of color from the red of the berry to



the green of the stem. Ah, hah! In goes the knife that slowly turns in the red of the strawberry and carefully extracts the green. She puts it down purposefully in her bowl. Looking carefully for the next berry, she again brings it up close to the good eye. Vision loss creates quite an impact for Alma.

### **Experiencing Hope in Vision Loss**

By our third visit, Rebekah (age 90) had an experience at the Blind Institute that was encouraging to her, turning a discouraging vision loss into a manageable life adjustment. When asked about recent discouragements, she describes her vision changes.

One of the things to the negative is that I started having problems with this eye. So I didn't know this before I moved here, that I did have macular degeneration. . . . Well my vision, some days it's really good and some day it isn't. One of the main things . . . the macular degeneration is on the center of my eye, and that's why the letters are dropping. So I drop the first letter of a word. And then it's also affected my writing because I guess I'm not seeing clearly and I can write, but if I write very long it gets small. I can't see it, or it goes up in the air. So while I was at the blind institute, I asked was there anything that they had now that they could give to seniors to help them with their writing if they're losing this central vision. [She then describes a writing aid that was shown to her]. So she gave me enough so that I could make copies of and that's helped me learn to write, because I can see the black line. . . . And some days I couldn't even write my checks, and I had to have somebody help me write my checks.

Rebekah then shared an experience she recently had in her Sunday school class:

I didn't want to feel that I couldn't read, but they wouldn't stop calling on me. So they called on me this one Sunday and I read without the magnifying glass and everybody started clapping. I said "What's going on?" [They said] "Well, you read!" So I found out if I do not concentrate on the idea that I can't see well enough to write, or to read, I can read and write much better! . . . When I'm making notes for my Bible study, I don't think about the writing, I think about what I'm thinking about!

She also described a threading kit she received at the Blind Institute "So, that way I can sew!" They showed her tabs for the microwave that she can feel to set the time and

start button, “how to set up a kitchen and arrange things if you are sightless.” “Oh man, it was really, really encouraging for me!” As she anticipates further deterioration of vision, Rebekah now can see how she can manage it. “These are things I’m looking forward to if this happens to me. I already have some plans how it’s going to affect me.” In her characteristic way, Rebekah is taking charge of her vision loss and creating opportunities for herself. She can now imagine herself managing her life if further vision loss occurs.

### *The Impact of Hearing Loss*

#### **“So, I Grin, and Smile, and Nod . . .”**

Hearing loss can bring other challenges, especially in social situations. For William this is particularly true as he eats in a common dining room of his up-scale residential living community. As he describes it:

Well, my hearing of course is a problem, and this is a major handicap for me socially. . . . So when I go down to dinner, the noise level is so high, I suppose maybe 10% of the conversations I’ll hear 90%, 20% I’ll hear less than 10% and so, that is just extremely frustrating. So, I grin, and smile, and nod . . . ’cause I know what the subject is, and from the inflections, I can tell when I’m supposed to respond (laughs).

Later in the conversation I asked about anything which has occurred recently that has felt bad or discouraging. “Well, as I said, because of my hearing problem, my social interactions are limited more so than I would want them to be.” In William’s situation, living alone in an apartment, more recently widowed, and being a very extroverted personality, his experience with hearing loss is discouraging. Being lost in a conversation in a noisy dining room leads to an isolation of sorts. For an intelligent and esteemed professional, and a widower unaccustomed to living alone, this can be a humbling reminder of what has been, and can no longer be.

### **When Hearing Loss Is not Worth Mentioning**

In contrast, for Norma's different life situation, hearing loss is so inconsequential she doesn't even mention it. Both her daughter and sister cautioned me about her hearing loss, and although I needed to repeat myself at times, Norma never offers her hearing deficit as an issue. Living alone in her home and spending much of her day there or one-on-one with her daughter, her experience of her hearing loss is not one of discouragement or social isolation. For her, this is not the voice she hears of her aging body.

Likewise, John who sits very close to me during our interviews, and at times seems to be reading my lips, relates that he has excellent health, and does not comment on his hearing deficit after he explained it to me during the initial phone call. This experience of hearing loss can be inconsequential for some, perhaps a minor nuisance for others, yet a major discouragement for others. One's lifeworld defines the meaning of each loss.

### **Hearing Loss and Marital Negotiation**

In the lives of the only married participants, hearing loss presents as a unique struggle. Both Walt and Madeline have hearing loss for which they use hearing aids. In a joint conversation, their struggles of having them in, or not having them in, is clearly a source of discord. Walt's confessed habit is to wear them at work, but not at home.

M: I haven't complained to him about this yet (laughs), like this morning, I came out and he already had the TV on. It was so blaring loud. . . . I had my hearing aids in, but he didn't have his. And so, I almost took 'em out because it was so loud.

W: And the rule of thumb is to let me know it's loud and I'll turn it down to where it's comfortable for you.

M: Yeah, this morning I thought, "Oh!" (Laughs).

W: See and my question is, "Why didn't you say something then?"

M: Well, I didn't want to complain.

W: That wouldn't be complaining. I would say, "Can you lower that a little bit?"

M: But I keep thinking maybe he'll hear better or something, but I wanna shout to him, "Put in your hearing aids" (laughs). But I don't.

In the lifeworld of each participant, the experience of vision or hearing loss, or sometimes both, has different meaning depending on how the loss fits into the context of their lives. In Madeline's world these losses are highly disruptive as evidenced by the multiple times she brings them up as she relates her story. For Norma and John, the impact of their hearing loss is so inconsequential to their everyday life, it is not even mentioned. Their hearing loss has little meaning for them. Could it then be said that this is not a loss at all? Perhaps it is merely a change to which one adapts without much thought.

### **When the Mind Reveals Its Age**

"My memory is not very good. It is frustrating and sometimes I write things down, and I forget where I leave the note."

*(Norma, age 93)*

"When I try to have a conversation, I want a word that just won't come to me. Especially under pressure, when you really need it, you don't have it."

*(Madeline, age 91)*

Comments such as these came from every participant. It is evident that memory loss of some kind is a part of the lifeworld, of the oldest-old. Each participant had their own strategies for compensating for this loss. Most had calendars with which they consulted every morning to be reminded of what the day would hold for them; a couple of them relied on their children. Loss of names, loss of words, loss of a thought, loss of where you are in your sentence; these are common frustrations. They are as sharp little pin pricks in your day that remind you of your old-ness, your advanced place in life. Memory loss can also bring with it humiliation, as Madeline expressed in the quote

above. In her case, this led to avoidance of outside conversation, which led to increased isolation, and quite possibly to depression.

We all bring to these encounters a life world and life-long context for how we view them and respond; how we live in these experiences. Our past brings us to our present, and with it automatic ways of interpreting possibilities for everyday life experiences. An engineer sees this as a problem to be solved; a deeply spiritual person brings it to prayer.

### *Strategizing to Remember*

William is an accomplished engineer. “Remember, I’ve had engineer training. And engineers always look first at what can go wrong.” And by extension, how to prevent these things from happening.

I’m quite talkative, and if I get into a conversation, I know what I’m gonna say for the next five minutes or five hours, but then, I get launched in it, and then, I don’t remember what it was that I was going to say. And so, I of course try to compensate. For example, I take Metamucil, and right now, I can look in the kitchen, and I know from where the jar is sitting that I had it this morning and I’m going to have it this afternoon. And so, I try to be more careful to replicate things. Most of my life, as I indicated, I tried to do something different. So, if I got in to a pattern, I consciously tried to change it. But now, I try to develop patterns that’re the same.

When doing things the way they’ve always been done does not work anymore, an engineer will change his strategy. He solves the problem, as best he can. In his small kitchen, he has the Metamucil strategically placed. One of his problems is solved. Yet, he doesn’t directly address the conversation problem. Perhaps forgetting what you want to say isn’t an easy one to solve and he chooses to share an example of a solvable problem. Or perhaps, having his stories memorized, and not being too spontaneous is the solution he’s alluding to.

Another comment William made here is highly significant. “Most of my life, I tried to do something different. . . . But now, I try to develop patterns.” After listening to his life story, I know William to be a man that in earlier years thrived on change and adventure. As he is fond of saying “My bags were always packed.” This adaptive strategy he has described is a tremendous change, a necessary adjustment to this time of oldest-old age and the memory changes that come with it.

William’s choice of the word “compensate” was apt for this experience, and what this experience of memory loss feels like for himself and others. Merriam Webster (“Regret,” n.d.) offers the following definition: “to provide something good as a balance against something bad or undesirable: to make up for some defect or weakness.” Memory loss is undesirable, even distressing. All participants related this. It indeed feels like a defect or weakness, albeit one that is seen by the participants as a normal change of aging; therefore one that needs to be coped with. All attempt to compensate, to balance this negative development with strategic reminders and cover-up strategies. Some are more successful than others; losses of words and trains of thought are often hard to disguise. Again, this lived experience of memory loss showed up for all, was noticed as significant for all, yet each assigned different meaning to it.

### *Puzzles, Numbers, Pneumonia, and More*

Interviews with Sarah (age 88) were pure pleasure. Being impressed by her memory in our first interview, I definitely noticed at the beginning of the second, when the name of her daily morning TV show slipped from her memory.

S: I typically get up about 11:00am. Not that I’m not awake, but I usually watch TV until about 11:00am.

I: What do you watch in the morning?

S: Oh, I watch . . . what is it that I watch? (Long pause) Isn't that something, I can't even [remember] . . . it's a, not a talk show. It's a game show . . .

Her response of "Isn't that something?" reveals her own surprise, even embarrassment.

This is the experience heard before—a common, familiar word or name, gone.

The third interview holds more stories of memory loss. With a big sigh, Sarah brings it up again in the beginning of our time together, describing what life is like at 88. "It's different. Sometimes I can't remember exactly what I want to say, it won't come out the way I want it to. But it's not bad. I'm enjoying it, because it seems like people enjoy being around me." Her lapses of memory are primary. As the first topic she brings up, it clearly has been on her mind. Sarah is saying that while her memory is a problem when she is having conversations with others, they don't seem to be bothered. People still enjoy being around her.

The following story Sarah shared later in the same interview, offering an example of how she has coped with many of the struggles and disappointments that have been a part of these later years of life. Her Lord is where she often turns for understanding and support.

I: So, you were telling me about after that [hospitalization] you were trying your word puzzles and things.

S: Oh my. One time they brought me a book in the hospital (shaking her head).

I: You couldn't do it?

S: Uh uh. And, then when I came home after these three months, it didn't make sense at all. So I just put the books away. I didn't touch 'em.

Finally one day I said, "Okay. I'm gonna try." And I kept looking at the puzzles and looking at the puzzles, and I found one that I could do a little. And then I got tired. And it didn't seem to work. So I put the book down. That night, I picked up the book, and I said, "I know I used to do these, but I don't know why I can't now." And it was like something said, "You used to say thank you Lord, when you would do a puzzle." And then said

“that’s why you can’t do the puzzles. You aren’t thanking Him.” And I started . . . I can do all my puzzles.

As Sarah related this story, it was clear by her face and her emotions that she believes this reminder came from her Lord. She experienced this as God meeting her deep need to be able to return to doing her puzzles, and providing the assurance of her recovery. A few other memory issues she relates later in the same interview.

S: Sometimes I can’t even remember my daughters’ phone numbers. Sometimes I do, sometimes I don’t. It comes and goes a little bit. Somebody asked me my phone number yesterday. And I was saying, “Uh, wait just a minute.” And I had to think of my phone number. Little things like that, nothing serious.

I: Do you have the experience of not being able to remember words?

S: Yeah. I’ve found that I used to be the kind of person that could hold a conversation and never have to worry about it. And I was writing a letter last night and I couldn’t spell pneumonia. . . . I used to win contests at the spelling bee. And I could not spell pneumonia.

I: Did it come back to you or what did you end up doing?

S: Uh, uh, I just stopped thinking about it and changed how I was writing. . . . Because I thought, “I am not gonna even get up and get the dictionary to find this word.” But yeah, the little things like that, words that used to be no problem with me.

Other participants shared this same story:

- “I do have a short term loss. Somebody called me yesterday and he said ‘I hope you remember. . . .’ Well, I didn’t.” (Louis, 93)
- “I don’t get out much. So, with my memory I’m afraid I can’t pull up the name or number, or word I need. So, I hesitate.” (Madeline, p. 91)
- “I take cholesterol, iron, another one . . . oh, I take . . . that’s another thing, I do begin to forget names” (laughs). (Douglas, 100)
- “I’ll start a sentence, and ‘What was I saying?’” (Betty, 87)
- “I’m struggling for speech sometimes. Not necessarily repeating, but it’s between the head and the lips. So, I’m having to think more carefully what I say. I have to remember what my economics teacher said to me ‘It’s better to keep your mouth shut and appear ignorant than to open it and remove all doubt.’” (Walt, 92)



While taking comfort in how common memory loss is, to William and to Sarah, and to most of the other participants who told of these types of lapses of memory, the experience seems to be a prick to the skin, of sorts. Or maybe a prod, a bit of a poke, or even a taunt. “Don’t forget . . . you are old. And I, am here to remind you of that.” The body speaks, the mind also reveals its age, and when they do so, the experience is often surprising, and usually one of losing a former way of being—one of loss. Loss, as the changes of body and mind of aging, interrupts and interferes with the meaningful ways in which these participants have been engaged with others and with their world. Losses of aging require new ways of engaging with, and thinking and being in the world.

### **Caring for the Aging Body**

“Old age demands that one garner and lean on all previous experience,  
maintaining awareness and creativity with a new grace.  
There is often something one might call indomitable about many old people.”  
*(Joan Erikson, 1997, p. 9)*

It is a phenomenological tenet that “we are always bodily in the world” (van Manen, 1990). Our encounters with others generally begin with observations and perceptions of appearances or bodies. How we encounter ourselves can be highly influenced by our perception of our own bodies. Through listening closely to the narratives of these participants as they have lived with and through their aging bodies, an understanding is being suggested that risks sounding Cartesian (Blackburn, 2005) and being perceived as promoting mind-body dualism. In very old age, the mind-body divide seems to grow ever wider. That is to say, there is a perception of the body, a manner of speaking about the body, even movement of the body that conveys a sense of it as “The Other,” as separate from the self or the person who I am. And this Other needs to be treated with respect, care, and kindness. Rather than as a unified whole, the aging body

can even be perceived as working contrary to my best interest. Yet, I will continue to try to coax it to work better and longer on my behalf. This can take a lot of work. And in spite of which, I can continue to live a life of meaning and purpose, fully engaged with others.

Max van Manen offered an interesting and related struggle (2002a) in his concept analysis of “Caring-as-Worry” (p. 265).

When I think of *zorgen* in the Dutch language, I have very different connotations than the terms *care* or *caring* evokes in English. Yet, it is not so easy to articulate the difference. In English, *caring* seems to be a nice and pleasant word, and indeed many want to claim to be in the caring business. . . . In contrast, *zorgen* seems to be a more ambiguous term, carrying strong connotations not only of caring but also of being burdened by worries.

This notion of care-as-worry and being burdened, seems to convey a subtle aspect of the experience in many of these narratives telling of care of the self-as-body, as change, adjustment, and adaptation is required. Vulnerability, with its worry about “what does this mean?” and the question of “where is this leading?” is heard loudly in these narratives of the oldest-old. The remainder of this chapter will present what was revealed through hours of informative, honest, transparent narrative and story, about caring for, adapting to, and living with the ever-changing, aging body.

### ***Getting up at Night: “When You Gotta Go, You Gotta Go”***

Perhaps because it is so prevalent, all the participants mentioned it, and because it is such an accepted experience of the aging body, this nightly phenomena of getting up once or twice was intriguing. Everyone spoke of it; no one complained about it. Getting up to go to the bathroom was related very matter-of-factly. Of the participants quoted below, five of them are very walker dependent. This experience is one of getting a very

slow-to-move, unsteady body up from bed, two feet squarely on the floor, hands firmly on the walker, in the middle of the night, thinking through each movement with some sense of urgency. None of this is done without deliberate thought and body awareness.

There would be no taken-for-granted movements for this group.

- “I try to drink my water early enough in the day so I reduce the bathroom trips as much as possible . . . my first trip is . . . about midnight to 2, the next one might be 4:30 to 5.” (Alma, age 91)
- “I get up a few times [at night]. Old man’s problems there. When you gotta go, you gotta go. And this is just one of those things that you have to put up with, but I do put up with it, and when I get up, if I go back to bed I get back to sleep pretty rapidly. I don’t have very much to complain about.” (Louis, age 93)
- “I get up at 4 or 5. I don’t sleep continually. I just get up about every two hours to go to the restroom. It is hard . . . Thing is, I’m just used to it.” (Sarah, age 88)
- “Well, you wake up several times a night when you get older because nature get you up.” (Douglas, age 100)
- “I slept very well [last night] hmm hmm . . . I fell asleep right away after I went to bed and I didn’t wake up, well, I woke up once to go to the bathroom, but I went back to sleep right away.” (Norma, age 93)
- “I sleep pretty good. I have to go to the bathroom. It seems like when I wake up and go to the bathroom, my chair beside my bed, it seems like it’s about every three hours. I didn’t used to. I just wake up and I have to go to the bathroom. (Sarah, age 88)
- “What time did I wake up yesterday morning? Because I know I went to the bathroom twice and generally I have that problem. You know, and I’ve had two surgeries [for bladder repair]. And I, every two hours or two and a half hours I’m up, and I try not to drink, you know, after three o’clock, but boy do I get thirsty. I always wear a pad...better safe than sorry you know.” (Betty, age 87)

Two participants mentioned purposefully cutting off their water early in the day as a tactic for having fewer trips to the bathroom. Betty gets closer to a complaint than others as she mentions how thirsty she gets as a result. An outsider’s perspective is seeing this sleep interruption and the necessary effort it takes to get up and back to bed as

a loss. Yet, this is not what is conveyed here. Like Louis, they all put up with it; like Sarah, they are used to it. It is a way of being in this aging body, at this late time of life.

*Alma's Paradigm: Daily Life Takes a Well-Thought-Out Approach*

Alma is a determined, articulate, woman with clear, thought out ideas and beliefs. Her religious convictions include a very holistic view of the person, health, and spirituality, and her role in caring for her whole person. Her daily life is occupied with purposeful acts of self-care. With her losses of physical strength, balance, mobility, and vision she has developed strategies to maximize her health and longevity. Of all participants, Alma is possibly the most strategic and purposeful in her daily routine.

I get up about 5:00 and the first thing I do is drink 2 or 3 cups of hot water and I put a quarter teaspoon of C crystals in a glass of cold water and drink that and then I heat up the rest and I put magnesium in that and drink that . . . Then I get my breakfast out because I don't wanna eat it cold so much, and have it sort of warming up to room temperature.

She goes on and describes her morning routine, how she obtains her various food groups throughout the day and then more of her well thought out approach to her day.

I like to chew my food as thoroughly as I can. I think people tend to eat too rapidly. Anyway, then after breakfast, I try to walk some way. I use either the walker or the poles or something for 10 minutes or more after I eat. . . . these [hiking poles] are good because they keep you more upright than the walker does. . . I try to drink my water early enough in the day so I reduce the bathroom trips as much as possible.

After explaining the two typical times she is up to the bathroom at night, I ask if she is able to fall back to sleep. "Yes, quite well. Except when I had this pain [pain from a fall]. I often have the tape recorder going and that tends to lull me off" (laughs). "Except when I had this pain." This statement was startling to me, as nothing up to this point alluded to pain except for a look at her arthritic hands with their oversized knuckles and crooked fingers. But then there was her fall two days ago, with pain in her side for which

she is going to see her doctor about tomorrow. In response to a question about her first thoughts in the morning, she offers the following:

Well, I like to thank the Lord I had a good sleep or made it through the night or whatever. Then before I eat my breakfast I like to read some little devotional book or something you know. I have one that's called God of Wonders . . . .

Alma's narrative is a story filled with considerations of how to care for and plan for the needs of her body. Taking care of nutritional and physical activity needs, maximizing sleep, and minimizing night time trips to the bathroom, are all thoughtfully addressed and carefully planned. Alma has done her homework on what is beneficial to keep her body as healthy as possible. She also is very purposeful in providing for her spiritual needs. Her story continues and tells of even more considerations regarding her body.

And then I finally brush my teeth and that's a challenge because of my vision. . . . I can't really see clearly. So about a year ago or better we found these little, well they're kinda like toothpicks, but I use them better than floss, I can, with my arthritic hands and stuff. Floss is not for me. So then, I do the dishes and then I have to get sunshine. I go out and relax and if the sun is hot enough, take off my shoes and socks and get a tan, and vitamin D!

More daytimes activities are described. Alma then relates another walk in the day and maybe more sunshine, a trip to the gym a couple times a week, cooking of healthy food items, and trips to various doctors. She gets a massage once a month to benefit her circulation. The evening involved another walk and a bit of enjoyment.

Last night we [Alma and her daughter] were looking at the sunset . . . I sometimes go out and I know when Venus and Mercury are close together . . . I sit on my chair, with the binoculars to look at it. . . . My husband was interested in astronomy and I learned from him. I wanna enjoy it as long as I have eyesight to see it.

Even her pleasure has aging body implications. Alma takes melatonin an hour before bedtime to prepare for sleep. “I get in bed, arrange the blankets and lean the thing back and then turn on my tape recorder and put my CPAP thing on.” She also has some sleep apnea which the CPAP “probably” has improved, but “at least it has improved my daughter’s concern” (laughs).

Alma was very unique in her concern for her diet and obtaining optimal nutrient intake. Norma, who lives alone in her own home, has another approach with different priorities. “I generally eat two meals a day. That’s all I eat. I don’t get hungry. . . I’m not as hungry. Well, I guess because I’m not active you know, probably, maybe that’s why.” When asked about her dinner, her reply is short. “Well, let’s see, what I like is fish...and I like shrimp. So, that’s probably what I’d eat. I keep fish in my freezer.” With that, she usually has “some canned vegetables, corn or mixed vegetables, you know.” Norma’s fish and shrimp are frozen fish sticks and breaded, frozen shrimp. Her vegetables are canned, her preparation easy. With a decreased appetite, she has very little incentive to cook or be too concerned about her diet.

Barbara, John, Betsy, and Betty do minimal cooking and have varied concerns about nutrition, vitamin supplements, and dietary considerations due to health conditions. Walt and Madeline, eat many of their dinners out, but prepare breakfasts that are fairly routine depending on the day of the week, yet thoughtful in terms of nutrient value and health needs. Louis, Douglas, William and Rebekah eat meals prepared at their residential communities. Each described food choices that are made based on food groups and nutrient value. Douglas eats a bowl of Cheerios most mornings, but every lunch and many dinners are eaten either at restaurants or the homes of his family. It is

safe to say he never has a need to cook. Sarah, has all her meals prepared by family members that live in her home.

Food considerations clearly take on varied approaches for these participants, depending on energy level, appetite, and living situations. Exercise, even though it takes on diverse forms for each individual, is believed to be essential in caring for the body and staying well.

### *The Primacy of Exercise: A Way of Being*

#### **Louis's Approach: "Get One of My Walkers and Down the Hall"**

Physical activity is shown to be a highly disciplined effort and for some takes on a very precise and calculated approach. Louis, takes just such an approach to meet the needs of his aging body. Due to an acute balance problem, Louis has lost the ability to walk independently and is completely dependent on his walker. Multiple walkers sit at various places in his apartment as he has discovered that different types serve best on different floor coverings, for taking in a car, etc. Although Louis has made his adjustments, this man of large and formerly strong stature has experienced tremendous and meaningful losses due to his loss of independent walking.

L: I wake up at six o'clock in the morning and start looking at the clock because I have some thought about getting up at 6:30, and why 6:30, I don't know. . . . And I just put on my shorts, and my shoes, and no shirt or anything, and get one of my walkers and down the hall, and if you walk all the way to the extreme end, it's a pretty good hike, and I'll pause along the way and rest and whatnot. And then on my way back, I come to an exercise room, and I go in there, and there's some stairs in there, and I go up and down the stair steps three times because that gives me some exercise that I wouldn't normally get because I find I'm most comfortable right where I am now [his chair]. Anyway, that's part of my routine. It's half an hour walk generally in the morning.

I: So, the stairs must have arm rails for you?

L: Yes, and I get ahold of both of 'em and I, today, I started with the left foot, left foot up, you know, so that I wouldn't get in the, because it's a

little harder to pull on the one side, you know. And then tomorrow I'll go with the right foot first on those stairs.

Sitting in Louis's presence, it becomes almost overwhelming to consider the impact of old age on his body and his life. A military man, now needs to rest during his trek down the hallway. Yet, he does it daily, and his precise approach alternates which foot takes the lead up the stairs. His past, bringing him to his present, has given him the habit of leading a scheduled and disciplined life. This serves his 93 year old body well. The thought of the "other-ness" of the body comes to mind as I listen to Louis. This old body is not a part of his identity, it none-the-less gets care appropriate to "its" ability.

### **William's Approach: "I Have a Fixed Routine"**

For other reasons, William is also very precise about his exercise routine. Having his neurological condition for about 70 years, he is keenly aware of his body's needs. This man, whose body is shrunken from muscles stolen by disease, has an incredible active mind and positive attitude. It all has gotten harder, but it hasn't been easy since his early twenties. He uses a motorized cart or wheelchair to get around. Transitioning from one to the other or to a chair or sofa, is laborious, but taken all in stride.

So, the afternoons at least half the time I will go swimming. For example, yesterday, I went swimming during the noon hour. And . . . today I'll get to go swimming after we finish our interview. . . . I do it on my own, and I, because of my [condition], I'm limited. I should not overtire. I have a fixed routine. I go up the pool, do some exercises, and go back down the pool. That takes four minutes. I do five of those. So, it takes me 21 minutes altogether. I am able to do the crawl stroke as vigorously as I can. I cannot kick. So, it's all arm which is interesting enough. Before the early 1930s, all the Olympic records were made swimming without kicking. That was a later invention.

For William, his disease-affected body has impacted his lifeworld and defined his bodily being in the world for all of his adult life. He treats it from his precise engineer's



perspective. Informed by the research, William does what he knows is right for his body, having a positive approach despite the impact the disease has now. He knows his exercise routine is essential to preserving what is left of his bodily strength.

### **Being Faithful to the Body: “Come Hell or High Water”**

When I ask Barbara what she continues to look forward to in her week, she quickly responds “Well, we have a class called ‘Exercise in the Swimming Pool.’ Tuesdays and Thursdays, and I go to that come hell or high water (laughs).” When asked about her typical day, her reply indicates again that this is the highlight of her week. “My week is broken up by Tuesday and Thursday morning. I go to the swimming pool for exercise which is wonderful (laughs) . . . . So when you get old, get in a pool somewhere!” It is clear, that her body feels soothed and re-vitalized after her water classes. Her enthusiasm for the importance of this reveals the need of her body for care through exercise.

Exercise and water aerobics came up several times in the course of my interviews with John. He has quite a different feeling about it than Barbara, but it doesn’t change the commitment and the conviction that it provides necessary care for his body.

On Tuesdays, Wednesdays, and Thursdays I go to water aerobics. I go on the bus at 3:30pm. And it’s a peculiar relationship. I really don’t enjoy it. But I need to do that, so I do it. The people at water aerobics are amazed. They tell me how I walked when I started, and I have confidence now that I didn’t have before water aerobics. I try to walk a mile every day.

Even Norma in her limited way makes exercise a priority. She is proud to say “I can still walk around the block. . . . I usually take my wheelchair and push it, then when I’m tired I sit down. I haven’t fallen yet!” She also spoke about her overall weakness and the lack of strength in her legs. Yet pushing her wheelchair, she has adapted a way to

make walking a part of taking care of herself. She has lived in the same town all her life, and the same house since her husband built it over 60 years ago. She has family that lives next door, so Norma has a sense of safety in her older, and largely unchanged neighborhood.

For Betty her commitment for exercise shows-up a different way. She describes her morning. “I do my exercise right away. As soon as I can’t sleep in the bed, you know, sometimes three, sometimes four, this morning I got up at five . . . but sometimes I go back to bed.” Betty has a stationary bike set up in her living room and a pulley type weight machine in her garage for her arms. Our next conversation reveals someone struggling with her body, which is speaking loudly to her.

I can’t walk like the distance that I used to walk. But you know I exercise on my bike every day. I’m real punctual with that because you know if not, my back hurts. I guess it’s my hips huh? But I noticed that. I’ve always walked fast, of course I’ve slowed down, but still, compared to my friends, they’re with canes or walkers or everything, and they call me the “Iron Woman,” but I kinda get tired. I’m not the same . . . but you know you gotta be faithful. You can’t be lazy. If I don’t, I notice it right away. You know, I try to do things for self, first (laughs). First Betty, because this other stuff can wait.

Being younger than many participants, Betty is in the midst of noticing body changes and coming to terms with what her body is saying to her. “I’m not the same,” is what it is saying. She is faithful with her cycle and arm weights; she knows to put this first among her priorities. Her body speaks to her rather loudly if she neglects it—“I notice it right away.” Betty has a sense of what is ahead for her and her body. Her best friend is blind, and her sister is five years older. She knows her stationary cycle helps manage her loud body and also her anxiety about what is ahead.

Rebekah's motive for exercising to care for her body may be different, but she is still committed to it.

I look at myself in the mirror and I see this flabby fat hanging. I said "Oh my God look at this, I've never had this before!" . . . I said "My legs is all flabby and they've always been so firm, firm!" The doctor told me "Oh just walk and they'll firm back up!" And so my sister and I try to walk. We walk down to the corner and walk around the whole building.

As independence and autonomy waivers, as control over many aspects of life and body wanes, most participants demonstrated a committed effort of caring for their aging, changing bodies through some sort of manageable physical activity, even pushing one's wheelchair around the block. Yet, when the inevitable illness or fall comes, it is often hard to rally. As Madeline related "I know I need to exercise, and I'm not gonna get any better...but I can't seem to budge myself."

### **Adjusting and Adapting to This Changing Body**

"Old age demands that one garner and lean on all previous experience maintaining awareness and creativity with a new grace."

*(Joan Erikson, 1997, p. 7)*

As long as these oldest-old have been living in their bodies, they are strangely unfamiliar with them. Bodily functions and abilities that were done previously without thinking, require new strategies. Betsy characterizes this beautifully as she describes what life has been like for her at 87 years old.

S: It's having to get used to a lot of things that are different. So different because I have to do things, think of what I'm doing. . . . And the different thinking, you have to think differently, and being adaptable, adaptability, persistence. I have to learn patience, patience (laughs).

I: You're laughing a little bit with that one. It's been hard?

S: Yeah, because I've always thought I was patient, but now I know I'm not.

I: When you say "think differently," can you tell me a little more about what you mean by that?

S: Well, I have to stop and think of what I'm doing . . . before I didn't, not that much you know, but now I have to think of just about every step. . . .

And doing everything too. Asking the Lord too. [Long pause] I have to ask the Lord “What should I be doing now?” Because I make too many mistakes on my own. So I ask the Lord a lot.

Some of these body inabilities or changes may seem inconsequential, yet these changes and new inabilities leave their mark on confidence and are reminders that the body is aging. Sarah cannot take a shower if she is home alone. “I have learned to do well with sponge baths.”

Betty, is very proud that she can still wear her high heels. However, there has been a new challenge that she chronicles in her humorous story-telling manner.

I still wear high heels. . . . But you know what? I find, I got a pair of high heels, you know the strappy, and now I find that my fingers won't let me pull the straps up! So now I have to get, what are those? Shoe horn! And I get the hook and I (laughs) gotta allow myself time, but what else do I have but time? So there I am before I go to church, you know, with a shoe and a shoe horn! (Laughs). . . . My niece says “Betty, are you afraid?” I said, “Well, thank you to God.” I'll probably fall now saying this, but I never have fallen. Yet.

Betty has yet another adjustment she has needed to make due to the arthritis in her hands.

B: This arthritis came up [holds up her bent and swollen hands] . . .

I: Can you still open jars and things?

B: I have those things, you know.

I: Those things that help open jars, hmm hmm.

B: And I don't buy, like big dill pickle bottles anymore. One time, I bought it, and I started on the counter there you know, and then I couldn't do it. So then I sat down, and then I started here [jar up at chest level], and then I started down here [between her legs]. I couldn't do it. So finally I just took it to my daughter and sure enough, they opened it. . . . Yeah, I couldn't. So I don't buy those big jars anymore.

Barbara too has trouble with jars, and like Betty, it's due to the end result of severe arthritis. When asked if she has any arthritis she says nothing, only hold up her hands for me to see, the back of her hands towards me. She has very enlarged knuckles and her fingers are bent.

B: I have said to people “Look at my hands—no don’t look at my hands!”  
[Laughs and pulls hands behind her back]. . . However, this has not hurt  
for years . . . they haven’t hurt in a long time.

I: How does that affect things?

B: Well, I can’t flatten them out now [She held both hands palms together.  
They do not flatten out]

I: Can you open jars and things like that?

B: I have a rubber gizmo, and if that doesn’t work than I have another  
gizmo that clamps onto it and shshhhhh [it opens]. And for my age, I’m  
pretty strong.

Barbara’s approach is a bit different, she uses her “gizmo.” Betty, doesn’t buy the jars.

Betty is a full 10 years younger than Barbara, and her approach could be better described  
as resisting some of the changes her body is suggesting. Barbara seems to have adapted  
well to the changes and to have developed more comfort in her aged body.

Madeline took some pleasure in relating to me one “funny” change her body has  
brought her. “Mine is that I’ve lost so much height. I can’t open my cupboards  
anymore.” She gets up and demonstrates that she cannot reach the high cupboard up over  
her stove. I reply “Good thing you married a tall man!” But no, that is not Madeline’s  
solution.

Well, I have a butcher knife [she gets it out of the drawer] that I’ve had  
ever since we’ve been married, and it’s got a thing out of it [a notch  
broken out of the blade], so it’s kind (laughs) of a little hook [she uses it to  
open the high cupboard door] and then I can get it under the cereal box  
and pull it out until I can reach it. And things like that. I have that other  
thing that you grasp but I don’t use it, I use my little knife . . .

Madeline offers an example of adaptive creativity to compensate for the aging body,  
demonstrated with pride and satisfaction.

As described earlier, Louis has some difficulty getting dressed in his suit for  
church on Sunday. His dear friend lives in the apartment next door. After relating how  
time consuming getting dressed for church is, he describes his next step.

I call her [his neighbor] at 8:15am and she'll say "I'll be right over." She comes over and helps me get my coat on. It's surprising. I can get the coat on, but it's a pretty good challenge for me because my shoulders are so arthritic, you know . . . it takes her just 10 seconds, and I've got my coat on.

This tall man of distinction, needs help putting on his coat. While this could be humbling, he describes it with gratitude that he has his friend is there to help. Certainly this is the creativity with grace that Erikson (1997) is talking about.

While there are many, many more examples of these "smaller" bodily changes that are in the stories of the aging body speaking, these demonstrate, in the midst of much more severe or harsh challenges, some that are met with humor, creativity, humility, and grace. Caring-with-worry, however is very much a part of these experiences. The notion of corporeality, of these oldest-old persons being bodily in their lifeworld, is seen in bringing their highly experienced past selves to these present moments when they are confronted with evidence of aging. This 'moment of aging' makes great and numerous demands on the human spirit, yet the resilience and resolve to adapt to the changes is impressive. However, the experience of pain, so much a part of the body's experience in old age is a challenge that can test the spirit.

### **Pain as the New Normal**

In a weakened state, disability and pain are unwelcome guests that not only refuse to leave but also threaten to move in and take over.

*(Billy Graham, 2011, p. 84)*

As an intensely reflective journalist, Florida Scott Maxwell (1967) gives a possible explanation of my experience in several interviews with my gracious participants:

Few believe in the pains of another, and if the person in pain has nothing to show, can forget the pain when interested, then where is the reality of it? In one's self, where it ought to be kept I suppose. Disabilities crowd

in on the old; real pain is there, and if we have to be falsely cheerful, it is part of our isolation (p. 32).

They needed to be asked directly about pain, or there was high probability that it would not be brought up. The clearest example came at the very end of my third and final interview with Sarah. Several family members live in her home, and are there to care for her however she needs. She had described her lovely Easter Sunday and her success in making her famous peach cobbler. Our talk continued.

I: Have there been any recent times where it's felt bad or discouraging to be your age?

S: Only when I want to do something that I can't do! [We both laugh].

I: What are those things?

S: I'd like to wash the woodwork, cook, go fix what I want . . .

I: In terms of cooking, is it more just the physical ability to do it that you don't cook for yourself?

S: I can't stand up. [Putting hand towards her back]

I: Because you get back pain?

S: Uh huh.

I: So you can only be up for short periods of time without that hurting you? [She nods] Yes? Alright, so that's a big deal. Now, you didn't mention that when I asked you about pain.

S: Oh, I forgot about that pain! [Both laugh]

Our laughter here implies that we both recognize that this is significant. Sarah has back pain so severe that she can't stand very long; and she forgot about it. Yet, the understanding becomes one of pain as the taken-for-granted new normal. Someone that doesn't want to be a burden doesn't speak about it. To make sure all the practicalities of her daily life that are impacted by this back pain are understood, Sarah is asked if there are other things she cannot do anymore?

S: Ummmm, [long pause]. I'm glad I don't have stairs . . . I can't handle stairs. . . . That's why I have to have a wheelchair.

I: Moving around has challenges, doesn't it?

S: It does.

True to her demonstrated attitude of gratitude, she first phrases this as “I’m glad I don’t have stairs” and then “I can’t handle stairs.” Sarah is not complaining, she is “glad.”

Louis, first talks about pain as he describes his Sunday getting dressed routine.

This prompts the questions of how much pain is a part of his everyday life.

Not a whole lot. I think this pain comes from the walker where I’m in this position and walking, like when I go down to the end here. These muscles right here are just working constantly. And some people may be able just to kind of hold on the walker and walk behind it, but I’m more of a “plow-er.” I’m plowing and I can’t seem to get over that.

He says “not a whole lot.” Clearly the thought is that the way he uses his walker, which is vital to his balance, has caused some significant consequences. It’s not until after a conversation in the next interview that how much he is minimizing this is fully grasped.

I: You talked about your shoulders, arthritis in your shoulders last time. How is that doing?

L: It’s not doing well at all. And I think it’s coming from the pressure of holding the walker. . . you’d think that for as long as I’d been doing it, I’d be over this now. . . but it’s worse today than it was a week ago you know. And so, you just kinda, I took Motrin today to get some relief.

I: Does it get in the way of sleeping at night?

L: No, fortunately that doesn’t bother me. I’m thankful for that. . . . This lady that lives next door has awful pain in her hands when she’s trying to sleep. . .

I: I’m glad it’s not keeping you awake.

L: Yes, I’m glad about that, too, and that’s a lot to be thankful for.

I: What other kinds of things does it keep you from doing?

L: Anything reaching up. If I get up about higher than this, it starts to pain, and then, it gets excruciating. . . . [Discusses possibility of a second cortisone shot]. But these few things happen to you as you get older, you know, you’re just gonna get more pains like this, and to think you’re not is just foolish (laughs). Because you’re going to.

I: Do you ever get really frustrated?

L: I do once in a while . . . no, I have my moments (laughs) when I feel sorry for myself (laughs) . . . it just kinda gets to you, you know and you say, “Why me?” (Laughs). And then, you quickly remember how much better off you are than a lot of people, and then you retract your first



thoughts, and back off, and thank the Good Lord for what you have. And I do that every day.

“It just is excruciating.” From someone who has known pain from past war injuries, this is not hyperbole. Louis moves to the edge of his tolerance, and then backs-up onto the safe ground of gratitude. This makes it okay for both of us. Coping habits such as this will be discussed further in a later chapter. Louis is not the only participant to experience gratitude as a response to pain or loss. But here, he provides us a look at his lifeworld with pain as his new normal. It is to be expected; “these few things happen as you get older.” This loss of a pain free life can lead to “why me?” moments, of feeling sorry for yourself. Louis adds little plugs of laughter to lighten the mood. But I am left with a deep impression about his resignation to a life being lived in pain.

The chronic pain experiences of Norma, Betty, Madeline, Walt, Rebekah, Esther, and Betsy have been told in their earlier stories. Perhaps, as Louis illustrates, part of living in oldest-old age is living with new-normal of chronic pain, and to think it’s not “is foolish.” To re-visit the idea of caring with worry, perhaps this also includes the worry about sharing it with others, and sounding ungrateful.

There is also the acute pain from falls that sometimes goes away, and sometimes does not. All participants have narratives telling of falls, worrying they would have one, or ways they are working to prevent them. Again caring-with-worry. They know falls and their aftermath can be fatal.

### **When Falling Is a Real Concern: Loss of Trust in the Body**

“Several years ago my doctors insisted I begin using a walker to prevent me from losing my balance and falling. I would have been foolish to ignore their warning”

*(Billy Graham, 2011, p. 83)*

While each participant has their own unique story that portrays this concern of falling, this fear, this bodily mistrust, this actual experience is most likely the single most universal experience of the changing body as revealed in this study. It is evident that when walking and turning take effort and undivided attention, fear of falling prevails. Old age is a time when walking becomes a very tedious and intentional process. The bodily knowing, in the sense of the idea of corporeality, seems to become quiet, and one's body in reference to the space around it, in the sense of spatiality, seems confused. The body speaks very loudly and if one doesn't listen, everyone knows the result can be devastating.

***Lack of Confidence: "Will It Work?"***

John, who walks fairly well and without a walker, articulately relates an aspect of his experience in response to a question about what has felt discouraging at his age.

J: I get discouraged with my walk. In other words my confidence in my steps, they are not as good as I'd like them to be.

I: Do you feel a lack of balance or weakness or what is it?

J: Confidence. The main problem I have is confidence. If I take that step is it gonna work?

I: So that's a big change.

J: I'm aware now of taking steps, whereas before I didn't think about walking, I just walked.

I: Is it each step you take? How is that?

J: It's mostly each step. I try to walk a mile every day. . . . In the midst of that walk I, in other words, step, step, step, step [pause] the repetition of that helps me not think about it.

I: Does that get tiring to think about it?

J: I have to work at it at first, but then it begins to be a routine and I watch neighbors' dogs, talk to the neighbors.

To imagine how this is for John: "Ok, here I go. Pick your foot up. Is this gonna work? Step. Is this gonna work? Step. Now, the other one. Is this gonna work? Step, Step. Okay, you're going now. Step, step, step. Okay, it's working now. Step, step,

step, step...step, step, step... ‘Oh, hi there!’ Step, step, step, step... ‘Cute dog, you have there!’ Okay, it’s working.” This is John’s world of his walk in his aging body he cannot trust.

### *Thinking of Every Step*

Continuing with an earlier story of Betsy’s, she relates a similar experience. Here she is talking about her need to think differently.

B: Well, I have to stop and think of what I’m doing . . . before I didn’t, not that much you know, but now I have to think of just about every step.

I: And you mean literal steps, right? Your feet taking steps and . . .

B: Yeah. And doing everything too. Asking the Lord too. [Long pause] I have to ask the Lord ‘What should I do now?’ Because I make too many mistakes on my own. So I ask the Lord a lot. I have to remember that...

Betsy then gives an example of how focused she needs to be on what she is doing.

B: Let’s see. Getting my breakfast . . . I have a shake in the morning and I have to remember what’s next, and I don’t want to miss anything. And because everything is important to me. I have a couple medications in there, no not medications, they’re supplements. . . . And so, I have to make sure I don’t turn too quickly, ‘cause then is when I get into problems, and I’ve fallen before. I have to make sure that I’m focused on one thing. I can’t have my mind over here while I’m doing this.

I: When was the last time you’ve fallen?

B: Gosh, I think it was right here in my bedroom. I just without thinking, I just turned. Just turned and boy, I fell. Thank God I was right there in my bedroom and had things to hang on to and get up.

Betsy’s experience is that falls happen if one is not concentrating and focused—“just without thinking.” Most of one’s life, one can turn without thinking, but not in oldest-old age. For Betsy, learning and asking her Lord for help has been necessary to prevent falls.

B: It’s a thing of learning. You know we think we learn so much, but boy, we have to learn a lot all the time . . . you keep learning all the time.

I: Just to get through the day without falling?

B: Yeah, I have to ask the Lord to help me, to keep me from falling. . . . Jesus is my strength, asking Him to keep my feet going.

As she experiences it, her body needs focus and careful coaching to stay upright.

On my second visit with Betsy, I spoke with her daughter who had been staying with her mother for a week, since her discharge from her hospitalization due to a urinary tract infection. Her daughter became tearful relating a story about her mother's mistrust of her body:

She was stuck with her walker trying to come out of the bathroom door. They don't know how long she was just standing there before a neighbor came to see her. She was afraid to let go of the walker to press her Life Alert. She was afraid she would fall.

Betsy could not trust her legs to hold her up even while she let go of the walker to press her Life Alert. She was stuck and could not move her walker through the doorway of the bathroom. Betsy is fearful of falling. This experience of living with a body that cannot be trusted is full of loss.

### ***“Here I Go Again”***

Louis has severe balance problems and is walker dependent. He lives in an independent living community where he has alert buttons close by, an alert bracelet, and a friend next door with whom he has a mutual agreement to check on each other “at 8:30 promptly” each morning. Louis's first fall story was told during our initial interview:

I had that largest walker on the left there . . . and I guess maybe I had a false sense of security since it felt real secure, and I was back from a walk with it. I was trying to get used to it, got back to my car, and I was going to pack it up, and put it in the car, and I'm kinda leaning against it like this, and the car, and all of a sudden, this thing starts moving you know? So, I took a pretty good fall on that one. And that told me, “you've gotta be more careful.” So, I must say I've had a pretty good record here in the past year or two. . . . I had my falls here, and in the bathroom and various places. But fortunately I have a signal here [his alert bracelet].

Louis talks fairly confidently about the more recent fall experiences and his good record. He seems to see these falls as incidental, a normal part of his life. Unfortunately, on our second visit, the first topic he brought up was a fall experience of the previous week.

And so, it was coming out of [the theater] when I had a fall, with my walker, and the slope was only about like this, but those wheels, they just kinda take off on you unless you're really compensating by walking over a little bit on the other side and putting your weight over. If you're not careful, you just go right with the thing. That's what I did . . . I scraped [my leg] . . . just kinda slid, you know. I was all dressed up in a suit and the whole bit, went skidding down. . . . People came from all directions to help me up and get me over to the car. I got my coat off as quick as I could because I knew I had a lot of bleeding in here, and I didn't wanna get it all over my clothes. So, that worked out pretty well. I didn't ruin my clothes.

He *only* scraped his leg. He then described what he was thinking as this happened.

I just had this awful feeling like, "Here I go again. I've been careless again." I'm thinking about being careless and in a sense, I was being careless because you can compensate for a little slope like that. . . . But if you go with the slope, and your walker's here, and you're going with it, first thing you know, you're just gonna go right on over. So, you need to be thinking all the time about the necessary cautionary steps to take. And I'd like to think generally, I am pretty cautious.

This narrative characterizes a tall, well-dressed, proud man, falling in front of many people while exiting a theater after a play. "I've been careless again. . . ." He blames himself; he wasn't compensating. As a seasoned walker-user, he knows the physics of keeping it upright on a slope. But he wasn't paying attention, he was probably talking with his daughter. Something that most would be doing after enjoying a play. As John and Betsy were saying, Louis "should" have been thinking about every step, and a slope.

### ***"Don't Back Up"***

Douglas, has his own stories of living in a walker-bound body. He lives alone in his home of 55 years. He is asked if it was difficult to adjust to using a walker.

No. I went over backwards at my son's house, opened up my skull last Christmas (laughs). That's when my daughter said, "You're getting this" [the walker]. That is something to tell older people, by all means, *never* back up [said with emphasis]. *Never* back up. If you have something around there, turn around very slowly to go get it. Because when you start backwards, you have no defense at all—you're gone. This way [falling

forward], you can kinda protect yourself [with your arms]. I just went over backwards. I knew I was gonna go, couldn't do anything about it. . . .

I: Going down steps, does it feel like you've gotta really pay attention?

D: Yes, and I'll tell you why particularly. When you lose this sight, I asked the doctor, "Now, am I going to be wobbling?" And he said "No, but you're gonna have a depth perception problem." He said "When you do something, put your head down and look." Yeah. And I do that on the steps very carefully.

I: Some people find using a walker to be a hard transition . . . .

D: That's vanity. . . . And I could care less if it's gonna help me. Yeah. Well, people laugh about it. I kid and I call it my Lexus and we have a lot of fun with it.

I: Have you had other episodes of falling?

D: Oh yes. I've fallen. Because the depth perception. You think you're on the level and you hit a curb and over you go (laughs). Two or three times, oh yeah.

His sentiment of "Do not back up" was felt by Douglas so strongly that he repeated it in the next interview. This time he added the story of a friend:

Had a dear old friend, he went back on his head, and it killed him right there. He died. Hit his head on the pavement. So, so dangerous. Holy mackerel. I take little tiny steps and turn around (laughs). I tell anybody who's getting older, "Don't back up, ever." You're so susceptible to losing it all . . . you're gone. You can't do anything about it.

Douglas was emphatic about giving this piece of advice. His fall experience, and the death of a friend, has caused him to recognize his vulnerability, and his body as not trustworthy. Tiny steps to turn around, use of his walker, watching every step as he goes down stairs. He thoroughly thinks through the details of moving his body safely from place to place. Douglas is a happy, humorous individual who admittedly always looks for the positive. Seeing vanity as the culprit, he will have nothing to do with it. Here Douglas demonstrates his perspective with humor, calling his walker his Lexus. It is his friend in this caring for and managing of his old body.

### *“I Have a Fear of Falling”*

Walt, identifies a body change as either an inner ear problem or “just plain poor perceptive imbalance.” “I have a fear of falling.” His wife Madeline is present and supports his concern, “he has been stumbling quite a bit more lately.” Walt relates:

Because like I came in from getting tomatoes and fell almost across the table [at noon today]. . . . Well, the poor perception thing, is knowing where you are in space. That your feet are where you think they are. And there’s a bit of dizziness, but nothing that affects the eyes. I’m watching ‘em very carefully in terms of driving.

A week before this interview, Madeline had experienced a very bad fall in their bathroom, that was related earlier in this chapter. She had a significant amount of bleeding and Walt had called 911. Falls have definitely been a part of their life and Walt’s fears seem heightened. Madeline is struggling to recover. They both have been very discouraged. Walt has been caring for her. It is another picture of the Care-as-Worry concept of van Manen (2002a). There is worry in this caring for and about their bodies. Both bodies are proving themselves untrustworthy.

### *More Stories*

Alma’s history of falls is fairly extensive; one of them was spoken of earlier. There have been several others however, one being fairly tragic. In 2009 after her husband died, while making funeral preparations, Alma suffered a severe fall and broke her femur. Due to her hospitalization, she was unable to attend the funeral. While her children offered to get her to the funeral, she felt strongly that she wanted the focus to be on her husband and his life, and not on her. She did not go. This has left long lasting sadness. This and more recent falls have left her with a deep sense that the potential for

falls is a distinct possibility for all. At the end of our last interview, I asked what else she might like to say about her experience of living this long life.

Don't take anything for granted. People that are getting up there and have really not had a fall and stuff, that is the most deadly thing you face . . . the possibility of falls . . . and that's one reason why I'm doing these stretches and exercises . . . to try to keep my balance. . . . But in going out today, I always have to see how far the step down is, the threshold and whatnot . . . and you just have to take time to do that . . . Safety first!

And there is Norma who is afraid of falling, pushes her wheelchair around the block. Her legs are not to be trusted. For Rebekah, her fear is such that she decided it's time to move in to a residential community so she will be "safer."

The situations and contexts are different; the fear is very similar.

### *An Experienced Faller*

William has a unique story which highlights a particular life experience that created a distinct lifeworld for him in oldest-old age. It is not being hyperbolic to say that William's body has been ravaged through 70 years of chronic disease. As he says it, "For a [disease] victim, life is a struggle."

I: Strategizing how you're gonna do this and how you were gonna do that, and get from here to there has that gotten pretty natural for you? Or is that a lot of work?

W: Well you see, I've had 70 years of that. And so, thinking it through doesn't bother me. The only problem I have is that my mind works faster than my body, and if I am not careful, I will have an accident.

He goes on to describe his history of falls.

I lost count. I suppose 10 years ago, I'd had by then well over a thousand accidents. See, I had to learn to walk when I was an adult, and so, I had all the falls that a child would have . . . I've had about three falls in the last five years. The [electric] wheelchair over there, I often have that arm tilted up when I'm recharging it. And I suppose within the past year, I sat down on it, only I sat too far over to this side, and I fell, and I banged my head against the side of the filing cabinet and split my head open a little bit. . . . I have fewer falls now, and I've been lucky because some of my



falls, if I've fallen a foot off of where I fell, I would've been killed or paralyzed, but I didn't (laughs).

The everyday lived of this disease survivor is almost too hard to imagine. His casual talk disguises the difficulties and challenges—"killed or paralyzed." While he clearly recognizes the potential danger, some resignation to this must come with all the years of dwelling in his particular body. His bodily changes are distinct.

Well, (sighs) see as a result of my having polio, for the last 73 years, I've always been having changes in my life, and so, I've had to monitor that constantly over that time. It's just a routine matter of course. I can tell you what changes I've had in the last week for example . . . I've always had to be very careful not to over exercise or to under exercise . . . so with me it's just a way of life. . . . I guess I've lost a little confidence in my stability this week. Now, next week it may be better.

William explains that his decrease in confidence is due to near falls, times he's caught himself. He describes it as thinking "Gee, I'm reacting more to this slight misstep than I was last week." As someone who has well over 1,000 falls, he knows all about falling. So acute is his bodily awareness in the moment. This experienced faller, tells of a moment of recognition that confidence is lost, for him a cognitive thing, due to a physical decline or misstep. So aware is he of his bodily deficiencies that he has grown accustomed to monitoring every move. The other participants speak to this as a recent, but imperative change of being in their bodies. In spite of the longevity of his post-disease challenges, his body is still changing; he still miscalculates the effort of getting securely onto the seat he is moving too. How much more difficult this may be to those new to this necessity of thinking through every move. Even as I write this I sigh, from the sheer exhaustion that must come from this work.

These lives reveal a body that is experienced as untrustworthy because it has weakened or been damaged from old age. Trust in the body is lost. No longer can these oldest-old persons take their bodies for granted. No longer do they have the luxury of automatically walking over to refrigerator, or not thinking about how or where their bodies are going. No longer can they quickly turn around to greet someone, or swoop down to pick up a dropped item off the floor. Everything needs to be thought about and thought through with focus. Do I have the correct walker for the journey at hand? Am I concentrating? Am I starting with the correct foot? Am I moving with the correct stride? Am I plowing my walker instead of merely rolling it? Is there a slope in the walkway that I need to be aware of? How far away is that seat? How deep are those stairs? Will my legs give out? If I let go will I fall? Someone from behind me calls my name and I am tempted to quickly turn. But no, I need to rotate my body slowly, taking tiny little steps, moving my walker around in a slow circle until I face my greeter. Take my walker, choose the right type of walker, push my wheelchair . . . .

### **Loss of Mobility: Fading Physical Strength**

Aside from the potential of falls, just moving the body from one place to another can pose its challenges, as William described above. Yet moving the bodies of the oldest-old, or lack of movement, involves other issues that are more subtle. Rebekah attributes her knee pain and difficulty of going up and down the stairs in her own home as the reason her daughter pushed her to find somewhere else to live. For Norma, it is her lack of mobility that she believes causes the deep aching she has in her muscles; weekly massages are helpful. “Since I don’t do anything, I don’t move around, I need that massaging.”

Betsy's expressions of her spirituality have been impacted by her loss of mobility. As she describes her private times of worshipping her Lord. "I have my hymns, I have worship. But I usually just (laughs) have a wonderful time with the Lord . . . moving, moving, I get up on my feet usually . . . I used to, [prior to illness] let's put it that way."

Choosing which devices are best for which situations is another aspect of mobility that can be complex. Sarah relates these various decisions that have been a part of her everyday experience of moving her body around. She uses a cane in the house, a walker on a walk outside, and a wheelchair for long outings.

S: Like when I go shopping, I go and they take the wheelchair and I go in the store. It's easier for them and really much easier for me. I used to could use a cane and go in the store, and then, push the basket. But now, I can't push the basket, it was much easier when I could push the basket, but now it's not very comfortable for me to try to walk with the basket.

I: How have those adjustments been for you?

S: At, first it was not easy because I'm a very independent person . . . I like to do things for myself.

Sarah's narrative hints at something more involved than just mobility aid choices for her weakening body. It is reflective of her independence. Independence revealed itself to be a highly significant experience for the oldest-old and will be explored more fully in the next chapter. But for now, we can be aware that the everyday, slow fading of physical strength and its resulting mobility issues can signify even more difficult realities.

Both Douglas and Louis have several walkers and have discovered that different walkers are better for different situations. For Douglas, one is left in his step-down kitchen so he doesn't need to carry one down. They both have lighter walkers that are more portable and easier to put in the trunk of a car. One walker is better on carpet, and another for smoother surfaces. All this has been thought through and is again thought through before any outings or even, moving from place to place. Louis has a smaller one

in the bedroom that he uses when he needs to get up to the bathroom at night. Moving the body around when it is no longer very moveable takes careful consideration of the equipment involved; thinking through the strategies is ongoing. The everyday world of movement, of being in the world as a very old person requires constant adaptation and strategizing to stay safe yet engaged in the world of others.

### *An Old, Old Story Told*

Louis illuminates his experience as he speaks of regret and discouragement about his physical limitations.

Well, there's always a sort of lingering regret that I can't get around better than I can and do some of what I would regard as very routine things effectively, like I used to be able to do. And of course, this is an old, old story. I realize that, but yes, this continues to bother me a little bit. And myself thinking before we go anywhere you know, "Well now, how am I gonna get into the place?" . . . And already on Thanksgiving, I'm a little bit concerned about that trip with the family. Although, I know they'll be ever at my elbow to help me every place along the way. . . . But there's still regret there that I can't do things that I did before. But this, I think is the normal result. You can hardly be happy about the fact that you can't walk without a walker, and that even with a walker, you've gotta be very, very careful. I feel regret a lot on this, and it's something that's kinda with me all the time, yeah. I haven't graduated from saying, "Well, I'm lucky to be like I am," you know. You feel that too, but you've gotta feel some regrets here and there.

Louis so poignantly tells "an old, old story" of life in a very old body. He certainly recognizes that he is not the first one to be in this situation. In typing this story now however, I almost feel more saddened than when I was in his presence, when he spoke it to me. Louis was very transparent here. His more typical attitude is one of gratitude, which is what comes through at the end of this passage. Yet, there is still regret. Not being able to do, needing to think through, "how am I gonna?" all speak of a passage into very old age, in a body that tells the story. Behind his words you can hear

him say something close to “I wish I could say I am thankful to be alive all the time. But there are times when not being able to walk well is very hard, disheartening, and discouraging, and I’m not sure it’s worth it.” He is walking the tightrope of aging; falling off with discouragement or regret, or staying balanced with gratitude.

### *Fatigue and Frailty*

“Someone asked me once what my biggest surprise was about growing older, and after thinking about it, I answered, ‘The loss of strength, the sheer inability to keep going.’” (Graham, 2011, p. 82-83). Billy Graham’s sentence carries incredible emotional weight as he describes his lifeworld of fatigue and frailty. The lived experience for Billy Graham and for most oldest-old, is indeed that these body changes and discomforts, while they vary in intensity from day to day, are here to stay. Life without them is over; they are here for the duration. Each individual confronts this in their unique way.

Betty, who easily looks 10 years younger than her age and in many ways is still the spirited woman she probably always has been, conveys her experience with a sense of humor and honesty. Although her movements are quicker than most her age, even energetic at times, she tells it like it is. “Of course, there are days I don’t feel like doing nothing!” Betty relates how she decided to completely cement her small backyard. She didn’t want to, but she just couldn’t do the grass and the flowers anymore. As she points to a potted azalea that is flowering, she laughing said “I can’t even take care of that when I’m sick!” Her aging body convinced her to change her yard. Still, she knows there’s more to come, as her friends all talk about old age:

Every time I talk to my friends, we always end up with old age, you know. Just yesterday I talked with a friend . . . she’s 89. And she was telling me, “Betty, I wake up,” she says, “I’m tired. I wake up tired.” And I says “Join the club” (laughs). I look at my recliner there and it’s really handy!

Betty acknowledges her change in energy level in recent years:

Eleven years ago when I moved in here, I used to be able to clean everything in one day. Now (laughs), I get tired and I'm here by myself, I say 'What's the hurry? What's the rush?' And I'll just sit.

For Jim, things are a bit more extreme. There is no humor for him in his situation.

On our second visit, although this was overall a positive experience, he related that his caregiver took him to a local presidential library. "And the thing I disliked about that, the pluses and minuses, was that I wasn't able to do all that I'd like to have done." His tiredness shows up in other ways. He describes his mornings.

I usually wake up about 7 o'clock, but then I roll over and go back to sleep. Recently I stayed in bed for 24 hours. . . . In other words, I'd wake up and the bed looked so good I'd go back and lay in it some more. I don't, and this is a big concern of mine, I don't utilize my time properly. I have a tendency to be lazy!

Perhaps Jim is not recognizing his body saying it is older now. It must be laziness.

Walt's life world still includes going to work four days a week. This clearly is life-giving to him. Even so, his fatigue is causing him to re-consider his abilities to keep going. Most days he comes home and takes a nap in the recliner before he is able to do anything else. As he describes what it is like to be 92 years old, fatigue is revealed.

The fatigue factor's the one I notice the most. I get tired a lot faster and can't do as much. And I'm increasingly lazy, just kinda wanna...two or three times I've come home and said, "I think I'll quit at Christmas." I haven't done that, but I think part of this was this." [Madeline's fall and slow recovery].

Despite, the gains and reward of his professional life, Walt is living with a body that seems to be resisting continuing things the way they have been for so long. His body seems to be whispering in his ear, "It may be time to listen to me." Walt is hearing, but has not yet determined his reply.

Douglas, the centenarian, peppers our conversation with laughter. Talking with him was always such a pleasure. He is resistant to talking about negative aspects of his life for too long. But Douglas is honest as he describes changes; and he does get tired.

D: Oh, not as vivacious as before. The desires are the same, but the ability to do some of 'em are not there (laughs). I can't take the trash cans in. . . . Little thing like that I have to have done. Or if there's anything that's manual labor, of course can't do that.

I: How would you describe your energy and fatigue level?

D: That drops, of course. I notice it more. I used to sleep eight hours. Now, I sleep about six. It's pretty normal for older people. But you sit watching something and fall asleep while you're watching (laughs). So, I probably get the eight hours a day in there (laughs). I never did that when I was younger, of course. I was too busy!

At other times in our talks he enjoyed telling me he was golfing at age 90, and traveling Europe at 85. Douglas has had an exceptionally long physically active life and noticed most of these difficulties beginning after his first fall at 91. He does seem to be resigned to his body-with-a-walker, and won't walk without it.

For Rebekah, her fatigue is one of the discouraging aspects of life at 90 years of age. Despite her positivity, she is living with a body that disappoints.

Well, one of the things you find that as you get older, your muscles get tighter and you can't move as fast as you used to, and you need more rest, and you need more sleep. I have not been used to going to bed early and 'cause before I moved here, I was up every night 'til one or two o'clock studying or reading.

These things of disappointment for Rebekah, do have to do with her 90 year old body.

Sadness and even surprise are heard in her voice, but she has resolved that this is a part of growing older. Rebekah is living her resolve to be happy in her new life.

When I first met Sarah, I was struck by her smile, and her frailty, which was evident even in the softness of her voice. She laughed about how easily she falls asleep during the day.

Sometimes we're in here in the living room. My oldest daughter comes over and we all be talking and they'll say, "Mom, you're asleep" (laughs). And if I'm in the bedroom, and they come over, and they say, "Well, we came to see you but you were asleep" (laughs).

Sarah, seems very comfortable about napping whenever she needs to. Her lively household doesn't seem to interfere. Fatigue also peeks in when she is asked about going to church during the week.

Not during the week. I go on Sunday, but they have Bible study on Wednesday night, but I don't go anymore. It's really tiring. So going, they put me in the wheelchair, and take me out of the wheelchair and take me into church. So once a week is enough.

Sarah seems satisfied with this adjustment to church-going, and the appropriateness of it.

She has a quiet comfort with her physical limits. No resistance to hearing what her body is saying to her is evident. With fatigue, she appears to have acceptance.

### **Fear Compounded: When Bodies Speak at a Different Pace**

Many participants spoke of fear as part of their aging experience. Fear of falling, another heart attack, further macular degeneration, being more fragile, a slow and difficult death, loss of ability to drive and the resulting loss of independence, or even an ambiguous fear that keeps one awake at night, were all in the narratives of oldest-old age. Fear and worry are evident in each single life, but perhaps it is further compounded in the lives of spouses.

Most people would say that living out a long married life with a spouse would be the most desirable way to live into oldest-old age. This still rings true. Yet, through spending time with the solitary couple in this study, it is realized that even this, has its exceptional challenges and changes, losses and gains. It is worth spending a short time relating this experience of living into old age as a married couple.

What was striking during the first interview with Walt and Madeline was the divergent trajectories their lives have been on, how they are negotiating retirement, and



how their bodies seem to be aging at differing paces. Walt's career has only gained momentum after age 70. That was fine with Madeline, as she traveled the world on her own until 85 years old. Now, in their early nineties, while the sense of aging has accelerated for both, Madeline is the frailer one, with compromised and fragile health. Her body is slower, in more pain; she has become more confined to their home. They are both coming face-to-face with old age, and they see it reflected in the eyes of each other.

The second interview was conducted with both of them together, as Madeline had recently had her bad fall and was struggling with recovery. For herself, Madeline related "I don't remember dreading getting old, but I dread the physical frailties." She worries about "being so tired all the time. I can't do what I would like to do and the doctors don't seem to be able to help me." After her fall, she spoke of having to struggle to do anything. "I get so dizzy and so woozy, I feel like I'm gonna faint." At this point Walt speaks up. "And that's kinda new. That frightens me." We continued to talk and Madeline admits, "I could live to be 100, but my mind has changed about that now . . . I don't wanna live to be 100 if I'm feeling this way. It's not worth it." Walt worries about her "throwing a blood clot" due to her atrial fibrillation, and the way she sits so often at the dining room table, with her head down. Madeline explains that "it's just so comfortable." It is quite apparent that for Walt, this is a foreboding image.

The conversation shifts to Walt who admits that the "fatigue factor" is getting to him. He notes that he is coming home from work, very tired. Perhaps on account of needing to care for his wife. Walt then discloses that "We kinda have a covenant that we're gonna die about 15 minutes from each other. So, if she's dying, then I'm not far behind." Later in our conversation, we begin to talk about how discouraging it is at this

time of life that recovering from illness or injury takes so much longer. Walt comments, “Like, we’ve had bad colds for about, well we’re still with bad cold residual. And you wonder if this is it.” Madeline, who is having a hard time paying attention, is asked “have you wondered if this [the bad fall] is your last illness?” When she replies “Yeah,” Walt asks her if that would be ok. Madeline responds “Yeah. As far as I’m concerned I’d be fine . . . I mean, except for him [Walt], I don’t care if I went.” As I sit there with the two of them, I can sense that this is very hard for Walt to hear. They have been married for 70 years.

Although Madeline is the one with the most recent decline in health, she has her concerns about Walt. She has noticed that “he is stumbling a lot lately.” The “noticing” of changes extends from herself to her husband.

M: He sleeps in his chair. He hasn’t said that, but he goes in there at four o’clock or so and turns the TV on, and then, he’s immediately asleep. And you sleep until I call you for dinner or something. Anyway, he does, have a problem with sleeping I think.

W: That’s what I call denial. I even forgot about it. But I have bronchiectasis, which means I don’t get all the oxygen I need. And then with the maturity happening, I don’t have the energy. So, when I get home, I usually say to her, “I need to take a nap.” And she doesn’t like that.

M: Well, I it’s not that. I just worry about him.

W: You know why she worries? [to me]

M: My (laughs) sister’s husband . . . she just sent me a birthday card saying that he’s been diagnosed with early Alzheimer’s, and he sleeps all the time. . . . I don’t think he has Alzheimer’s, but he sleeps all the time (laughs). Well, maybe.

Later, Walt confides his concern about her possible depression, and that all this time she’s been watching what’s been happening to his career. “But she had a very similar career. But in this thing of aging, you retire, if you really don’t have anything that grabs you, you have 18 months. So, she’s lived beyond that.”

For Madeline and Walt, their long life together carries with it worries and fears for one another. They exchange concerns for self and concerns for the other. When asked about what Madeline would take a picture of if she were given a camera, she chooses the beautiful harp standing in the living room. They bought it one Christmas not too long ago, with plans of learning to play it. Neither her nor Walt have done much with it, “We just don’t do the things we want to do.” Walt’s ongoing career has satisfaction for him, but the guilt of being gone when Madeline most needs him is evident. It is taking his energy, and he realizes it. Madeline’s worry about him may also carry with it some of the vulnerability she senses. “What if something happened to him? What would happen to me?” Their aging bodies are speaking loudly to each other.

### **Conclusion**

Our bodies affirm our existence. As such they are said to be primarily existential (Schuster, 2013). Through our bodies we experience the world in an existential, life affirming way. We understand, receive from, and respond to our world through our eyes, ears, mouth, hands and feet. Our various emotional responses, desires, and needs show-up and are made known through our corporeal self (Leder, 1990), our bodies in the world. As phenomenology seeks understanding beginning in the lived experience, it is vital to commence this work to understand aging, with an understanding of how the oldest-old experience their bodies, and their bodies in their world. We have heard from them.

These very old people speak to the whisper of the aging body; the gradual call to a walker, the inability to open a jar, the forgetting of words. They also convey a pin prick of sorts, no more knitting, gray hair everywhere, weak knees, the slowness; just little jabs of reminders from their “old-ness.” And then there is the shout of aging that cannot be

ignored, the devastating fall, the sudden loss of eye sight, sickness, and excruciating pain. This range of losses of the body's abilities accumulate and challenge the spirit of the very old. Even this is a loss. This noticing of the body's changes, being controlled and preoccupied by the body's ever increasing needs and demands for accommodation, wondering about the significance of these voices of the body, and worried as one responds and cares for it are new ways of being.

Phenomenologist Drew Leder (1990) proposes that even as “the body is the most abiding and inescapable presence in our life, it is also essentially characterized by absence.”

The younger life is largely lived with corporeal absence. He goes on:

That is, one's own body is rarely the thematic object of experience. When reading a book or lost in thought, my own bodily state may be the farthest thing from my awareness. I experientially dwell in a world of ideas, paying little heed to my physical sensations or posture (p. 1).

What is intriguing about his view, is that these participants seem to be telling of an opposite experience that is the reality of oldest-old age. In a metaphorical, even interpretive sense, they are experiencing their bodies as speaking to them—very often and very loudly. Gone are the days that are not filled with bodily considerations and reactions to its world; gone are the days that these late-in life persons do not have to listen to, attend to, and care for their ever-changing, slowing, untrustworthy, and often painful bodies. And what does this mean to them? Quite possibly, in order to quiet down their bodies, they choose to sit long, take naps, get hearing aids, use walkers, and do their best not to fall. All of this body presence and awareness in their world is a reminder. It is the whisper, prick, or shout, that the body is aging and in a personal way. “You are very old.” This converts to “I am very old. I need to care for this body differently.” This

care may be filled with the burden of worry about the “oldness” of this body and thought to its finitude.

If, as Leder (1990) proposes, we largely are embodied in this world in a way that takes very little consideration of how our physical selves function, as least when we are in good health, listening to these 13 people tells a different story of oldest-old age. The body disappoints and demands much. This of course, does not come as a complete surprise. The length of this chapter affirms that this story of the old and aging body, as described in these narratives, is a complex and ever lengthening one. And, it needs to be heard.

These body changes are interpreted here as losses of former abilities or health of a younger body. Loss of the body that is rarely the “thematic object of experience.” According to van Manen (personal communication, October 20, 2014), “Ontologically speaking, everything is always contextual.” These bodily losses are contextual; they do not occur in isolation. The oldest-old experience the aging body from an extensive past, brought into the present, and with hope of a future. In light of this, one of the challenges that this group has in common, usually as a result of the aging body, is the tension between maintaining independence in light of increasing dependence. Each individual comes to this time with their own past, present, and hope for the future concerning their independence. The following chapter will relate some of the story as told by those in the midst of living this “moment.”

## CHAPTER FIVE

### THE CHALLENGE TO INDEPENDENCE AND AUTONOMY

“I have a duty to all who care for me—not to be a problem,  
Not to be a burden. I must carry my age lightly for all our sakes,  
and thank God I still can.  
Oh that I may to the end.”

*(Florida Scott-Maxwell, 1968, p. 31)*

"Hope prevents us from clinging to what we have and frees us to move away from the safe place and enter unknown and fearful territory."

*(Henri Nouwen, 1979, p. 77)*

Phenomenology wonders about and seeks to understand experiences of coming to know how to live in everyday lifeworld situations in a meaningful way (Attig, 2015; van Manen, 1990). There is also value, even emphasis, seen in exploring the singular experience of an individual as we are each the center of a unique and distinct world of our own. We do not choose our world, we are born into it. As such, temporally speaking we are each historic beings, living in the present, and imagining into our future. We are learning to understand, make choices, and create meaning as we go through the world caring about our social and physical surroundings, and our being in the world. Our identities are found through the impact of our life histories on our present and anticipated unique daily patterns of interacting with this world, social relationships, and our divine reality, in a caring manner.

With this understanding as the underpinning, during the interview process it was recognized that the impact of each participant's history and what matters to each participant in the present tells a story full of distinctions of each life. Yet, there are commonalities and shared meanings of lived experiences brought on by living long and in to this oldest-old time of life. Bodily changes due to aging alter some possibilities for living and limit or completely eliminate others. Influenced by phenomenologists Husserl

and Merleau-Ponty, Leder (1997) offers the notions of “I can” and “I cannot” that may be helpful here in understanding how things “I can no longer do” impact one’s bodily knowing. Lack of trust in the body, and the accumulation of things “I can no longer do,” interplay with the availability of independence and movement to dependence. While Leder is not addressing old age per se, extension of his ideas of bodily knowing, the control we have as the “I can,” and the control we do not have as “I cannot,” are useful in understanding the narratives of the lived experience of aging.

We have seen that there are commonalities and shared meanings among participants in losses and/or declines related to vision, mobility, memory, and more. More than any other challenge, this struggle with maintaining or losing one’s independence, the awareness of the growing “I cannot,” was evident in the lives of all participants. So prevalent were the narratives of challenge and loss to the view of oneself as an independent and autonomous individual in this time of life, that it was deemed wise to explore this lived experience on its own. Through the use of paradigm cases, two individuals will portray differing experiences of being confronted with this challenge. The first is the narrative of someone who sees herself as having moved through a transition to a more dependent but still autonomous self; the second, the story of fearful anticipation of what is yet to come. Rebekah and Betty tell their stories.

### **The Paradigm of Rebekah: The Passage Into Old Age**

In the previous chapter, Rebekah was heard using the term “the shocker” to relate how she was confronted with the meaning of oldest-old age as she began transitioning from living independently in her own home into a residential community facility, albeit in an independent living area. Although she took charge of choosing a new residence for

herself, Rebekah was shocked by all the gray hair and wheelchairs that occupied the places she toured and the new place of residence she selected. Even though she has a very full head of now-acknowledged grey hair, perhaps because she is still active, using only a cane as a mobility aid, and still experiencing “I can,” the image of wheelchairs everywhere was shocking. She was struck by all the residents that “cannot.” The realization that “I am old” was a sudden one for Rebekah, almost as if she had never had that thought before. Through all three interviews, Rebekah tells stories of her entry into, struggle through, and finally peace with what living in these oldest-old years has meant in her life.

Early in our first interview, she confides that “When I look back over my life, the biggest changes were to give up the life that I love so much.” This life involved decades of work for her church and religious denomination. Rebekah describes her multiple roles in leadership, training, and advocacy for various projects. Two years prior to these interviews, Rebekah’s daughter (who lives across the country), developed fear that her mother’s weakened knees would give out on the stairs in her mother’s home. She had asked Rebekah to begin searching for an assisted living facility. And unbeknownst to Rebekah, out of concern for her mother’s overall health, the daughter had asked Rebekah’s pastor to ease her out of her roles at church. In hearing her story, it is easy to question if this was necessary.

She was afraid I was going to fall down the steps so she told me we [Rebekah and her sister] needed to go around and look for apartments, but I had no idea she was trying to slow me down at my church as well . . . she had contacted my pastor and told him “Please slow my mother down and stop her from doing all this stuff.” Until finally he told me, “Please don’t be angry with me. Your daughter did this. She said she was afraid that you were overdoing it and you would not stop because you loved what you were doing.”



She describes a time of confusion. Without being a part of this decision making, a daughter and pastor, perceived by Rebekah as loving, were making decisions about her life. They were deciding what she was able to do and what she could or should not, possibly stealing meaningful engagements from her.

Well, one of the things that I found that I had to give up all the things that I love so much, to go into the next phase of my life. It was just like somebody had cut my whole life away. I didn't realize that this was a state of depression that I was going into, but every time I went to church I was crying . . . I'm not used to sitting and watching everybody do everything. And that was a hard thing for me to accept. One of the things of getting older, is that you have to get over the fact that it's not over, it's just beginning. God always has a plan for your life.

It is important to see that twice Rebekah relates "I had to give up the life I love" and "I had to give up all the things I love." She was essentially told she needed to let go of her life of meaningful engagement, purpose, and happiness, for a new life. Rebekah now sees meaning in this as her God, her daughter, and her pastor were gently transitioning her into this next phase of life. However, in this new phase, Rebekah was clear about one thing. "One of the main things was that I wanted to maintain my independence."

In searching for a new senior living residence, Rebekah did not want financial help from her daughter.

I wanted to stay independent, to be in charge of my own money, be in charge of my own affairs as long as I could do it, and I wanted to fall in the range of money that I was able to take care of myself.

"I wanted to stay independent" illustrates that this was foremost in her mind. Rebekah wanted to "be in charge," at least financially.

She then goes on to make a statement of both conviction and understanding of her own needs at this time of life:

And one of the things I find in getting older is not losing your independence. I've seen too many people that have totally given up because of their children. . . . I'm so glad that I have maintained my independence, and I feel that this is one of the reasons, too, that I'm happy. I'm very happy here, because I don't feel as if I've lost anything. I feel that I am most fortunate as an independent person.

Here Rebekah is speaking to her financial independence. Her ability to support herself and manage her own money. This is highly meaningful to her as a woman who supported herself, looked out for herself, and was a leader in many of her roles in life. In spite of the pressures from her daughter and pastor, and the resulting losses, Rebekah makes it clear that she has chosen happiness. In this she is also independent. This is a choice that others cannot take from her.

In the second interview she told more of this experience of change and the meaning of independence:

When you first move into a community like this, the shocker comes . . . I'm losing my independence. Especially if you were an active person that was able and willing to do stuff for yourself . . . but when you move into an environment like this, first comes the thing of anguish. Why am I here?

Rebekah uses strong words as she relates this experience: "the shocker"; "losing my independence"; and "the thing of anguish." Anguish is a strong and emotionally laden word that conveys despair. It starts with anguish, as in a grief over a loss; a loss that begins with anguish and ends in resignation.

Then I realized look, it might be nice not to have to cook three meals a day, not to have to wash and you have a laundry and a housekeeper . . . I worked all my life to have what I wanted. In about a month's time I began to think about it. And one of the things that can happen is, that if you let it linger in your mind, you become depressed. Easily become depressed because you're losing your independence.

Despite trying to make herself focus on the positives of her move, when she really allows herself to think about it, to linger on it, she recognizes that depression over her loss of

independence, and perhaps how she has been treated even disregarded by those who love her, is the result. Rebekah shows ambivalence about her actual state of independence; sometimes she has it, and sometimes it is lost. Yet, she acknowledges what has happened to her and what it is. It is a loss and she is depressed. Moving forward in the story, Rebekah relates another struggle in terms of her independence. This is the question of driving.

In the first interview, Rebekah touched only briefly on the meaning of giving up her driving, “I sold my car, which killed me.” Killed, another emotive word. The full story of this relinquishment was described in the second interview as part of her narrative of the loss of independence. A couple months after her move it was discovered that she had macular degeneration. In the company of her daughter who was visiting, she went to an eye specialist. Her daughter pressed the eye doctor for a definite answer to the question of whether or not her mother should be driving. Reluctantly, he responded “I would rather she didn’t.” Rebekah describes what followed.

So she said “Okay, now mother you see the doctor says he doesn’t want you to drive. I don’t want you to drive. I do not want to be on the east coast and have somebody call me from your place there and say your mother was driving and she killed somebody.” I said “okay.” But I thought she was being mean. So when she went back home she sent me an article . . . these two ladies went off to lunch when the daughter had left the keys . . . the old lady drove the car to take a friend out to lunch, had an accident, and killed her friend.

Her daughter didn’t comment, just sent the article, trying to let the article speak for itself, and speak to her mother’s conscience. Later in an email, the daughter asks “Is this what you want to happen to you?” I got upset and I said to myself “No!” I was sitting in my house in my big chair. She remembers the moment; she was sitting in her favorite chair.

She reasoned with herself that her living community has busses to take her places, she doesn't need much anyways.

That Sunday I went to church and sold my car. . . . As soon as I put it up on the board somebody bought it that same day. . . . But the thing that was the hardest for me, even though I'd gone through this period of depression and loneliness, I'm thinking I don't belong here [residential community], I'm too young to be here, I'm not 90 years old. I'm younger than that, it's just in my head. That Sunday evening when that man came and brought his daughter, and when I had to hand my car keys over to that man, it was just like it pulled my heart out. That was the instance I knew that my independence was gone.

The symbolism of the car in our Western world is profound. The car gives independence and freedom to go wherever and whenever one wants. Without it, independence is gone. The reality of this "pulled her heart out." Again, an emotionally-laden expression, indicating the deep significance to Rebekah. This loss reached into the depths of her soul. Rebekah has changed. She is now dependent; she is now old.

Rebekah continued to describe how the support of her church, her pastor, and being confronted by her caregiver moved her forward in her acceptance.

And so I have a caregiver . . . she took me to church and I was crying and carrying on, and she said "You've got to look at the fact that you're alive! You don't have to worry about anything! You put yourself in here, so stop crying and think about how blessed you are." Well, I was so active in my church, I felt indispensable! I'm just going to be honest here.

Others were deciding for her. People in her church told her it was time for her to rest. Instead of telling her "you can," they were telling her "you cannot." Instead of promoting meaningful engagement in the world, they were limiting that engagement, in a manner that felt and appears to be premature. They are limiting her "I can."

I couldn't see that. I couldn't see it because I still felt . . . "I'm not crazy, I can still do all of this stuff." But as you age, in your mind, if you still have all of your thinking faculties, you feel like "why am I not doing this anymore?"

Yes, why indeed. One Sunday her church family prayed for her. Her pastor recognized that she was struggling. He also recognized that she had trained “every one of us” and that she was deeply appreciated.

“So, we’re gonna pray that she will settle down and realize that this is her time now to rest.” And rest is not in my vocabulary! (Laughs). . . . And so it took me a whole year . . . a YEAR! I did not realize I was depressed. Many people offered to give me a ride to church. That kinda eased it some, but then I felt I became a burden on the people. . . . And that was making me cry. Once you get to the point where you can realize that you still have your health, you still have your strength, and as I pray continuously . . . thank you Lord for my eyes to see, feet to walk, mouth to talk, that I can still move my hands in praise and all of that, it made a TOTAL difference in the way that I was accepting it. And finally I was able to accept that I am 90 years old. And I’m not gonna lie, it’s not total acceptance yet because I’m very active here. . . .

Her comment about “total acceptance” is interesting. It seems she is saying that total acceptance about her age would be evident by less activity, less “I can.” Rebekah then relates all the activities and leadership positions she is involved with in her living community. She is the president of the Resident Council, she sings in the choir, plays the bells, leads a prayer group and a Bible study. It is evident the staff and residents recognize her as a leader. She is developing “I can” in her new community.

Let it not escape our notice that Rebekah links loss of independence with that of feeling like a burden. Being a burden made her cry. This strong, independent, talented woman is living through a time that she thinks of and feels herself to be a burden. This brings great sadness. Her unstated resolution to this may have been to not attend her former church as often. Instead she attends services provided at her residential community. Perhaps this is to avoid the feeling of being a burden.

My friends say “What else do you want to do, you do everything!” And my Pastor said “See I told you, God had a space for you, wherever you are going to go.” So, I enjoy living here now, but it took almost this whole

two years for me to get to this point. . . . I tell them, it's a slow procedure. It will not happen at once. You may have to shed a lot of tears over it, but in the end you have to think of this: why am I still here? There's a purpose for me still being here.

Rebekah's story is one of many tears and feeling both abandoned and supported by those that loved her. She seemed to be blindsided by the reality of her age, or at least the reality of those around her. Rebekah's self-image did not fit with being 90 years old, gray haired, having peers that need wheelchairs, or being someone who needs to slow down and rest. Having weak knees which needed a home without stairs, in her mind was her lone concern. Failing eyes which led to giving up driving, soon followed. While she herself chose her residential community, the move was prompted by her daughter's suggestion. It remains uncertain, having only the one perspective, if leaving her church role and giving up driving were actually necessary. Yet, Rebekah has resolved this crisis of independence for herself in a few ways. Her perspective is focused on maintaining her financial independence; she is providing for herself and paying her bills. By creating new and meaningful engagements and leadership roles in her living community, she has chosen to transfer her skills and interests rather than abandon them. In this way, she has maintained independence or autonomy in many of her choices.

It has been thus far, a two year journey, but Rebekah is focusing on the positive, what she still has, not what she has lost, which allowed her to move toward acceptance of her aging self. She has transferred her abilities and leadership skills to her new community. They recognize her gifts and are supporting her in this role. At the very core of Rebekah is her need to be actively engaged in the lives of others. For now, she has reconciled her acceptance of old age, her body's changing needs, her loss of aspects of independence, and her finding of continued purpose in the passage of being 90 years

old and older. Rebekah demonstrates the pathos of this time of lifegiving-up and making new, as well as how well-meaning others can add to the angst of this work.

### **The Paradigm of Betty: Anticipation of a Loss**

Whereas Rebekah's loss of independence came as a startling shock leading into and through a time of depression, Betty's lived experience is one of anticipation, even fear and worry. At 87, Betty is a lively woman with an active sense of humor. As a daughter of Hispanic immigrant dairy workers, she grew up in the middle of a large family who lived in a rural condemned home without hot water, toilets or air conditioning. She took seriously her mother's warning, that when she left home, she would not be coming back. The children were raised to take care of themselves. Betty sees this as creating her strong sense of and need for independence. She takes pride in the fact that she didn't rely on her mother then, and she doesn't rely on her children now.

Early in our first interview, Betty relates a story about the grandparents of her granddaughter's boyfriend. She describes the grandmother as being from South America and having "never left the nest."

His grandma asked my granddaughter, "Your grandma lives alone?" And she says, "Yeah." Then the grandma asks "Isn't she scared to stay at night by herself?" And my granddaughter says "No. My grandma's very independent." I says to her, "Honey, next time anybody asks you if I'm scared just tell 'em I'll really be scared when I have to go live with you guys!" (Laughs). Then I'll get scared!

While she laughed heartily here, she alludes to her fears. "At least once a week I can't sleep. My mind gets carried away, you know, 'what if, and what if'." Although she has type 2 diabetes, hypertension, high cholesterol, and arthritis, the "what if" is referring to macular degeneration. What if it gets worse? What if I can no longer drive?

Further on in this first interview, she is asked if there is anything she still wants to accomplish. Her quick and firm response is “I hope I never quit driving ‘til I die.” At this point she discloses the reason for her concerns: “I have macular degeneration.” Describing her interaction with her doctor in regards to making a return appointment to get the shot in her left eye where she is having some bleeding, she further reveals her concern.

“Doctor, you know,” I says, “It’s so hard to lose your independence.” I says, “I have a hard time getting somebody to take me. My daughters work, you know, and they got their plate full,” you know?

Sure enough, he squeezed her in that afternoon so she didn’t have to make additional arrangements to go back in two weeks. It is so hard to lose independence. For Betty, this is anticipated as her vision worsens.

Early in our next interview, these concerns appear as we talk about her desire to remain in her own home as she ages.

If I ever find a rest home that has a ballroom, then I’d move in (laughs). But you know only the dear Lord knows what’s gonna become of me. You know, because who wants to lose their independence? I’ve been so independent all my life. And like I told you last time, my mom told us “When you leave this house, there’s no coming back.” And you know, I’ll never forget that. That’s what I told my kids too. And I don’t have ‘em here yet.

Her greatest fear at this time “is leaving, leaving my condo here, not being able to drive. No independence. See that’s what’s killing my good friend.” Betty’s close friend has lost her vision due to macular degeneration. Her older sister gave up driving at 92. What this means is very clear to Betty. No more driving equals no more independence . . . and dependence, and perhaps loneliness. “I don’t know what it is to be lonely. Because you



know, I am always doing something. . . . And, I don't have to depend on anybody . . . physically or financially.”

Betty links dependence with loneliness, and these are linked to ability to drive. However, she does speak with pride that she is able to do all her own bills. “I can still do it. . . . So far, you know.” She doesn't pretend that these things won't change. Despite the admission of worry about this, she also speaks of living with this anticipated loss.

It's getting harder for me to see out of this eye. I don't know how much longer I'll be able to drive. But, if you let it get a hold of you, you go downhill (laughs). No, I still keep doing, you know, and I have a magnifying glass. . . . Because, I figure the dear Lord's been good to me, and the day He calls my number, I'm due. Why be worried that I'm gonna go blind in two, three years?

During this second interview, Betty realizes that her worry could get the best of her.

Here she expresses the ability to rest in knowing that her life has been good. It is useless to worry about tomorrow when, as she implies, tomorrow may never get here. Blindness may come, but it is not here yet.

Right away, this topic comes up in our third and final interview when Betty is asked what it is like to be 88 years old. “Well, my health is number one, and then I can still drive . . . I'm still very independent you know . . . and the main thing is that I still have my independence.” The main thing is—“my independence.”

She then tells her story of an incident that occurred since we last met, that illustrated clearly how independent she is, and how proud of that she is. Betty, a friend, and her sister had plans to go to a church event and she was driving. When she tried to start her car the battery was dead. Getting it started by a friend she made it to the event, but then it died again. She needed a new battery. The point to her story was that she was able to get to the event, get her car fixed, and get home the next day without any help

from her son, who had volunteered to help several times. When he called her the next day she was able to say “‘Taken care of, son’ (laughs). I says, ‘I hope I teach you something. I hope you learned something from your ma’ (laughs). So I didn’t bother nobody.’”

There is the word “bother.” Betty was so pleased that she navigated this whole dead car battery incident completely on her own without bothering anyone. I then asked what she would do if she couldn’t drive anymore. Now she can, and when she cannot?

B: I’ll just have to do what everybody else does that is blind and depend on your kids. Depend on whoever will do you the favor or whatever. That’s what I’ll have to do.

I: Which will be hard?

B: Oh gosh, yes. After being so independent. There’s nothing any worse than losing your independence. Nothing any worse.

*Nothing* worse. Betty states this very emphatically. Despite saying “Why be worried?” the last time we spoke, it is clear this event reminded her of how significant staying independent is. The picture of a tightrope walk comes to mind again. She is afraid, she does worry, yet she clearly doesn’t want to dwell on it because “if you let it get a hold of you, you go downhill.” Betty is trying to hold that balance bar steady and not let worry get a hold of her. She is very proud of herself; there is nothing worse than losing your independence.

Continuing with this, Betty describes her family situation, and acknowledges that others won’t have time for her dependence. Laughingly she says again “Everybody’s got their plate full, you know . . . they can’t be dragging old folks around!” Knowing a bit about her family, I suggest that they might want to help her as much as they can. Her reply is quick. “Whenever they can do it, but it won’t be at my convenience (laughs). It won’t be at my convenience, hmm hmm . . . Because this is what I hear from everybody.”

“Everybody” tells her, people will help at their convenience, not yours. Betty knows this is on her horizon. Dependence is on its way. If her eye problems progress, she will not be able to continue driving. A new cannot. She will get around when it is convenient for others. The very thing she most dreads is looming. This topic continues to surface.

In talking about other losses, body changes, and taking care of herself, she simply states “I don’t know how well I’m doing. I’m not the same of course, but I still think I’m still pretty independent.” Independence is Betty’s measuring stick. She is living with the constant awareness of threats to her independence. When asked what has brought her satisfaction and happiness in life her reply is “Well independence, my independence.” Independence is Betty’s theme; it gives her meaning in oldest-old age. The loss of it brings fear and apprehension. She knows it is coming, a time of entering the unknown territory of increased dependence. What is also unknown is if her family can find time for her. “They can’t be dragging old folks around.” And why not?

Of course, there is a larger cultural story here. Betty is in good company. Modern society and western culture in particular, aptly noted by Gawande (2014), has come to venerate the independent self. Through the eyes of an American physician and as a second generation eastern Indian, he contrasts the old age of his wife’s grandmother’s growing old alone in her home in the states, with his father’s father growing old in rural India, surrounded by three generations of family. As Gawande sees it, it is not the worship of youth that has replaced the honor of the aged. It is the veneration of independence, and the demotion of the family in western culture. Children gladly leave home; parents gladly let them go. All want “a way of life with more liberty and control, including the liberty to be less beholden to other generations” (Gawande,

2014, p. 22). He goes on to add this “reverence of independence” does not take into account that eventually in the long-lived-life, illness or disability will make independence and the resulting isolation in one’s own home problematic, even impossible. And what will we do when we can no longer live with that ideal? Betty is not sure. Yet other participants, including Rebekah, have walked this path before her.

### **Exemplars of Loss of Driving: Loss of Independence**

While Betty is the youngest, she is also one of the most independent. There were only two other participants that continued to drive, both with limitations. What Betty is anticipating, most of the others have already experienced. However, this desire to drive dies hard. Living in a part of the country where people are very car dependent, several of the participants spoke longingly of driving and the independence it offered, and acknowledged the difficulty of letting it go. The idea of “going whenever you want to go” was mentioned as a key loss when driving oneself is no longer an option. We go, and go, and go, preferably at will. This *going* does not seem to be as significant as the *going-at-will*. With energy levels lower, the desire to be always on the go isn’t as strong as in younger times of life. The loss of control over life that driving offers, the self-reliance, and the independence, is very clear when one no longer has this option. Again, this symbolizes the reverence for the independent self; and perhaps conversely, the beginning of the demise to the dreaded dependent self. And one more reminder that one is old.

Alma, who also struggles with macular degeneration spoke to this loss of driving and its significance. “It’s terrible . . . but it’s another milestone you have to take . . . grieve over it, go on with it.” She made a serious error during her driving test about which she still is uncertain if it was a visual error or a cognitive one. Speaking proudly

of making the choice to quit driving herself, Alma stated “It’s important to quit while you’re ahead.”

Frail and soft spoken, Sarah also laments her inability to drive when she is asked about times that it’s felt bad or discouraging to be her age. “Only when I want to do something that I can’t (laughs)! I like to . . . go where I want to go, when I want to go. And I used to drive and I can’t drive anymore.” She quit driving at age 82, when she had a stroke. “But then I look at the news and there are so many accidents . . . and then I realize I couldn’t handle it.” Despite the longing for going when and where she wants, Sarah recognizes that she made the right decision and adds “My daughters take me wherever I need to go.” A dependence is created.

Ninety-three year old Norma related a car accident she had which was her fault. That incident prompted her to give-up driving. About driving and aging, Ramona shared her thoughts: “There comes a time when you’re not able to do things and you just have to accept it.” Her adaptability and her acceptance was evident when she later stated “I don’t drive anymore. I have to depend on somebody. At first it was hard, but I’m used to it now.” “There comes a time”—this is what Betty is dreading. “When you’re not able to do things”—this was Rebekah’s struggle. “Depend on somebody”—this is at the core.

At 100 years old and walker dependent, reflecting on what life is like for him, Douglas alludes to a similar struggle.

One of the things, not disappointing, but you wish you could still do, is drive a car. I gave that up at 95, when I lost sight in my right eye. And I do miss that. I miss the freedom . . . I was willing to do it because it was myself. I voluntarily gave it up. I just went down and turned it in. I said ‘That’s it. I’ve had it. I’m not gonna drive anymore.’ I felt like I did something I wanted to do. I don’t feel sorry for doing it ever, but I miss the ability to drive.

Choice, as Douglas mentions, seems to be an important aspect of no longer driving. Eight of the participants mentioned this choice, and the idea that it made it easier for them to quit. Driving and a car bring freedom. Driving and a car maintain independence. No longer driving brings dependence. He also conveyed two additional consequences of no longer driving, added vulnerability and the sense that one is a burden.

### **Dependence: Feeling Like a Burden, an Imposition, a Bother**

Douglas and others spoke to this feeling of being a burden on family due to an inability to drive and becoming dependent on them. More than any other participant, he has multiple family members living very close to their life-long home in which Douglas still resides. A benefit of living to 100 is that his children are retired and seem to involve their father in their weekly, even daily lives. Yet Douglas still tells of this feeling, and chooses the idea of “imposing” to express this inability to drive, which results in a lack of freedom. Here Douglas has met an “I cannot.”

I feel like I’m sometimes imposing on them even though I know they’re family and yet, if I didn’t do it, (laughs) I’d sit here. And I don’t wanna sit here (laughs). . . . I miss the ability to drive (laughs). . . . And I think that’s so I wouldn’t have to bother everybody all the time . . . you realize they have families and they have things to do, you know. And they’re so willing that it’s wonderful.

Rebekah also described this in her sense of “feeling like a burden” now that she needs to rely on friends to take her to church.

After I sold my car I thought, “How am I gonna get to church?” Well, I had people calling me saying “You don’t have to worry about it.” I had people from all over the place who would come out to make sure I got to church. Well that kinda eased it some, but then I felt I became a burden on the people . . . That I had to ask somebody to drive me to church and to pick me back up. That felt like I was putting them out . . . and that was making me cry.

In a similar manner, Betsy expresses the experience of asking. “I have to ask somebody to take me wherever I want to go.” Asking is difficult, it means “I cannot,” and leads to the sense of being a burden. Later, when talking about the rewards of being this age, she relates:

The positives . . . I’ve learned that I’ve needed help and they’ve [her family] been right there in everything, everything I’ve ever needed. All I have to do is ask. I hate to ask them. But I’ve learned to . . . I have to. And the wonderful part is they’re willing, they’re there to do it.

Betsy speaks further to positive experiences in her dependent situation. “I’ve learned for one thing, to depend on them [my family], and the wonderful part is that they’re dependable . . . they’re dependable. They do anything I want or ask them to do [becomes teary eyed] . . . completely. They’re wonderful.” She also speaks to a spiritual dependence on her Lord.

For one thing, the Lord has slowed me down a lot. He has kept me. I’ve given up my car, and that right there will keep you a lot slower, shall I say . . . quiet . . . It’s been a different kind, different kind, completely different, complete dependence. I’m completely dependent upon the Lord.

Betsy’s journey into dependence has been one of discovery. She has discovered that her family is dependable and along with this she has gained a new appreciation for their availability and willingness to help. Betsy sees her Lord as dependable too.

In the face of increased dependence, Alma extends her independence by using local transportation offered to senior citizens. She uses the word “intruding” to express her experience with loss of freedom to get around. “My daughter takes me sometimes, sometimes I almost feel like I’m intruding. But I have used transportation services a lot.” Her fortitude and determination to be as independent as possible drive her to seek outside

resources. This maintains Alma's experience of "I can" and also allows her to avoid this feeling of intruding.

Intruding. Asking. Being a burden. Imposing. Bothering. These are all words that are spoken reluctantly, bringing sadness and feelings of neediness, and dependency. They imply a relationality, or lived relations in their lifeworld, that phenomenology addresses (van Manen, 1990). "We are social beings" (Attig, 2015, p. 3) living in relationship. Often defining ourselves in relation to others, we exercise our freedoms or give them up, and are challenged to live meaningfully and responsibly with the world and people around us (Attig, 2014). And we search for a sense of purpose in life and reasons for living in our lived relations with others and "in the religious experience, of the absolute Other, God" (van Manen, 1990, p. 105). Western-American culture subtly presupposes to the notion of independence, the idea that we are completely autonomous individuals. Rather, phenomenology sees human beings in the world always interdependent on each other (SmithBattle, personal communication, June 25, 2015). Our interdependence waxes and wanes throughout our lifetimes depending on various life circumstances including finances, life stage, illness, and relationship. Yet, our aging family members are left carrying the burden of this treasured myth that they should desire to live out their final years of life independent of others, beholden to no one. In actuality, this is never the case; we are always interdependent beings.

In oldest-old age, the social world shrinks to fewer friends and, as demonstrated by these participants, family once again takes on a dominate role, for better or worse. There are challenges evident in these relationships as independence waivers, and needs increase. Seeing oneself as an imposing burden that intrudes on the lives of others can



impact one's sense of dignity and worth. Further burden is actually placed on our aged as they learn this new skill of asking for help, which can be very new to some.

This struggle to maintain independence can also involve autonomy at a different level. Even though moving about in the world is more difficult, making one's own decisions as a freely-choosing individual is an additional struggle to consider.

### **Exemplars of Loss, Maintenance of Decision Making, and Role Reversal**

#### ***Relinquishing the Finances With Gratitude: John's Exemplar***

This realm of relationality also appeared through the narratives as issues around how decision making and control are negotiated between the oldest-old and family members. Three distinct experiences of these issues of autonomy and decision making are portrayed.

John is a grieving widower who is longing for a second wife. His wife died three years prior to our interviews. John believes that when she died, he lost his decision maker.

I got to the point that I relied too much on her. I forgot how to make decisions (laughs). I make a lot of decisions, but they're usually wrong (laughs). But so, I want very, very much to get another companion and I'm going about it all in the wrong way. . . .

He has been very "generous" with women. As a result, John's son has taken over his finances. John now receives an allowance. "I would imagine that that was very difficult for my son, but it's been very, very helpful to me." Seeing his close relationship with his son as a gain in his old age, John also sees himself as dependent.

My dependence on him is very much like the dependence I had on my wife. I think he's a bit frustrated because I'm his father, and I should be his superior, but I'm not. I'm his inferior . . . I'm more dependent on him. I think he's a bit uncomfortable about me being his child because that's

more what I am now, than his father . . . He has formed a new role and I think he's fulfilled it very well.

John expresses gratitude that his son has stepped in and taken charge of his finances. His son has saved him from unwise financial decisions. He has described the role-reversal with his son, which is actually seen as a positive situation for John. This life world of dependence, satisfies John. Other participants express this differently; one man's gain is another woman's loss.

***“Not Ready for That Yet”: Alma's Exemplar***

Quite the opposite of John's is Alma's view of dependency:

My daughter can be quite obsessive at times, and that's hard to deal with because then you have role reversal, and I'm not ready for that yet. I think, though to be perfectly fair about it, that somebody besides the family ought to decide whether I'm capable or not.

Alma goes on to describe an incident when their air conditioner went out and her daughter was insisting that Alma leave and go to a clubhouse where it was cooler. Alma refused and knew that she felt fine, the heat was not causing her problems.

I just figured look, until somebody, a group that is not personally involved with me, declares me to be incompetent and stuff, I'm gonna stand up for my right to make my own decisions, for as long as I can. . . . I happen to believe that God made us individuals, and I have the power to think, and to do, and I'm going to do it until someone else says, “No, you better. . . .” I just feel like God has given us each the power to think and to do, and it's a sacred trust to me . . . That time may come, I don't know. I'm going to make my own decisions as long as the good Lord enables me to make 'em.

The ability to be her own decision maker is of tremendous importance to Alma.

Throughout all our interviews, Alma revealed a highly independent woman who wanted to be in charge of her life. The potential for conflict with her daughter seemed real.

Alma is a woman of definite opinions, plans, and goals. Her desires are quite different

from John's, who seemed relieved to not be in charge of his finances and some of his decision making. Sarah reveals yet a different response.

***“So I Smile”: Sarah's Exemplar***

For Sarah, it has not been easy to become the cared-for person. In describing the adjustments that have been made due to her mobility issues, Sarah tells of her transition from being able to walk using a cane to go into a store, and then push the basket. Now she is no longer able to push the basket; she goes in a wheelchair. Her reply to an inquiry about how these adjustments have been for her gives insight into her lifeworld of family relationships and decision making.

At first, it was not easy because I'm a very independent person . . . I like to do things for myself and if I want something done, I wanna do it. And the minute they see me get up, “Mommy, I'll get it.” “Nana, I'll get it.” And I used to feel really bad, but now it seems to make them happy that they can do it for me. So I smile and let them do it . . . It's hard but I don't complain.

Similar to Rebekah, Sarah hears the “I cannot” from her loved ones. Behind this comment, one can almost hear the “but I think I can.” As I explore more with her, Sarah brings up their financial arrangements, and a small area of control. “My daughter is in charge of my spending . . . and I try to select one [charity] I feel is most needy.” She explains that she chooses a needy charity and explains her reasoning to her daughter. This is one area of decision making, in regards to her finances, about which Sarah feels satisfaction.

Living in her own home with a daughter, grandchildren, and great-grandchildren, Sarah is well loved, and well taken care of. Yet, she reveals that this may be a bit too much. Getting used to them doing everything for her has been difficult. She has

retained, or is allowed this one bit of decision making in her finances, and she chooses very carefully. She is still choosing a way to give.

I was left wondering if, out of love and concern, Sarah's family is doing too much for her. They are deciding her "I cannot." She doesn't complain because she can see that taking care of her makes them happy. So, she smiles. Their needs are important to her. Although they act out of love, they may be loving her into dependence by taking away choices and decisions she can make. Here again, this meaning in relationships, impacts choices in one's everyday lifeworld. Aging is done in context.

*And for Others . . .*

The experience of independence is unique to each person, each family. The mild and peaceful Norma draws her line: "They'd have to drag me out of here . . . I wouldn't leave." Her family is supporting her decision to remain in her own home.

Louis, who has come to rely on others to drive him to his few select places, a caregiver to get the morning coffee ready, and his good friend and neighbor to help him with his Sunday coat, relates that he is pleased with his level of independence.

I thought I would be more dependent on things and people around me than I am. I find I'm quite independent here. Which I like. And while there are a lot of things I can't get done for myself, fortunately I have people who help me. . . . I am contented with the way things are going, and I am able to do as much as I am able to do for myself.

This man who was the leader of many, has found a place of gratitude and appreciation for the independence that he is able to find in his everyday life. He stays focused on what he can do for himself and is pleased and contented.

And finally Rebekah. Despite her struggles with her daughter's desire to slow her down, she has come to a place of understanding with a level of independence that they

both can live with. In describing how age 90 is for her, she conveys her love and appreciation for her only child, her daughter who lives across the country.

I just was looking the other day at my daughter, my one sweetheart and the joy of living, how she and I got along so well together, and how blessed I am to have her so interested in my life, and making sure that I have everything I need. . . . Although I'm very independently taking care of myself right now, but she's there if I need her.

Rebekah has been on a journey to a place of peace at this point in her life, living with this balance between independence and dependence and the losses involved. She continues:

So these are things that, when I was so depressed and so down, that I had to realize that being 90 isn't so bad. . . . How joyful for my child to come from the east coast three times a year to visit me and take me on vacation. . . . I thought she was being very dictatorial all the time, wanting to tell me how to live . . . but being 90, has given me a new sense of appreciation to realize that now she's my mother, and I'm her child. The roles have switched to the extent that I had to learn to appreciate all the things that she's doing is not trying to tell me how to live, but to express the love to me of what I gave her.

Rebecca makes meaning in her losses, by ascribing them to her daughter's love. She describes a role-reversal and coming to an understanding of her daughter's love in this formerly unknown place of oldest-old age. Appreciation for her daughter, and the security and blessing in the relationship, are perhaps making Rebekah's losses manageable.

### **Conclusion**

Considering the research question of what counts as loss for the oldest-old, through listening to these narratives, the waning of independence is clearly seen as a loss. What is not always stated outright, but clearly conveyed is that independence is a primary concern during a time of life in which dependence is seen as an ever-present threat. Inability to drive, and no longer having a car are two very symbolic losses that contribute

to this diminished independence. What is this experience of loss? It is a time of a passage into being old, of growing dependence on others, of not going where you want, when you want. It is being alone more than you might choose, and perhaps having concerns for your safety and health. There are possibilities that your child may move into the role of the parent, have control of your finances, or make decisions for you. The experience may also be of anticipating this loss as you witness friends and family pass this way before you. It may be the recognition that your failing body may soon dissolve the independence you have, and of waking up at night worried about it.

Dependence, feeling like a burden to others, or as described by Scott-Maxwell (1968) of trying not to be, of sensing the burden of your own vulnerabilities, these experiences weigh heavy. In a culture that values independence, the car, going and doing, this is not insignificant. What is not spoken of, but is profoundly felt, is the finality of it. Once independence is gone, it is gone for good.

To the listener, the observer, oldest-old age also appears to be a time of mustering resources to stay positive, to search for the positive and actually find it. You may recognize, as did Betsy that your family is there for you; that you can learn and grow, adapt and change. Like Rebekah, you see that time doesn't stop. It moves you forward, depression may visit for a while, yet meaning and happiness can be found in new ways, in your present lifeworld. Keeping a grasp on the "I cans" you also have an awareness of the mounting number of "I cannots." You may recognize, along with Sarah that your family enjoys caring for you. Habits of mind learned in your earlier years, may help you focus on the positive, to stay grateful for what you do have; to even share Louis's surprise that you are as independent as you are. You may find that this takes work, even

mental discipline. The tightrope seems a bit wobbly at times, but usually you can hold that bar even and balanced. This is what has been heard from the stories shared.

Henri Nouwen's view of hope seems apt here: "Hope prevents us from clinging to what we have and frees us to move away from the safe place and enter unknown and fearful territory" (1979, p. 77). The human spirit is inclined towards hope. The understanding of the lived experience of oldest-old age gained here, demonstrates hope in the face of loss. There may be a longing to cling to what has been, to life as it was in younger years, to revere the myth of independence. Oldest-old age with the aging body and mind, can give a push and loosen the grip, and even force a move into the "unknown and fearful territory" of being old, less independent and more dependent and vulnerable. It is a difficult passage that is symbolic of being in the last years of life. Yet, these participants, through the stories told, the narratives offered, tell of moving forward, living in the present, often coming to a place of peace, and as spoken by Rebekah, "giving up and making new." It is possible, if the actual interdependence among us was fully appreciated and recognized, the burden of fearing dependence could be lifted from our oldest-old and simply be acknowledged as one of many times of waxing need for others that occur in our lives.

## CHAPTER SIX

### ACCUMULATING LOSSES: THE ENDLESS LIST

“ . . . the reality of age’s toll on our minds and bodies: declining strength . . . failing vision . . . trembling hands . . . arthritic joints . . . forgetfulness . . . loss of hearing . . . loneliness . . . fear of increasing frailty . . . the list seems almost endless.”  
*(Billy Graham, 2011, p. 9)*

“I’ve always been, very much of a loner . . . but now I’m getting a little tired it.  
I’m getting a little tired of it . . . I’m getting tired of being alone.”  
*(Betsy, age 88)*

While we have talked about losses of body and mind and then loss of independence, it must be recognized that loss is neither singular nor in isolation. The longer one lives the more loss occurs. What became increasingly clear over the course of the interviews, is that loss is no stranger in the lives of the oldest-old participants. Losses grow in number; losses are highly variable; losses accumulate. The increase in episodes and variability of loss in the very old life can tax even the most strong in spirit. And while the oldest-old may experience similar losses of body strength and function which lead to corresponding losses of independence, each story is also woven with additional and distinct personal losses, with differing significance, meaning, intensity, ordering, and frequency. Loss in aging carries its own meaning as it is narrated, revealed, and reflected in the life of each participant. The life of Betsy is one story of accumulating loss, and a life world lived daily with the resulting impact on her embodied self, with her personal past, present, and future.

#### **Paradigm of Betsy: “Getting Tired of it”**

At age 88, Betsy lives alone in a one-bedroom apartment in a large complex designated for those 55 years and older. She has neighbors close by. Her space is small and tidy, even cozy. Sitting in her overstuffed rocker with her books piled high and her



glass of water with its straw on the end-table beside her, it is evident that this is where she spends much of her day. Betsy's husband died nine years ago. They had been American missionaries in Mexico for much of their mid-adult life. Even though she is of Mexican descent, this is when she learned Spanish, as her parents did not teach their native language to their children. Betsy is very small in stature and her kyphosis only emphasizes this. She no longer walks without her walker. Lost to her are days of walking freely, with strength and confidence. Her head hangs low as she sits, her voice is quiet; her weakness and frailty is evident. Yet this physical appearance does not convey Betsy's strong spirit of faith and hope. "I believe in Jesus . . . and I love Him. He's my life."

During each interview, Betsy related her longing to return to her work and people in Mexico. "I retired because I can't go . . . (becomes tearful) but my heart is there." Another time she is even more emotional "What has been more discouraging than *anything* [with emphasis] is not being able to go down to Mexico. I want to go. That's the only thing that discourages me." In our final interview when relating her sadness about not being able to go, she adds another sadness. "Not being able to give. That makes me sad. Not being able to give." It is quite likely that as a former missionary, Betsy has the lowest income of all the participants. Since her husband's death, she has had a very small income that is supplemented by her children. She has lost financial security, and the ability to serve or give even monetarily to people she cares for.

Talking about these losses, Betsy describes her need to "adapt to a new way . . . of being and doing." This "new way" no longer includes her husband or her missionary work which she loved. She is alone and unable to work. Large parts of her day now

involve reading her Bible, praying, listening to music and singing to her Lord. “I usually just (laughs) have a wonderful time with the Lord . . . moving, moving, I get up on my feet usually. I used to, let’s put it that way. Before my illness.” Her recent illness has weakened her so much she has lost the strength to stand and sing to her Lord. She is adapting to a new way.

Betsy spoke to another new way. One of being alone, and learning to be dependent. Her time of being with others is lost. Also lost is her independence.

I’ve had to learn to depend on other people, which I never have before, and which has been not good. It has not been good, because I inadvertently have put them at a distance. And that’s not good. It’s not good . . . I’ve learned to get by myself, and that is not good.

She went on to explain that because of her introverted, reserved personality, rather than ask others for help, she withdrew and tried to make things work on her own. And she’s been alone.

I’ve always been very much of a loner. But now I’m getting a little tired of it. I’m getting tired of it. Like the other day, I had a person, my friend . . . she stayed here and rested, and it was so good to have somebody here. It was so good. So, like I said, I’m getting a little tired of being alone.

This led her to explain that she lost her car and gave up driving because of the expense. She could no longer afford the car, maintenance, insurance, registration, etc. She chose to quit. “I could still drive and I didn’t feel threatened or afraid or anything. It’s just, the cost was too much.” This added to her losses . . . those of independence, freedom, and contact with people.

Her unique set of losses of aging have created in Betsy’s oldest-old years a sadness, a void, and a change in her way of being in the world, in an embodied way, and a social way. Her vocation, in the way she lived it as a missionary in Mexico, has been

changed to praying from afar for those she loves. No longer able to give financially due to her loss of income, Betsy's sense of sadness and separation has increased. With the loss of her husband of more than 60 years, she lost companionship, and someone with whom to share daily life. The resulting aloneness is wearing on her spirit, and "getting old." The loss of a strong and healthy body, due to increasing frailty and health challenges has resulted in a loss of confidence in making moment to moment decisions and movements. Falls have become very familiar. She has been pushed to an increased reliance on her family and her Lord. Betsy clearly sees how she has needed to give up her old ways of being in her relationship with her family, being in the space in her house, even being in this time of life with the recognition that time here is limited. Her spirituality and faith in her Lord provides her with hope, vocation, and relationship, as she has chosen to learn a "new way of being and doing."

Betsy has been challenged on every level to remain a faithful follower of her God and a contributing family member. Her responsive, willing, and determined spirit has chosen to learn "new ways." Family members have responded to her in a manner that has allowed her to trust these new ways. The tears and words of her daughter conveyed a recognition that her mom is old and in need. The arrangements that her family has made to be present during her recovery from a recent illness and hospitalization demonstrates love, commitment, and availability that enables Betsy to feel secure with their presence in her life. She believes that her Lord also provides for her in ways that are meaningful. Her losses have meant learning new ways of being and doing in a time of a shrinking personal world and fragile body. Betsy is learning how to be Betsy, in her own distinct way, in the oldest-old time of her life.

### **Loss of a Spouse and Life Partner: “My Life Course Changed Precipitously . . .”**

When asked about loss in their lives, what almost all participants spoke to first was the death of their spouse. With only one divorcee in the sample, all others were widowed except for the married couple. All had been married for 60 years or more, except for Barbara. Her second husband died 11 years prior to our interviews, after 20 years of marriage. Her first husband died of a sudden heart attack in his late forties. Nine participants had been widowed after the age of 85. While any death is devastating, the death of one’s spouse brings about one of the most significant life changes that can occur (Gilbert, 2004). As was evident through the stories told, many adjustments need to be made when you have lived with someone for more than 60 years.

Along with losing a spouse, there is the discovery of the variety of other roles that the spouse fulfilled and now are lost. An example of this is the decision-maker role of John’s wife as was discussed previously. It often takes time to fully understand the implications of the death of a spouse. If the spouse’s illness has been long and debilitating, some of these losses are adjusted to before the death. Several participants had this loss experience. For the deaths that were more unexpected, the grief continued to impact their live in difficult ways. So unique was this to each participant, that brief exemplars are offered to illustrate the diversity of situations and responses, and the impact of this loss experience at this time of life.

#### ***When Loss Comes Suddenly***

##### **“This Is What I Have to Do . . .”: Sarah’s Exemplar**

Sarah, is the most recent widow. Her husband, at age 94, died a short time after an accidental fall almost one year ago. She continues to struggle with two issues around

her grief. The first being around why his death happened the way it did. He fell down the back stairs yet he knew he was not supposed to go out that way because of the hazards involved. Why did he go out that way? Where was he going? Yet, what is further complicating her grief is long term hurt she experienced in her marriage. “I was holding that in. And that really, really hurt me because I couldn’t understand why, and then he got sick. And I’m trying to take care of him and all these things that has happened, no explanation.” She was very conflicted during his dying process. Not understanding him and the past hurt he caused her, she no longer felt love for him. And then the way in which he died, trying to leave the house, also left her confused.

Every day he would say ‘I love you.’ And I would say ‘I love you,’ but I wasn’t feeling that. After the funeral I had to pray and pray to get rid of this hurt and ask the Lord to forgive me. Because there’s nothing I can do. But, I’ve come to grips with it [long term hurt and forgiveness].

In the third interview, this compounded struggle surfaces again as we talk about Sarah’s ways of coping with pain during her life. She reviews her confusion surrounding his fall.

I never thought about my husband dying, and then him calling me and telling me he has fallen and he’s outside and he wasn’t supposed to be able to go out there and that took a lot. But some days it’s pretty hard . . . ‘cause I think why did he do that? And I’ll never know.

And then, I ask if she has been able to make any meaning of it for herself.

(Big sigh) Not quite. I know there’s life and there’s death, and it was his time, but why that way, and then I have to say okay, you don’t have the answer. Don’t worry about it. He’s at peace and he was at peace when he was in the hospital.

Sarah cannot make sense of the way her husband died. She believes he is at peace, but she is not. It is clear that hurt and confusion still surface for Sarah. His former dishonesty with her, causes wonder about where he was going when he fell. His

declarations of love in his final days felt hollow, and were followed with his difficult death. This struggle is a lonely one. Like other participants who were mothers, Sarah also described holding in her long hurt and her grief, for the sake of the children. Despite the fact that the children are middle-aged, there was still a desire to safeguard them from her grief, and to protect their respect for their father. This grief of loss is complicated by a hurtful marriage, and continues to weigh heavy on her. At a time when she has been confronted with so many of her own health losses and problems, she tells of her spiritual resource that helps her through. “And that’s when I really learned that God was my only help.”

Later, responding to a question about other losses in her life, the loss of her husband comes up again, this time with a different impact.

I never had to pay a bill. He took care of all the financial bills. It was something I never thought about. I’ve never had to worry about if anything went wrong at the house . . . like the water, the plumbing, electricity, I didn’t have to do that. But when he got sick and passed, this is what I have to do.

While Sarah’s grief is unique due to a hurtful marriage, there was a very positive role that her husband fulfilled that is now vacated, and which she must fill. It is very late in Sarah’s life to be learning these new skills, especially with her own health and memory challenges. Fortunately, her children are highly supportive.

### **“I Have a Big Problem . . . ”: John’s Exemplar**

The death of John’s wife was even more sudden and unexpected. More than any participant, John conveyed a deep sadness in the loss three years ago of a very fulfilling marriage. He continues to grieve the loss of his wife and her primary role of being his decision maker. At the very beginning of our second interview, his immediate response

to the inquiry of “How are you feeling?” begins with “I have a big problem. I miss my wife. And I don’t know what to do about it except just, just cry (laughs). Of all the things that exist, that’s primary.” Later when talking about the difficulty of getting himself out of bed in the morning, John describes his dream pattern.

I do a lot of dream recalling. The dreams involve my wife and me building houses or updating rooms, and I get irritated at her, she didn’t do the right thing (laughs). In my older age, I dream. . . . The dreams that I have now are always involving my wife. She’s participating. If painting needs to be done she does it!”

For John, the experience of his relationship with his deceased wife continues as he daily feels her loss. As has been revealed earlier, John’s loss of his wife includes his decision maker. From the perspective of an outsider looking in, of a listener to his story, it appears that John has also lost much of his reason for being in the world. He is trying to learn how to be in the world without his long-term mate. The term “my other half” comes to mind when listening to John. His sadness, even distress is evident. John has some insight into his situation and has been in grief counseling since a few months after her death. John’s loss has meant learning to be alone, a new unfamiliar and painful way to be.

#### **“You Live Through It . . . ”: Norma’s Exemplar**

Norma also lost her husband suddenly, four years ago. He died two days after collapsing from a heart attack. Yet, her experience and adjustment to his death is distinct to her. When asked how that time was for her, Norma responded calmly, even peacefully, with minimal emotion. “Oh, it was kinda hard. To see him over there, but well, you live through it, you know?” They were married for 69 years, yet she describes her adjustment: “I’ve gotten used to it now. It was hard at first, of course, but then we

all go sometime. We're not here forever so, but it was hard losing him." Thinking of John, I asked Norma if there were things he took care of that she missed him doing. It is interesting to note that in her marriage, Norma was the partner that did day to day life for the two of them in their late years. "I did everything for him. He never cooked or did anything. I did everything for him, so there was nothing to miss." But she also reassured me that "I miss him a lot, sure. We had no problems. He never double crossed me . . . that I know of! (Laughs)." And she expresses gratitude to him. "He was a hard-working man. He worked hard, he was a carpenter. Worked all his life so I'm all set now. I have no problems." Later in the final interview, Norma conveyed a bit more of her experience. "You live with a man for so long and all of a sudden they're gone . . . so it was a hard adjustment to make. But he always said that he wanted to go first. He got his wish! (Laughs)." She speaks in the past tense. Norma has adjusted to life without her husband; she also has children actively involved in her daily life. Her husband told her to never leave their home while she is alive, and her intention is to honor his request.

Norma has grown used to being alone. John clearly has not. Sarah has regrets about her marriage which she says have been let go, but her continued struggle is evident. It became clear throughout the interviews that assumptions could not be made about long marriages, coping, or grief responses. Each has their own story, as relationships also have a past, a present, and, as in the case of Sarah's struggle, John's dreams, and Norma's desire to stay in their home, a future.

### ***When Loss Is a Long Process***

A very different journey of losing a spouse was conveyed by those whose marriage partner suffered a long illness. This journey usually involved a time of high



stress and demand for the caregiving spouse. Barbara, Alma, Louis, Douglas, all described times of stressful caregiving when they were over 85 years of age. When the situations deteriorated, all but Louis ultimately decided that a nursing home was necessary.

### **“I Did Well at This Time . . .”: Louis’s Exemplar**

As Louis describes it, the year before his wife died, he recognized that she needed his full attention and time as a caregiver, so he folded up his dance band.

I’m really thankful that I did that because when I think about the things that I should have done for her, I can think of lots of thing that I didn’t really do too well, but I did well at this time when I became a caregiver. So we were very close and I felt like I had really given her the type of care she deserved. . . . Whatever shortcomings I had shown over the years, I had shown some real strengths on this occasion.

Here Louis, indirectly relates that he did have shortcomings over the years, but his ability and devotion to caring for his wife at the end of her life, was his gift to her and perhaps even himself. It is evident that Louis had the opportunity to redeem himself and heal some regrets. Yet the pain of his loss is conveyed. “It was a rough transition for me. Being married 60 years, and we were so conscious of the 60<sup>th</sup> year, you know, we did make it, but we really didn’t enjoy the last couple, it was tough.”

During the third and final interview, when asked about losses during this time of life he returned to his wife.

L: I just keep going back to losing her . . . that was a great loss. And naturally it would be a great loss after living together for 60 years.

I: Would this be the most difficult loss of this later time of life?

L: Yes, certainly more so than losing my parents. A lot of people who were close to me during the war in combat situations, and that is always difficult too, but still, losing my wife, this was the toughest.

I: How are you with that now?

L: Well, it’s something I live with all the time. And I’m thankful for the months and years that I gave as a caretaker when I really took care of her,

to the very best of my ability, and so, whatever other shortcoming involving her that I demonstrated, I feel kinda comforted about that.

“It’s something I live with all the time.” This conveys the reality of his loss. “All the time.” He continues to live with the loss of his wife. In another sense, he continues to live with his wife, in the forms of memory and absence. Louis’s wife’s slow decline, and devastating illness became the focus of their lives. When she died, he lost what had essentially been his life’s focus for over a year. What he gained was an opportunity to right some wrongs. Louis’s grief has a personalized element, as he also honestly spoke of an inability to forgive himself completely for these past wrongs. Similar to Sarah, when a death occurs, the opportunity to seek forgiveness and understanding can be lost. Louis was forthright in describing thoughts that he cycles through on a regular basis, regarding self-forgiveness, and forgiveness from God. In very old age, life review can be difficult especially when the ability and opportunity to change the past is lost and current regret remains. Grief and loss is a very personal and nuanced experience. Particularly with loved ones with whom there is so much history, as in the lives of the oldest-old. There have been so many opportunities to act well, and so many opportunities to make mistakes; so much to live with, and without, when the other is gone. This is Louis’s loss.

#### **“I’m Just Thankful . . . ”: Alma’s Exemplar**

Alma also describes a caregiving decision she made at age 86, for which she is thankful. Her husband of 61 years had a long decline due to dementia. Towards the end, she needed to place him in a board and care, as caring for him became too difficult. As his decline continued and she knew the end was near, she brought him home for his final weeks. Although experiencing resistance from her adult children, she stood her ground. He was able to die in their home. “I’m just thankful I brought him back when I did.”

Alma has no regrets to add to her loss. She related the notion of an “ambivalent loss” as her experience of his slow, progressive disease. The loss was felt early in the disease, but did not reach completion until his death. Alma moved slowly into the role of widow and life without her husband.

**“It Is More Difficult . . .”: William’s Exemplar**

William tells of a life world, his world of social being, which presented difficult challenges with the loss of his wife. “My life course changed precipitously about four years ago when my wife died.” This is a man not prone to exaggeration, so his use of the word ‘precipitously’ has significance. His life changed dramatically. William and his wife made the decision long ago to move into a residential community. He has been quite pleased and it seems he has discovered old friends from high school, college, and his military days that live in the same community. When his wife died however, he lost his place in his village as a couple.

In this small venue, you know, you do many things as a couple, most things. And so, that was sort of shut off. So, it is more difficult. And so particularly at mealtime, it is open seating, but you go down, and there are couples, maybe two couples sitting at a table for four. That makes it very difficult. Eight months ago maybe, I decided to go to a smaller dining room, which is in assisted living. And in effect, I have a reserved seat for lunch with two other individuals.

William had also mentioned another socially awkward aspect of his living situation.

“And so, it is more difficult now, particularly for a male, because I suppose maybe the ratios of women to men is three, three-and-a-half to one . . . .”

This experience of a 92 year old, recently widowed man, wheelchair bound is worth some thought to fully appreciate. Imagine, riding your electric wheelchair into a dining room where you’ve always sat to eat with your partner of 60-plus years. You scan

the room quickly, it's too hard to spend too much time doing this. Tables for four are full. At a glance you see couples you use to eat with sitting with other couples. Or there are tables full of women, not a safe choice. You see that you must sit alone. Sadness is triggered, a reminder of the loss of your wife. A dining partner is forever lost. A reminder of this is a part of your daily experience. His loss means aloneness.

Being the problem solver, William eventually made a change to his dining arrangements and has an "informal reservation" to eat lunch with two other widowed men. At their table they reminisce about former times of life, the war, their college days, and more.

#### **"It's Fine Now": Douglas's Exemplar**

After losing his wife of 74 ½ years, at the age of 97, Douglas's pain was of a different sort. His wife's decline with dementia led to a final placement in a long term care facility. He describes losing his wife before she actually died. She began thinking her husband was her dad, and would argue with their daughter.

We were sitting in the den, one day. My daughter would say to me "Dad . . ." and my wife would say "He's not your dad." Then my daughter said, "We're going to go, Dad." And my wife said, "He's not your dad." And I got to thinking afterwards, I didn't realize it at the time, but afterwards, she'd gone back to 18 years of age and I'm 95. How could I be her [the daughter's] dad? It was hard. She'd recognize me and the kids some of the time, and sometimes not.

In response to a question about how things are for him now, Douglas replied,

It was a little tough at first, but it's fine now. There's another case of relief because you don't wanna see anybody suffer like that. That's ridiculous. And not only you, it's evil because they don't even know you as their husband, or their children, but you go hoping they will and it never happens. . . . She was a good woman.

He lost his wife, and he lost the mother of his children. So calmly, and peacefully does Douglas talk about this now, that it is only his statement “it’s evil” that truly reveals how devastating this loss was to him and their children. He does seem fine now. Douglas had a long ongoing loss.

### **“I Lost Him Gradually”: Betty’s Exemplar**

With another caregiving experience, due to her husband’s Parkinson’s disease, Betty provided care at home until it all became too much and he was too sick. Once he was placed in a care facility, she sold their home to their son and moved to a small home near his location.

You know you can’t give up. I don’t give up! . . . Of course losing my husband, I lost him gradually. I took care of him two years and three and a half years in the rest home . . . and I was so tempted to pull the plug, but I couldn’t get myself to tell the kids you know. So I just waited. . . . Three and a half years just existing there. You know, I told my kids, I got it on my will. Pull the plug!!

Her loss was slow and dominated many years of her life. He died 11 years ago, and at this point she is clearly pleased with her lovely, small home in the senior community with nearby neighbors. Her loss was evident however, as she spoke fondly of him.

I used to, when I’d get my medicine, I’d give him all the literature, “Read it for me.” He would read all that for me. And when I bought a juicer, and reading those things, I said, “Oh, I miss you Pete (laughs). But he would read all that, and then of course, cars, batteries, and TVs, and that’s way above my head. He used to be so handy, he made everything work. I used to call it Mexican ingenuity. I’d always tease him about that.

Betty speaks fondly of her husband. Her memories of him are vivid. While she relates losing her reader and repair man, it is clear that her loss continues as her own abilities decline. Loss can mean doing it all alone.

Losing a life-long partner at this late age, for these participants, has meant that one will be single, and perhaps live alone for the rest of one's life. None of the participants have remarried. As a listener to these narratives, I felt both a hope and a sadness. The stories of loss of a life partner vary greatly in cause, process, result, significance, meaning, and response. With the exception of John, the nine other widow(er)s have moved forward with good and redeeming memories. Clearly, the loss of a spouse demands a lot from the surviving life-long partner whether it is sudden or slow. The total loss and meaning of it may even be unexpected, yet resilience, adaptability, and the involvement of family, particularly children, as narrated by these participants, can allow for a meaningful life to resume even in the oldest-old years.

#### **Out Living so Many: "I Don't Know Many People My Age"**

It was a bit humorous at the time she said it, but when Barbara was asked how her health compared to others her reply was "Oh, I think I'm better off than most people who are my age. Come to think of it, I don't know very many people my age!" This sudden realization brought laughter. Yet the truth is, the longer one lives the more deaths and losses one experiences, both of one's contemporaries and even those younger. Of course, sadness can come with this experience of the oldest-old, even overwhelming sadness.

#### ***Those That Are Younger: Exemplars of Loss of Family***

Barbara told the stories of the loss of her two husbands without offering much insight into her experience of grief. However, while describing the loss of a stepson at age 57 and then a step-grandson at age 50, both to cancer, she teared up. Here was the only time in the interview process in which she demonstrated any emotion other than laughter and humor.

I felt very bad when my stepson died, it was such a shame. He was only 57. . . and cancer got him . . . and that was hard because he was so young. I was very fond of him, but the fact that he was cut down at such a young age, it seemed wrong. So, then my stepdaughter lost her son after that. He was about 50.

Barbara, normally upbeat and undemonstrative, became emotional when relating the deaths of her step-family members to cancer. Earlier in the interview, I asked if it felt like she has lost a lot of friends. Barbara's reply was in her usual matter-of-fact, why-worry-about-it tone: "Well, in a way, yeah. People do not live forever."

Worse for Douglas than the loss of his wife, was the loss of his son to complications of diabetes. Losing a child is known to be one of the most painful losses to bear, no matter the age (Worden, 2009). Douglas describes this loss as devastating.

But before, he started to lose kidney [function], and they put him on dialysis. That was horrible. That was a terrible part of my life. Taking him down there and watching him go in. . . . He passed away. That was a sad time. That's the worst part of my life . . . he suffered so badly the last year that you kinda hoped the Lord would relieve him.

He was 89 when his son died. Knowing Douglas approaches his life world with humor and positivity, his choice of words are meaningful: Horrible, devastating, terrible, and sad. He is not prone to exaggeration. This was indeed the worst time of his life. Douglas was descriptive and honest, but it was evident he did not want to linger on this difficult time of his life.

### ***"I'm Still Here": Exemplars of Loss of Friends***

In our first interview, Douglas mentioned his daily lunchtime ritual of going to his favorite local diner. Eating lunch daily with a group of friends was his habit. He has outlived them all and I chose to explore that further.

D: I was the oldest one of the group and they're all gone. Five of 'em.

I: I know you don't dwell much on things like that . . .

D: No, I can't. You can't.

I: But do you remember having thoughts of that as your friends passed?

D: Yes, and I still think of 'em, some of 'em. We talk about one occasionally when we're having lunch. I miss 'em. Their passing. But you can't dwell on that because life goes on. (laughs) . . . living to 100, you've seen many people die."

Norma shares this similar experience of losing longtime friends. When she was asked if she knows many people older than she is, she laughs and responds "I can't think of anybody!" I then pull in a bit closer and ask if she has had deaths of friends that have been hard.

Yes, there was four of us that used to hang around in high school and go everywhere . . . all three of them are gone, and so I'm still here. And I did miss them a lot because we used to get together on birthdays and go to lunch you know, and reminisce about old times (laughs). And about the things we used to do that we shouldn't have done. They're gone.

Lost are her childhood friends. She alone remains; she now reminisces alone. She then shared that even though she's the oldest in her family, she has lost two of her younger sisters. Only one sister remains and they are quite close. Norma's long life has brought many losses of family and friends, yet she remains peaceful and able to live with gratitude as the oldest person she knows.

Rebekah's story of a current good friend who is very ill and near the end of life reveals a difficult time for her. "She's very bad." This friend is dying from emphysema and is having a very difficult time breathing. "I just get overwhelmed when I go over to visit her. . . . It's overwhelming. She weighs about ninety-something pounds." For Rebekah this was a grief and loss of a friend which was occurring during the time of our interviews. It is not a memory, it is her now. Her emotions are real and raw; she is feeling this loss. Rebekah is witnessing suffering and it is overwhelming.



Like Douglas and Norma, William has several lifelong friends, from childhood, college, and the military. When I ask him about losses at this time of life, his first thought is of his wife. He then tells several stories of long term friends and various deaths and illnesses. I comment that he has lost several friends in these last years. William's response relates the expectation that comes with living in these oldest-old years.

W: But now, you expect to lose them, and you know, occasionally I'll look at obituaries or obituary news, and they're always younger than I am."

I: Yes, and you notice that. Does that bother you? Affect you in any way?

W: How can't it? It's inevitable . . . I was looking at my wedding picture, and we had a fairly elaborate wedding. And so, people directly involved in the wedding, there would be maybe 16 people [in the wedding party], and then . . . guests, maybe 60 or 80. And I'm just thinking, I'm the only one of those still alive. But no, I don't have that nostalgic feeling, but I'm the patriarch of my family (laughs).

This is interpreted to mean that these thoughts do not stir much emotion in him, but he is cognitively aware that he is the oldest in the family. All who attended his wedding have died. He alone is alive. This realization came to him in a moment of reminiscing about his wedding. Yet, it doesn't seem a moment of pathos. He expects to continue to lose friends, even younger friends. As a more thought oriented, cognitive individual, William finds these realizations interesting and even humorous, but not particularly emotional. He admits it is inevitable, but emotion, worry, or fear are not expressed and not evident. Living with the expectation of loss also implies the inevitability of his own death, and that someday he will be lost to others. But he doesn't venture into that topic.

This topic is something that Walt did venture into when he was asked about losses at this time of life.

I think losses of peers. I get a list from the church every once in a while. I'm totally bemoaning the fact of how many of my friends have died and how many of my colleagues have died. And not too long ago, we had one of our giants [important person] down here die, and I went to his memorial. Found myself rehearsing. My day will come, and they'll be there to pay their last respects.

Walt has imagined his funeral. What will people say? How will they feel? Who will come? As a man who has touched many people's lives, at age 92 he has experienced the loss of many who have died before him. His frank discussion illustrates his recognition that we all are in this world temporarily. Being in the world for Walt is recognizing that he will not be in this world forever.

Living long into old age carries with it the experience of seeing those older than you, then people your age, and then even those younger than you die of what our world calls "natural causes," or even "old age." More and more one's final day is anticipated. More and more the oldest-old recognize that yes, "it's inevitable," yes, "my day will come." Other than in the life history interview, when asked directly, deaths of parents and even siblings were not told as losses. For many, they occurred years ago. Some had a difficult time even remembering dates and causes of death for parents, brothers, and sisters. Peers and friends however have a different impact. As the circle of friends and peers shrinks from loss, one's present world and tomorrow's world shrink in a similar fashion. One's past is rich with meaning and full of memories that are carried into the present. Lunchtimes of reminiscing with friends are full of sharing this meaning and memorable times of life with others. The narratives offered by these participants are those of recognition that much is behind them as memories, and what is ahead as a future has grown very, very short. However, this thought is not dwelled on. Perhaps living in the present day and remembering days past, along with the people that filled them, make

these losses of spouse and friends, this shrinking world, as manageable, and living into life's remaining possibilities, as possible.

### **Loss of Meaningful Work: “Outlived Usefulness”**

Rebekah's narrative of “giving up of the life I loved so much as an educator” that marked her journey into being old was told above. Yet her words carry a poignancy here. Others were telling her to rest, and rest was not in her vocabulary. This giving up of work showed up with different faces in the loss experiences in the lives of the participants. Some which have been previously touched on, hold meaning here in this realm of loss of meaningful work.

Walt is the sole participant that continues to be employed. Even so, he told of the experience of being recognized as old in an institution that continues to appreciate his contributions. Although very accomplished, he is living in the tensions of having rich purpose through work and a body that is setting limits. In response to a question about recent good or rewarding experiences, he offered provocative insight.

It's kind of a joyful sadness. . . . At this point because you're in a category, I don't get asked to speak as much as I did. I don't get asked to join committees I used to join. Even in my own program, where I could give them the benefit of 40 years, they wanna do it themselves. It's a kind of outlived usefulness.

An outlived usefulness. Or is it ageism, the perception of others sending messages of exclusion, that may be creating premature losses? There is a pathos here for Walt, yet his philosophical nature realizes he has much to be grateful for. Even in the workplace where he is highly valued, he is made aware of his “maturity.” He is in a category; the category is “old.” This is recognized as exclusion, by subtly being left out of things. It has not escaped his notice.

One of the first times I was aware of my maturity too was this young woman, a girl, opened the door for me and I thought “Well, what are we coming to here?” And she did it out of genuine concern and care.

How many ways does this subtle reminder of age show up for the oldest-old? How often does it prematurely create losses as for Rebekah and Walt? Both subtle and not-so-subtle reminders of age appear in their life world. Walt was able to recognize this act as kindness. But, as kindness towards an old person.

Also receiving these messages, but from her family, is Sarah. As a mother and a former homemaker, Sarah expresses her experience of feeling discouraged when she can't do what she wants to do. “I'd like to wash the wood work, cook, go fix what I want and go where I want to go.” Her life is largely spent in her chair and being told by her loving, attentive, and well-intentioned family “Mommy, you can't do that.” Perhaps this is a subtle message, or not so subtle, that she has outlived her usefulness as well. “You cannot” accumulates.

Betsy's deep sadness is from her inability to continue as a missionary in Mexico. This was the vocation she shared with her husband. “I can't go, but my heart is there.” As mentioned earlier, her aging body has given Sarah the same messages as Walt's colleagues and Sarah's family; she has outlived her role as a missionary. Her body has prevented her from returning to her beloved work and people. This is clearly a loss to her. A loss of aging into her oldest-old years.

Having recently received a prestigious award in his professional field, William has been reminded of what has been, and how he used to live in his professional life. Lost to him are the days of having his bags packed and prepared for any professional opportunity that came his way. He comments “Of course, that is shut off now.” Shut off

is an intriguing way to express this loss. His professional work is over. This time of life is closed to him now. Lost are the abilities to be spontaneous and create change. “I cannot” accumulates. Despite this loss, William seems to be occupied and challenged with keeping his life routine and manageable, and taking the best possible care of his aged, disease-disabled-body and forgetful mind as he can.

Louis’s thoughts of this experience are a bit more wistful. In his response to the question of what thoughts may go through his mind at the end of the day, it is evident that for him, it takes a bit more work to make accomplishing “nothing of consequence” be okay.

I’m somewhat conscious of the fact that I’m really not accomplishing anything here to speak of. And so, I kind of go through that and think about, “Well, now, what did you accomplish today?” And I invariably go through this little routine, don’t spend long on it, but I’m often disappointed to realize, what I did today was (laughs) I read the paper today, and went to dinner, and to lunch, and not much else. And then, I sorta say to myself, “Yeah, but you’re retired. Nobody’s expecting you to do a whole lot here.” And so, it’s a little matter of convincing myself because I’m accustomed to a life of feeling like I had accomplished something, you know, that I could either take pride in or take (laughs) something in. . . . Yeah, I was loaded with responsibility.

He was indeed loaded with responsibility. Having no expectation of accomplishing anything, because you’re old and retired, and your body is old and in pain, is experienced as a loss for Louis; an “I cannot.” For someone whose being in the world felt significant, this change to possible insignificance can be hard. Yet, he is careful to say “I don’t spend long on it.” His overall approach to his daily lifeworld is one of gratitude and an offering of his memories of significant world events to the memory of others. Louis wants me to know he recognizes that in spite of his loss of responsibility and daily accomplishment, he appreciates all he has and is thankful for his life and his current “I cans.” Even when

they are a shadow of those of his past life. This perspective is common among the participants, as is the presence of giving up former ways of being and doing in their world.

### **Losses of Former Pleasurable Activities: Faded Energy and Interests**

Author Florida Scott-Maxwell describes in her articulate, reflective, writer's manner, the loss of a body that cooperates leading to the loss of activities, which brought her pleasure and distraction.

I used to draw, absorbed in the shapes of roots of trees, and seed pods, and flowers, but it strained my eyes and I gave it up. Then ten years ago I began to make rugs. A few were beautiful, though never straight. As I created patterns, banged and pulled, the wool and I struggling – the wool winning sometimes; at great moments I in full command—my heart knew peace, and my mind was as empty as a cloudless sky on a summer's day. But my hands were too arthritic, it had to end, and now only music prevents my facing my thoughts (Scott-Maxwell, 1968, p. 13).

Her drawing was lost to poor eye sight; her rug making lost to arthritic hands. Similar stories of loss of the cooperative body and activities of leisure and pleasure are present in the lives of all participants. Each brings to their personal loss unique meaning and a distinct perspective to these new “I cannots.”

Perhaps because she is the youngest and one of the most able-bodied, Betty is in the midst of experiencing several new losses of ability related to diminishing eyesight and increasing arthritis. She spoke with sadness about times gone by, of car trips she and her good friend used to make. “So, we don't do that many outings . . . she can't help me . . . and I need her help. I can't drive that much. I wouldn't attempt it. She was a wonderful partner to go out.” Betty's vision loss is wrecking-havoc on her abilities. “I can't sew straight any more. I noticed it, black, or dark colors like that, I mean it's really hard for me . . . I can't see 'em.” Betty's livelihood for more than 30 years was sewing.

She made draperies as a business and sewed for pleasure. Sewing has become a discouraging struggle. And then, there is her difficulty reading.

The paper's getting too hard, and I get frustrated, you know . . . the words bleed together, they go together on me. The letters [on the TV], I can't see them from the recliner. I'm always in the bedroom, and I can't see those letters anymore. I might see a word or two, but I'm straining my eyes.

One additional ability that Betty is quite proud of is that she can still wear high heels. She enjoys "strutting her stuff" in her strappy heels. However, recently she has found that her arthritic fingers have difficulty putting these shoes on. For now, she can accommodate this with a shoe horn and extra time, but it is clear that losing this symbol of youth has been difficult. She is watching as old age is making itself ever more present in her life and body, and is reminding her of her imminent loss of independence.

Whereas Betty expresses sadness, disappointment, and frustration over her recent difficulties, others take it in stride and let it go without much resistance or emotion.

Norma related her story about knitting. Something that she thought she could now return to, but her discovery revealed otherwise. It is an "I cannot."

My hands wouldn't go! (Laughs). . . . I thought, get some yarn, give me something to do, but I just couldn't do it. And I used to knit up a storm, crochet and knit both, but I can't do it anymore. . . . It surprised me! (Laughs) . . . I thought well, if I can't do it, I can't do it!

For Norma, the discovery of hands that can no longer knit is viewed as a humorous surprise. She indicates no regret or sadness, and has resigned herself to it. There is no threats to ability, independence, or the sense of impending loss to which Betty speaks.

Douglas has unique notoriety due to his loyalty to sports teams. He attended so many Los Angeles Dodger baseball games that Vin Scully (the longtime Dodger

announcer) called him on his 100<sup>th</sup> birthday. When telling of changes he's experienced, he described a meaningful loss.

I used to go to all the Dodger games. I can't do that anymore. I watch it on television. I don't have the ability to get in and out of the stadium with a walker and everything. And I went to all the college games and I don't go there anymore. . . . My desire to do things is no less . . . it's the physical body. And I get sleepier earlier than I used to . . . now I can't wait to get to bed.

Between baseball and football, Douglas's life was filled with attending sporting events.

While admitting his desire to go hasn't changed, he communicates a recognition and acceptance that this time is over. His body is no longer up to it. It is a part of his past, an important part that will be no more. It is an "I cannot"; it is a loss.

It seems old pleasures may lose their attractiveness when you can't handle them anymore. Taking a brief pause in these narratives, to consider Heidegger's ideas (Dreyfus, 1991) of solicitude and living-into-possibilities, may bring added thoughtfulness and insight into this experience of being in oldest-old age. As understood by Heidegger, the idea of solicitude is that we are "solicited" by possibilities that are available to us, and are no longer solicited by what is no longer possible (L. SmithBattle, personal communication, July 19, 2015). Being-in-the-world involves living into possibilities, being attracted or drawn towards things that are possible (Dreyfus, 1991). Conversely, we are not drawn to what is not possible, or perhaps in oldest-old age, things that are no longer possible. "Coping with the available proceeds by pressing into possibilities" (Dreyfus, 1991, p. 186). What is available as relevant in one's lifeworld, what is possible and do-able, what is attractive and holds our interest and passion, is a changing reality. These oldest-old tell of this changing of possibilities due to ability or stamina. Sometimes this is first recognized as loss, other times as lack of interest, of no



longer being solicited. Something that was formerly meaningful may no longer be relevant or possible. Possibilities change. And wondering begins as a question arises: What if nothing calls, nothing solicits? What does one do with the emptiness of nothing calling? Of sensing no possibilities? No one tells this story, yet.

While describing times when her daughters comes by to take her wherever she needs to go, Sarah reveals a former enjoyable monthly routine for which she no longer has energy. For years, each month she changed her table setting and decorations. “Like this past week was the time I changed my table. I don’t know if you noticed that.” Her table was indeed decorated beautifully for spring and the Easter season. “This was one of the things I used to do once a month, but then the older I got, I don’t think I feel like going through all this. So now I change it by the season.” Sarah’s energy level has led her to cut back on her tradition. She has however, adapted to her current energy and interest level, but has not completely surrendered her decorative table setting. She is living into new possibilities.

Madeline’s narrative demonstrates a similar surrendering. She traveled all over the world on botanical-type adventures. These adventures define her retirement years. Even so, Madeline is clearly tired. During our first interview she describes former goals.

Well, I had a bucket list until my body kind of failed me, . . . ‘there are two specific types of orchids I haven’t seen and they’re in New Zealand and Nicaragua. . . . And I wanted to see those. Those are the two bucket list things I want to accomplish . . .’

Her use of “I want,” the present tense, is significant. By our third interview, and after her serious fall, Madeline’s thoughts about orchid hunting had changed.

But right now, I can’t figure out how I had the strength to do all that, because I told myself, “I’m not gonna go anymore if I can’t handle my

own luggage.” And so, I don’t think I could handle the luggage now (laughs). I don’t have a yearning to find those orchids anymore.

“I don’t have the yearning,” is a highly significant statement. Energy is gone and Madeline’s interest has gone with it. In Heidegger’s terms, she is no longer solicited by this interest. The possibilities have changed. For both Sarah and Madeline, their decreased energy has swallowed up formerly pleasurable interests; they have lost their appeal. The goal of fulfilling her bucket list is lost for Madeline. It has become “I cannot.”

Similarly, Rebekah actually expresses loss of joy in her Bible reading due to her loss of vision and concentration.

I used to read a lot because I was studying and teaching all the time, but it’s amazing how I have lost interest in reading. I think it’s because my concentration isn’t as strong as it was . . . I have to read it two or three times to remember what I read, or get a perfect understanding, whereas I read before and I got it quickly. . . . Since I teach this Bible study every week, I find that I have to make myself stop because my eyes get tired. And it’s not as much of a joy as it was before.

Reading has become tedious, no longer joyful. This is a loss for Rebekah. The experience of reading and studying has changed from joy to work. Her words, “used to read a lot,” reveal that she is no longer reading as much as before this time of being old.

Old age is not a time separate from the rest of one’s life, but rather the needs and possibilities of earlier times of life are left behind as new ones emerge. These new needs may be for routine, regularity, rest for the eyes, naps, an earlier or at least a regular bed time, knowing that physical demands are manageable and what is possible. Narratives of these oldest-old show a time of life where former interests die out most often due to demands of the aging body, and some perhaps imposed by others. Some former interests and pleasures pass away suddenly, such as Norma’s knitting; others pass slowly, such as

Sarah's table decorating and Walt's work. It appears that when interest dies first, a sense of loss may not be as recognizable. For others, the ability dwindles first and the loss of what was pleasurable precedes the loss of interest. This can bring sadness, or just a willingness to let go, live into what remains possible, and retain the memories. These losses, these "I cannots," are experienced uniquely to each.

### **Living With Regret: Life Review May Have Some Difficult Spots**

Some thought has been given to finding a location for a brief walk through the experience of regret for these participants. Placing it here among the loss experiences seems a proper home. Regret carries with it the idea of permanence, of the loss of opportunity to make changes and "a feeling of sadness or disappointment about something that you did or did not do" (Regret, 2015). Lost is the ability to change the thing presenting as regret. For the purpose of understanding the lived experiences of the oldest-old, regret is seen to reside with that which is lost; an "I cannot."

For some regret may be an understood idea, but not a personal experience. Norma clearly stated "I've had a good life. I don't have any regrets." A similar self-assessment but with a different slant is William's take: "If I had to do it all over again, I'd make the same mistakes." He too is content with choices he has made in life.

Rebekah has her own experience as well.

Sometimes I can remember a lot of things, and other times I've been able to wipe out the unhappy memories from my life. . . . I prayed that I would wipe away the unhappy memories so that I would not grow old and be looking back and thinking how unhappy I was.

Rebekah has chosen to forget unhappiness so as not to remember and hold regret. Her experience with an unhappy past is that it creates unhappiness in her present. She is choosing to embody happiness at this time of life. As Rebekah prays to forget, she is

creating a present world which will be free from regret. She will grow old remembering her life as happy; she is living into possibilities.

For others, manipulating memories to forget unhappiness or regret is not their experience in old age. Life review for them may carry some of a regretful past into the present. For Betty this lingering regret is revealed as sadness over a lost opportunity. In her response to the question about lingering regrets, she speaks to a deep longing.

I wish, I wish I would've had more schooling, college. . . . My folks didn't have that kind of money . . . I wish I could've had more education . . . you know, because it makes life easier for you.

Betty grew up during a time of racism and segregation, and in a large and poor family. Her experience with regret is perhaps a disappointment of the time in which she lived and even of her family circumstances. She is not carrying self-blame into these late years.

Sarah's regret carries a deep sadness about questions that will never be answered. While not stated as regret, her description of her husband's last days and her hurt and confusion in her marriage reveals deep sadness and regret over lost opportunity to find answers. Living with this confusion and hurt seemed to block her understanding of his impending death. "It was hard for me to cope." He was then taken off life-sustaining medication "and I'm still standing there not believing . . . I don't know what to pray for. And then he took his last breath." Her continued description tells of a woman who, rather than grieving her husband, was grieving a lost opportunity to have understanding, of a wife who wasn't prepared to be left holding this hurt and confusion.

Sarah did not say that she has been able to forgive him. She did say "I've come to grips with it." Her eyes, and her low-tone and slow words convey a deep, deep sadness and doleful regret over many years of a confusing and hurtful marriage. She carries this

still; her memories have not been filtered. She is alone in this experience and doesn't talk to anyone about it, except her Lord. "I had to pray to get rid of this hurt and ask the Lord to forgive me. And I think that's when these seizures started. It was right after that."

Sarah has been hospitalized multiple times since her husband's death. The first hospitalization was determined to be seizures from an unknown cause. While not specifically stated, her narrative indicates that she sees the cause as this grief and regret.

Losing someone to death at any time of life can bring regret, and painful grief. In oldest-old age, one's strength and resources can be limited. In a vulnerable and dependent time of life, the oldest-old may be left carrying burdens that challenge their ability to reach resolution. Louis's regret, which has been touched on earlier, also lingers in his life.

I generally review a few things in my past, you know, about things I wish I had done a little differently. And things I might've done for my wife who died here eight years ago that I didn't do. Yet I feel heartened by the fact that I was her exclusive caregiver. . . . I do feel that I was a really good husband at that time of her life, and at other times, maybe not quite as good. . . . So, I sometimes go through some of this . . . and I say my prayers and always include her . . . and how I'm hoping she's in a good place and everything.

Towards the end of our last interview, Louis explains:

I have not been able to forgive myself and I often say that in my prayers . . . things like that are on my mind . . . but it's a bit of a burden that you carry . . . it's there all the time.

It is evident, Louis has guilt and regret over how he was as a husband during earlier times of life. Eight years after his wife's death, these memories linger almost daily in his life review. He speaks of being grateful for an opportunity to show his love and care during her last years. Louis was able to demonstrate to her and to himself, his sacrificial love. Yet, this has not erased his regret over past "shortcomings."

For these three participants, Betty, Sarah, and Louis, regret is a part of the life experience in these oldest-old years. When so much of one's life lies behind, and so little in the future, life review and reminiscence can take up a large portion of thought life. Late-in-life regret can be ever-present in this life-review and therefore ever-present in one's days. Yet, the prevailing attitude of all three is one of gratitude. Other participants did not speak of regret; most expressed a good life as their lived experience.

### **Death and Dying: Living When Death Looms Near**

Of course the ultimate loss is death. Being very old brings with it the reality that even in the best of circumstances, life won't continue much longer. The view of death through the eyes of these aged participants is as individual as each of them. Some are philosophical, others very matter-of-fact.

Barbara, expresses her very practical and unreflective view of the end of life. In response to a question regarding her thoughts she quickly responded "I am not at all worried. . . . When the time comes and goes, and I don't worry about whether I go to heaven or hell (laughs)." Later she commented about her life overall "I've enjoyed life. I'm not sorry that it's coming to an end but who knows, I may live another few years." My sense was that this is truly Barbara's sentiment about it. As a 98 year old with very few health issues, financially stable, living independently, she's not at all worried. She continues to live into life's possibilities.

Norma, a woman of few needs and even fewer concerns, also sees death in a very practical unaffected way. As she realized she is outliving everybody she knows, I asked if she ever worried about being next. "No, what's gonna happen is gonna happen. I have no power over it. No." Again, Norma's response is very similar to how she approaches

life. She takes it all a day at a time, with few needs and few expectations, living into possibilities still available to her.

For John, a self-described Christian who continues to grieve his wife, his current purpose is “To live the kind of life that would be acceptable for me to be back with my wife in heaven.” Death even seems inviting as he anticipates being reunited with her.

During her recovery from her devastating fall, Madeline was very discouraged. She told of her former desire to live to be 100, but her mind has been changed. “I don’t wanna live to be 100 if I’m feeling this way.” I asked if it had seemed to her that this accident could lead to the end of her life. “Yes, and as far as I’m concerned, it’s fine.” Living into possibilities, for Madeline can include death. She went on “I’ve always felt it would be okay [to die]. But before the fall, I felt like I was doing ok. But now, I don’t care. I mean, except for him [her husband], I don’t care.” So difficult was this time that Madeline did not care if she lived or died, except for the impact it would have on her husband. She was clearly tired and ready to give up. Madeline and Walt share the same belief in an afterlife. In our last interview, when she was much improved, Madeline again shared her thoughts about death. “I have no worries, but I don’t wanna have a prolonged illness. I wanna just die and get it over with. That’s what I’m hoping.” Perhaps this answers the question above: What happens if nothing calls, nothing solicits? This may be what the emptiness of nothing calling looks like.

A woman of faith and strong convictions, Alma doesn’t spend much time thinking about the end of life. When asked her thoughts about the end of life, her reply reflected her beliefs.

Well, it would be lovely if it was just an overnight thing. . . . I’m not worried about it. I can plan as best I can, but it’s up to God. . . . I have no

idea how long I'll live now, you know. But that department's up to the Lord. Every breath and every heartbeat has got to come from Him.

In a later interview, as Alma is telling me about her surprise birthday party, she revealed what may be on the mind of many as they celebrate late-in-life birthdays. "You know you get to thinking, 'Well, how long am I gonna be around?' and everybody else feels the same way." In her frank manner, Alma expresses what may be a common thought: "How much longer?"

Yet, she did not reflect much concern or emotion about the topic.

Betty, true to her expressive nature responds with emotion to the question of what she worries about:

B: Dying. I don't want to go . . . I wanna stay alive!"

I: Is it the dying process, or the being dead, or both that bothers you?

B: Well, I hope I go quick you know. But you know, who are we to choose? I know there's a heaven and a hell, and there's a purgatory. Okay, now what if I get stuck in the purgatory? Where am I going? (laughs).

I: Is that something you think about?

B: Oh, of course. And then I say, well gee, you know, let your conscience be your guide, I guess huh?

This lively woman has an active thought life of which she is very honest. She often thinks of her death and what that means in light of her religious beliefs. Betty is still actively engaged in life, in recognizable yet threatened possibilities, and is not at all ready to see it come to an end.

Louis, with his thoughtful and reflective honesty, conveys yet another way of living with thoughts of death, in very old age. During our first interview I asked about his thoughts regarding the end of life and an after-life.

Well, I just hope it's sudden, you know. And yes, I believe there is an afterlife. Although I confess I have some doubts that keep cropping up in my mind, you know. I just can't visualize how I will ever meet up with



my wife again. . . . I just can't hook this all up together, and I don't know, even when I say the Lord's prayer, certain parts of it sort of give me pause, like I'm 100% Christian, I'd say, but I do, yeah. You asked that question. So, yes. I do have some beliefs.

Louis is an individual who considers questions of life and faith. In our final interview he expressed his lived experience of living with death as an imaginable, possible reality.

L: You don't have to do much arithmetic to know that you [I] don't have an awful lot of time left, you know . . . I mean there's a limit to everything, but I certainly don't dwell on that or worry about it.

I: How do you manage that?

L: I think I have a very good philosophical attitude on this particular subject, that I'm convinced that if tomorrow would be the day, you know, I really can't get distressed about it, or disappointed about it. I feel like I've had a full life and I've got loving kids and they have this little [his autobiography]. So, that's part of my general comfort, and I really don't dread any thought of being out of the picture.

Louis has what he considers a good attitude on the subject. Probably meaning, he has thought this through and he is at a place in his heart and mind, where he accepts the idea of not being alive in this world. He has written an extensive autobiography for his children. Louis is prepared and doesn't "dwell on that or worry about it."

With the exception of Betty, the idea of death in very-old-age wasn't revealed to be the fear or concern that it was anticipated to be. Each participant has their own distinct thoughts, beliefs, and ideas about the end of life and what, if anything, comes after. These people each have lived a long life of being embodied, or bodily in this world (corporeality); now in a very old body. They also have lived in this body, in this world, for a very long time, as an embodied being with a past, a present, and a future (temporality). These two phenomenological existentials provide an understanding of how each individual comes to the present with a view and a way of being now, with losses and changes of possibilities in his or her own lifeworld, and a view of how to leave

this life as it is presently known. Even with faith, there may still be doubts and unanswered questions about the after-life. Yet, most participants have come to terms, in their own way, with their finitude. In some narratives, there is a hint that death could bring welcomed relief. There may come a time for some when death is not seen as a loss, but as a gain, as an attractive possibility. It has been suggested that “Death is largely a threat to those who have not yet lived life” (Rohr, R. 2011, p. xxxvi). Oldest-old age, may bring this resolution as one of its rewards.

### **Conclusion**

With each step into the lives of these oldest-old participants, the uniqueness of each individual, each lifeworld, each way of being in the world is more and more apparent. The ordinary life, the commonality of aging seems to disappear into the realm of forgotten expectations. Coming into this very late “now” of life, is a single and distinct past of each individual, rich and deep with meaning and filled with decisions and choices that present themselves. Their time, their life-time, their lived-time, has created a story of meaning and possibility in their situated present.

It is clear that each person has come to where they are in their world by way of being in specific circumstances. These circumstances are particular to each and create both freedom and constraint in available choices of how to respond. Opportunities, choices, and possibilities for life now and in the future, are presenting themselves differently depending on where and when one has lived, is living, and how one projects one’s self as living in the future. Each participant has their own dreams, hopes, and disappointments they hold as they are living out their own story. It is a privilege to bear witness to these lives, and give recognition to these losses.

Hearing these thirteen life histories allowed for recognition of some predictable commonalities. All participants experienced pain and suffering in early life. All seem to accept that loss and suffering is indeed an aspect of being in the world. There is no expectation that life should be easy. From the perspective of this listener, there was no complaining and no self-pity expressed. No one is keeping a tally of losses, no one is searching for an understanding of why loss is being experienced. In fact, rarely does a participant focus on loss as an experience unless asked. Yet, I would not want the reader to think that these loss experiences are not taking their toll.

The longer one lives, the more disability, weakness, pain, and “I cannot” become life companions. Companionship formerly offered by spouse, family, peers, colleagues, and friends can be lost to death. This can lead to an ever shrinking life world. Added to these losses are those of responsibility and work, a sense of accomplishment, pleasurable activity, and declining interests. These are all revealed to be possibilities of loss in the life experiences of these oldest-old. As aspects of aging, these experiences can present burden and struggle that are subtle or quite obvious, and can bring with them discouragement, fear, and vulnerability. All participants spoke to having “moments,” bad days, hard days, challenges, and difficult times.

Considering what is involved in navigating these losses of aging brings to mind the image of walking a tightrope with a balance bar. Falling off the rope would be giving in to depression, sadness, despondency. The balance bar is the work of the mind and heart in identifying the gains, the positives, the blessings in one’s life to keep the one balanced and steady under the weight of the losses. These participants are highly focused on maintaining an attitude of gratitude and thankfulness for their lives and situations.

This keeps them balanced on the tightrope, looking forward. To be sure, there are near falls, and recoveries.

The attempt is to balance perceived losses with perceived gain. Sadness by happiness; disappointment by satisfaction. While this potential for gain and changing possibilities also continues, there seems to be a time in the oldest-old years that loss seems to prevail over gain and challenges one's resilience, and hope. The gains of living in the oldest-old years of life will be the next step in listening and developing an understanding of the aging experience from these oldest-old individuals.

## CHAPTER SEVEN

### ACCUMULATING GAINS

“The flame may be unsteady but it can be clear,  
for it is still the greatness of being alive.”

(Florida Scott-Maxwell, 1968, p. 37)

It took a bit of thinking to choose the word which could best explain the concept that is the opposite of loss, an antonym of the word ‘loss.’ ‘Gain’ was selected as the word to convey the notion of acquiring something new. For the purposes of this exploration into aging, it is meant to refer to something new that has been acquired precisely because one has lived into the oldest-old years of life. The ‘gain’ could also be viewed as a reward for the effort at living long, or that opportunity remained available to acquire something merely because one’s life is not short-lived, there is more time. It was deemed important to be open to hearing all that is positive about living very long despite the appearance of constant and overwhelming losses. Narratives of positive gains were explored through questions asking for instances of gain or reward, happiness or satisfaction. Instances describing the gains or rewards of very old age also came up as part of the conversation without any prompting whatsoever.

What is recognized as gain, as has been seen about loss, is largely due to personal perception. Individualized experience through one’s lifeworld, what has meaning, and what is seen to have value or importance is a result of the history of one’s being embodied in circumstances relative to time, space, and relationship. Individuals weigh gain and loss concerning themselves with a mindful sense of what matters to them in their present, as opposed to their past, and as they might see in the future. In considering the gains and losses of oldest-old age, an understanding which has been revealed through the narratives of these specific participants, bears repeating. Old age is not a time

separate from the rest of one's life, but rather the needs and desires of earlier times of life are left behind as new ones emerge. New appreciation for what has been in the past also emerges as a gain. This perhaps, is a reward.

### **The Paradigm of William: “Rewards Come to Those Who Wait”**

Much has been told about William's aging experience already, therefore a detailed history is not necessary. He has been selected for this paradigm of gain because of what I wrote about him after our first interview: “An amazing four hour interview with a man who seemingly has had more life packed into one lifetime than 10 people.” And partly because of what I wrote after my third and final interview: “Listening to William one is left thinking that it can't be all that hard growing old. He lives purposefully and has lived fully.” And finally, while not stated directly, he has kept the positives from his past and lives in his successes, but also stays very present, maximizing each day now. He does not dwell on his losses. I have to ask him specifically about them, and he answers honestly.

William, age 92, was widowed five years ago. His unique history is the development of a chronic debilitating disease when he was 22 years old, recently married, and preparing to leave for his deployment as a military officer in World War II. With several advanced degrees William had a highly successful career in his field. He was also a world traveler and consultant on three different continents. Two years ago, at the age of 90, William was recognized along with two deceased colleagues with a highly prestigious award in his field, which carried with it a monetary prize. “I'm all for posthumous awards, but this was even better.” True to his sense of humor and with a large smile, he commented “Rewards come to those who wait.”

Relating that he “never expected to live this long,” William also explained that “I was projecting that I would deteriorate faster than I have and the deterioration in the past year has really been pretty slow. So, I’m surprised.” With the majority of his life embodied with the neurological effects of disease residual, he sees this as a tremendous gain. His purposeful care of his aging body has yielded positive results. There is no complaining about the extra work this disabled body requires, only the recognition that it has gone better than expected.

One gain for William in his old age is the ability, the “opportunity” even, to reflect on his life.

At my age, obviously I have less to look forward to. And so, more opportunity to look back . . . but my reflection is that I’m sure it’s more through luck than through good planning or decision making, but I would have to say . . . the decisions I’ve made, we’ve made, which at the time were difficult to make, almost always turned out to be the right decisions.

William’s reflection brings him the satisfaction of having a well-lived life. His decisions were the right ones; he has no regrets. A long life offers the gain of time for reflection, which in William’s case has led to great satisfaction. Knowing he has more life time behind and less life time ahead, also allows the motivation for living fully each day.

At several points during the interviews, William’s story revealed his social way of being and caring in the world, and the manner in which memory interplays with his temporal way of being in the world. “You have memories. And so with time, it becomes diffused. So life together and memories after, it’s almost a continuity.” He has created some of his own opportunities for gain at this time in his life. As mentioned earlier, he has his daily lunch reservation with his military training school buddies, he has stayed in touch with very long term friends with whom he reminisces, and serendipitously he lives

in his “village” with a couple from his Midwestern home town, and several friends from his college alma mater. William has almost collected people around him with whom to talk about former times of life which were both meaningful and gratifying. His technology savvy enables ongoing daily connections with friends in other areas of the country and world. For him, this is clearly a satisfying gain of a long life. He has gathered his own village of people with whom he can live in these oldest-old years and share in the memories of all that life offered, and all that William himself created.

One of his and his wife’s mid-life decisions was to move into his beautiful retirement facility. They moved into the assisted living section before she died which offered her the assistance she needed and the care William could not provide. He continues to live in this area, recognizing it as a place “where I have all the care I need.” The assurance of having what he needs in the future is a recognized gain. William admits “life is a little hard for me because of my limited physical condition. And so, dressing is a little difficult. And I know it’s a little more difficult than it was three months ago.” In the discussion of these changes, he acknowledges that “I know time passes on.” Due to his recent, severe heart attack with its long recovery, he has “had plenty of time to reflect on those things. . . . And so, it’s really been a question of how much effort I wanted to put into recovery (laughs).” William knows how to take responsibility for his recovery; he has learned that through his years of living with disability. I complimented him for taking his recovery seriously. He replied: “Well, but for a [disease] victim, life is a struggle. In effect, I have had to compete against people who had four active limbs most of my life.” Having learned how to care for his body in his earlier years, he has continued with this mind-set into very old age. An observed gain is the mental stamina



he continues to have and the commitment to recovery that he has brought to these late years despite life being “a little hard.”

But it is his family in which William finds his primary gain or reward for living a long life. He has lived long enough to see his four children into retirement and his grandchildren into adulthood.

Well, all four of my children are retired. And so, the pressures of the job have left them. They are in a position to enjoy the advantages of retirement. My grandchildren . . . all have active lives. And either through them or their parents, I keep very close touch one way or another.

This brings him ongoing pleasure. According to William, they too have realized that their father and grandfather will not be around forever. Both William and his family have recognized his temporality; as a result, they have been very attentive. They too are choosing to live as fully in relationship with him as is possible considering time and distance.

When asked directly if he has experienced rewards of old age, he quickly responds. “Well, the answer is ‘yes’ because I have four charming, successful children, and four charming and successful grandchildren, and lots of friends including people all along my life that I still have phone contact, or email contact.”

William’s narrative is of a physically challenging life. Despite this, he squeezed life for every opportunity that could be found. One of the gains or rewards of his very long life is many years of living with this contentment. He has created a way of being, of living in relation with others, interpersonal connections, which provides for recalling, remembering, and sharing of vivid memories. Another gain or reward he identified is the ability to share in, observe, and live vicariously through the lives of his children and grandchildren. Williams sees himself in his daughter and granddaughters, and as it turns

out, he is very satisfied with himself, his choices, and how he lives his life. He makes the connection between the importance of this and his current life at 92.

You consciously try to have some correspondence between your goals and what's realizable. . . . So my older daughter who I say does everything [like I would do], I live vicariously through her and especially my four granddaughters who're of the same nature.

His realizable goals are limited now to his small village, but its through his like-minded daughter and granddaughters, that he receives his vicarious rewards. A long life has allowed for this pleasure. Similar to William, enjoying one's family, staying connected, is a very common gain or reward that was expressed by most participants.

### **Staying Connected Through Family: It Takes a Village, or Maybe a Family**

It became very clear as the interviews progressed, that family relationships and connections are often perceived as highly satisfying and bring happiness to these oldest-old participants. The saying relating to child-rearing "It takes a village," is also applicable to supporting and bringing happiness to those living very long. While proximity, number of children, and character of family relationships varied, all narratives spoke to the importance of family, and several to these relationships being definite gains of living a long life.

#### ***"Because of Family Relationships": Douglas's Exemplar***

For Douglas, his loving family makes a tremendous difference in his life, and he knows it. As he describes his daily and weekly routines, what becomes remarkably visible is the importance of the involvement of his children. "I have friends that pick me up to take me to lunch at my favorite restaurant two days a week, and then the family fills in the other three days." And further, "[My daughter] takes care of my doctor appointments and everything; she goes right on in with me. . . . She's a good one." He

sees his surviving son for dinner weekly, and has a weekly ‘date’ with his daughter-in-law, the wife of his deceased son. Several of his grandchildren, who are well into adulthood, are also involved in his life on at least a weekly basis. Douglas is fully aware and appreciative of his family’s role in his well-being.

But you have to think positive. You must . . . because you’ve got things to do and you show your family, and if you still feel important to a degree, then you always will . . . because of family relationships. I imagine if the kids had moved all over and I never got to see ‘em, then that would be different. You’d have a very, very easy time to feel sorry for yourself.

This last sentence makes the subtle admission that self-pity could be easy to find, if it was not for family. Yet for Douglas, partly because of the devotion of his family, he is able to stay positive. A gain in his oldest-old years is the strengthening of these ties, and feeling so valued at this point of his life.

***Family Caregiving—“They’ve Been Here for Me”: Sarah’s Exemplar***

Sarah’s family culture is unique in its long history of family caregiving. She had it modeled for her, she modeled it for her children, and now her children are continuing this family way of taking care of their old family members. Although probably not recognized as notable to her, during the family history interview in which Sarah related the extensive history of her very large family, a culture of caregiving emerged. During her childhood, they cared for two old grandparents and her dying father in her home. When Sarah had a family of her own, they moved her elderly mother in with her family, even though it required giving her mother her and her husband’s bedroom. They all took care of grandmother until she died. Currently one of Sarah’s daughters, and a grandson and his family, share Sarah’s home. They are all involved in her care. While, I’ve wondered if they are doing too much, caregiving too much, it appears to come from love

not obligation. This is how Sarah views it “I used to feel really bad, but now it seems to make them happy. So I smile . . . .”

When she is asked about what brings her the most satisfaction and happiness at this time of life, Sarah responds: “Having my children and grandchildren and family members around because they call me—“Well, I just wanted to hear your voice.” Her life is full of people, full of phone calls. “Every day I talk with my daughter, and my granddaughter, my grandson and his wife and daughter lives here with me now.” While mentioning that not doing for herself has been a hard adjustment, she also knows that “My daughters come by and they’ll take me wherever I wanna go.” She is visited daily by her children who also take her to church every Sunday. Summarizing the impact of her family at this time of life, she states simply “I feel blessed. They’ve really been there for me.” And indeed they have. Sarah tells of being surrounded by family. Whereas many oldest-old are left to struggle beyond their abilities, Sarah’s situation may be quite the opposite. They are very eager to help, perhaps too eager.

When asked what she would take a picture of to symbolize this time of life, she points to and describes each family picture that decorates the walls and bookshelf. Her gain is experiencing their love and commitment to her during these very late years of life.

### ***Family at the Center: Gains Identified by the Oldest-Old***

A brief synopsis from several participants will illustrate how prevalent is this recognition that family relationships are a distinct gain for living a long life.

Norma relates that having her family with her brings her happiness. “As long as they’re happy, I’m happy.” The flip side of that is that “when they hurt, I hurt.”

Through Betsy's deeply spiritual perspective, a distinct reward for her is the satisfaction of living long enough to witness "so many wonderful answers to prayer" in the lives of her children and grandchildren. "She's [granddaughter] on her way now . . . and the Lord is going to continue the work in her." Mentioned previously, what has also brought Betsy happiness is learning to depend on her family; "the wonderful part is they're dependable."

Walt and Madeline have two different perspectives on the difficult relationship they've had with their son. There is a history of chronic illness, substance abuse, and hurt between them. Although her relationship with their son continues to bring sadness, Madeline's gain in living long is "watching the grandkids do well." She has lived long enough to watch the grandchildren grow up, and become happy, successful adults. Walt states it this way: "Longevity allows for making peace with difficult relationships." There has been continued disappointment in the relationship with their son, but each identified a distinct and personal gain that a long life allows, even in difficult family relationships.

To return to Betsy's story told above, she relates a similar need for "making peace," which was not recognized by her as a gain of living long, but perhaps is. "It's so important to have forgiveness, for people in your life. It's so important." A long life can provide for more time, and new perspectives in the healing of relationships. As family members recognize that life will not go on forever, opportunity can be taken, as Betsy and Walt testify, to reconcile, make peace, and ask for and offer forgiveness, thereby allowing for happiness and satisfaction in late life. For family, it can offer a way of peaceful release of a loved one when the time comes.

While none of his children live very close, Louis's family relationships are clearly rewarding and viewed as a gain of living long.

I think the relationships, that's been a growth that's occurred over the past few years that I've just become more and more thankful for the type of adults that I've gotten from my children and the kind of people that they are. And so, that has been a growth, and a reward, yes, over my earlier years.

His longevity and possibly the loss of his wife, has allowed Louis to be the focus of his children's attention, as they are of his. He recognizes, with gratitude, that they are people of good character and they love him deeply.

Well, I feel a real warmth and a real pride in my daughter who has become such a wonderful wife and so thoughtful now as a grandmother, you know, and she's just a jewel, and she's very active in her church. . . . My oldest son . . . I'm very proud of him. . . . my youngest son . . . he's been a very good son.

In our final interview, Louis responds to the question regarding the most significant gain he has received in this time of life.

I think without a doubt that it's just the unconditional love I feel from my children and grandchildren. They really love me . . . and they make me know that. And that's very comforting, you know, to realize that the people that should be closest to me now are.

During our period of interviews, Louis was visited by each of his children. He was bolstered by their love and attention. Ways of being in the world in old age seem significantly impacted by perception of love and involvement from family. Family can be the carrier of gain and reward to the oldest-old. It is remarkable to note that for all 13 participants, gratitude for children has surfaced as a distinct and treasured gain, or source of satisfaction in oldest-old age.

### **The Value of Friendship: “Make Sure Somebody Cares”**

For several participants, friendships and relationships other than family members have decreased. Yet for some, friendships were identified as a gain for living long. William, as previously described, has many friends that bring companionship for reminiscing on a daily basis. These are people that know how it was, what he has gone through, what life was like, way back when. And they come closer than children and grandchildren in knowing what his life is like now. For a widower, this is a gain.

So it turns out, at an advanced age, I live in quite a small homogenous village, and it's organized somewhat like a village . . . the people here all have been successful, and all the rough edges have been knocked off.

This village, their common memories, and experiences are a recognized gain in living long.

Louis also lives in a “village.” He has many friendships and acquaintances, yet it is one friendship that he speaks to as a gain in this time of his life. Louis describes his daily routine of going down to lunch:

My neighbor, she's a good friend and we go down together. And so, that togetherness has been really important to me too. Because I had known her before, and when we started talking about moving into a place like this, we talked about, “Wouldn't it be nice if we could get adjoining apartments?” And so, we came in here, and at that time, it was possible.

This friendship provides comfort and companionship for both. They check in with each other during the day to make sure each is fine, and they dine together twice a day in the community dining room. This “togetherness” is a treasured gain for two oldest-old who have lost their spouses.

An endearing story of thoughtful and appreciated neighbors was told by Walt and Madeline. These neighbors recognized Madeline's increasing frailty and vulnerability to

falls as well as her being alone while Walt continued to work. As long-term neighbors and friends, they knew of Madeline's love of dogs and recognized her inability to care for one and the possibility of a dog knocking her over. They bought a new dog and told Madeline it would be her dog, but they would raise it, train it, and bring it over to visit her daily. This care and consideration by her neighbors was almost overwhelming for Madeline, and deeply appreciated by Walt. A very long life can lead others to offer caring acts. Being recipients of this type of kindness was identified by this long-married couple as a reward for living very long lives and having long-time friends.

Rebekah spoke in her narrative of the "joy of being in a community." And later, "It's just now that I realize how beautiful life can be." For Rebekah, her way of being in the world in lived relations has flourished in her new village. As she sees it, "making sure somebody cares" is a primary responsibility of the oldest-old. A reward she has experienced for living long, and adapting to life in this new community, is her ability to make a difference in the lives of others in her new home.

### **Life Has Been Good: "It Is a Wonderful Life"**

Some narratives were filled with recognition and gratitude that life has been good; however, this did not mean that pain and hardship were absent. Perception matters.

Louis' view is a perfect exemplar for this perspective.

I feel great satisfaction. Over the course of my life and what I achieved, and so, you can sorta forget some regretful things . . . mistakes you've made . . . but the overall effect, . . . I feel like I've had a wonderful life, and many wonderful opportunities, and opportunities to be around wonderful people.

He did in fact have an amazing life which he has compiled into quite a lengthy autobiography. However, as a career military officer during three wars, he has seen and



experienced pain and suffering. “But the overall effect” is, upon reflection, a wonderful life.

Barbara offers another exemplar of this overall effect and grateful perspective. Responding to a question about what has brought her satisfaction or happiness she replies, “People, yeah people in general.” When she is then asked about disappointments she replies “Life has been very good . . . and maybe it’s my fault . . . ’cause I wanted it, I expect it to be good.” Barbara knew pain and suffering too. Her father died when she was seven, her first husband when she was in her forties and her second husband eleven years ago. Yet, is this what she speaks to when asked about disappointments? No, “life has been very good.”

Walt marvels at where his impoverished childhood has led him. His life too has been good, although he was born to a single mother, left to be raised by his grandmother, and didn’t meet his father until he was twelve. “My life is a miracle.”

Ramona too speaks to having a good life with no regrets. Her very impoverished childhood takes no prominence in her mind. She is grateful to now have “no one else to worry about.” William marvels at his opportunities in life and “would make the same mistakes all over again.” Even in reflection, he chooses not to focus on his physical disabilities.

Douglas also sees his life as one of privilege. Yet, he was abandoned by his father as a young boy, and left to his own resources at age 18, in the beginning of the depression. But life for Douglas has been one filled with good people and his own efforts of being a good person in the lives of others.

Not recognized directly but eluded to when talking about memories, is the notion that, for those with the ability to remember, living to be very old leaves time to sort through one's life. There is time to forget what needs to be forgotten, and remember with vividness what has made life good. Participants in this study offer narratives filled with what the good life has brought. They were able to identify and describe the difficult, the sorrowful, and the painful yet, as Louis said; "the overall effect" is that life has been good.

### *Having a Comfortable Place*

Walt and Madeline, Louis, William, Douglas, and Rebekah are people with extraordinary careers built on hard and persistent work providing a privileged situation in late life. They have resources which allow freedom from worrying about finances and ability to live comfortably. Through her husband's professional work, Barbara's situation is also secure. The others, while not as wealthy, have their needs met. All are appreciative of their material comforts. Yet the comfortable place that each was observed to have, was of a different type. This comfortable place of their own was a personal space, usually a chair, where they spent much of their day. Most participants kept their calendars, as reminders of their daily events, in this place of comfort.

Louis's observation prompted me to be mindful of this for the others. "I find I'm most comfortable where I am now . . . I tend to stay here and read." He sits in an upright, cushioned chair at a small dining table which faces the living room window and affords a beautiful view. He has his glass of water, cup of coffee, telephone, calendar, newspaper, books, mail, writing supplies, and his trumpets close by. For Barbara, it is a similar upright chair at a dining room table which faces a window overlooking her front walkway

where the flowers attract hummingbirds. All her essentials for daily life, including her calendar, are there.

Madeline's place, again at a dining room table, is overlooking the garden. Walt's place, depending on whether he is working or resting, is either the recliner, or his well-used and very cozy office. Alma has her recliner in her bedroom where she sleeps, but it is an upright chair with a side table that provides her the proper positioning and access to her daily supplies for reading, writing, and keeping her calendar. Betsy's place is a rocking recliner, with her Bible, water, writing materials, phone, Kleenex, and worship music on the end table. Also in a recliner, Douglas's place sits facing his television, with his well-supplied end-table sitting beside.

The corner of the couch is Norma's place, across from her television, with her crossword puzzle books and telephone on the coffee table in front of her. Likewise, Betty and Rebekah have very similar places, with their calendars close by. Sarah too has her chair, from which she receives her guests and has a view of her family pictures, with the end table next to it holding her supplies. She has a second place, her bed with the nightstand where her puzzle books are kept. William is the only one whose comfortable place is a computer desk with his desktop computer, iPad, mail, and writing supplies. He has his electric wheelchair parked charging close by. For him, these electronics are necessary pieces of equipment for staying in touch.

In hindsight, it is only John that does not appear to have a specific comfortable place. It is possible it is his bed, as he spoke of "liking the bed." He was also newer to his apartment and perhaps his comfortable place was not yet established. The coffee table was the resting place for his mail, autobiography, telephone, and calendar.

This comfortable place appears to be a gain or reward of sorts, experienced by these oldest-old participants. It provides familiarity, convenience, security and safety, as well as a chair that positions the body in such a personalized way that pain is minimized and rest is found. This is a time of life where select necessary items are needed close by, a walker or electric wheelchair within easy access, a near-by calendar as a friendly reminder displaying the day's events. All in a comfortable place where one can just "be," resting and napping when needed.

### **Being Celebrated for Your Age: Still Feeling Important**

While most people enjoy being celebrated, the oldest-old are often recognized and celebrated precisely because of their very old age. Several participants shared a pride in surprising people with how old they are and the distinction it has earned them. Betty laughs when she talks about her neighbors. "Because I'm so old and all . . . they call me the 'Iron Woman', because they can't believe my age." Louis mentioned that "I take pride in telling others I'm 94." He also told of his weekly experience of being celebrated and honored for his distinct service.

### ***Being Celebrated for Service: Louis's Exemplar***

As Louis relates his weekly Sunday routine, he tells of a way of being honored and celebrated that is unique to him, in a manner that clearly provides him with a sense of recognition and being celebrated.

After the [church] service is over . . . we go over to the Veterans of Foreign War . . . for breakfast, where they honor me with no charge for breakfast, because of my World War II background. And they stick to it. The waitress comes out and she says "No charge." I don't know how important that is, but it's kind of flattering . . . and I'm the only one graced at the moment.

Later in the interview, when asked more about this, Louis adds some more detail.

It is satisfying and I must say that I'm just showered with attention, and goodwill, and "Here's the general coming," and they have a special chair for me there that they bring up, with arms on it so I'd be comfortable. So, it's a bit of an ego boost there, too.

This is a deep and meaningful recognition to Louis which he experiences each Sunday. His military service is a source of flattery and appreciation, which most people don't experience.

### *The 100<sup>th</sup> Birthday: Douglas's Exemplar*

I met Douglas soon after his 100<sup>th</sup> birthday. His family threw him a large formal party with over 250 guests. When I asked in our first interview about a recent instance where it felt good to be his age, he quickly replied "My birthday . . . 250 people at the party. It was wonderful, absolutely wonderful. Yeah, took a lot of pictures with a lot of friends and had a lovely patio party and a nice dinner and entertainment and absolutely wonderful!" With the resources of his family, quite a gala was thrown, and Douglas was thrilled. Friends and family flew in from all over the country. He was known to be a long-time, avid Dodger baseball team fan. He received a call from the Los Angeles Dodgers' announcer Vin Scully. Showing me the program, the menu, and the guest book, and describing the two big and beautiful donated chocolate cakes, he was demonstrably appreciative and overwhelmed.

Tears came to my eyes when Douglas showed me a note which had been placed in his church bulletin: "On behalf of [the church] community, we would like to wish Mr. Douglas \_\_\_\_\_ a happy 100<sup>th</sup> birthday and thank him for the life he has breathed into this parish." Tears came to his eyes as well. In a beautiful card, his priest wrote:

Dear Douglas, Someone said if the only prayer we ever said in our life was, 'Thank you,' that would be enough. So, thanks for the joy you radiate, and your faithful, growing love for God and your family. Thank

you for your kindness to me. I pray you may have a happy, holy, healthy birthday and continued life. My life is richer because of our paths crossing and hearts touching.

As I comment on how many people love him, Douglas responds, “I love people.” This is indeed apparent. People enjoy being around Douglas. As he alludes to later “if you still feel important” then you will be able to stay positive. If you are positive, people will seek ways of reminding you that you are important.

***“I Just Wanted to Hear Your Voice”: Sarah’s Exemplar***

Sarah is another positive person whom people go out of their way to be around, and to remind her of her importance. In the interview just after Easter, she explained two instances of this for her at church. “I had a couple and their three children come over to me, and he was telling me ‘I will always remember; I will never forget that you were my Sunday school teacher.’” When I commented that this could be a reward of living long, Sarah replied:

Um Hmm! And I saw a girl at church . . . and she was telling me “I always remember coming over to your house, and how nice you were to us,” and I hadn’t seen her for years. Her daughter had just had a baby and they brought the baby over to see me, where I was sitting.

This woman sought her out to express her appreciation and introduce her new grandbaby.

Sarah was celebrated in these moments. When asked what brings satisfaction and happiness to her life now, she shared this: “Having my children and grandchildren and family members around because they call me – ‘Well, I just wanted to hear your voice.’” What she hears in their voices is “You matter to us.”

Her very large family is planning a reunion in August, and Sarah has been getting calls from family members near and far.

I have all these nieces and nephews that have been calling me. It's like, nobody but auntie, we don't have anybody but auntie . . . even so many come to see me that have lived here all this time. And their children are coming to see me, and they're calling me, and I thought "Gee whiz, all these relatives!"

Sarah is essentially being recognized and celebrated for being the last of her generation, for living very long, for being very old. She is still feeling important.

### *And Others*

While she said she sat in her chair most of the time, Barbara was celebrated by a large gathering in a local park planned by her family for her 98<sup>th</sup> birthday. Lots of family and friends came by her "throne" to talk with her. Walt, Rebekah, and Alma had all been given parties in honor of their 90<sup>th</sup> birthday. Walt's party was quite a gala to celebrate him and his contributions through his professional work. Rebekah was celebrated by family and friends along with her sister; this event continues to offer her memories to review and treasure.

Alma's smaller surprise party was given by family and friends, but was no less meaningful to her. "I was blown away!" She disclosed some intimate thoughts which went through her mind as she was being celebrated. They were telling of how meaningful these moments can be, in perhaps unexpected ways.

I remembered I drove to Yakima, Washington and went to my sister's 90<sup>th</sup> birthday in 2000. She was born in 1910. I don't remember exactly, but it was less than two years after that that she fell and broke her leg. She survived the surgery but then died in the recovery room. And so you know, you get to thinking, "Well, how long am I gonna be around?" And everybody else feels the same way.

Alma's being in the world is very much impacted by the notion of temporality. How much longer will she be here? She thinks others share this same wonder. She was being celebrated at 90 and she and everyone else was wondering if she would be around to turn

91. Even in times of celebration, the very old and those who love them may be wondering how much longer they will “be around.” The relationality, which is present in these celebrations of one oldest-old person by others, takes on a distinct awareness of the temporality, or sense of lived time, that is involved. The fact that we are finite beings, particularly in oldest-old age, is the dark backdrop before which the light of the celebrated one is projected. Yet, the oldest-old and their loved ones choose to focus on their life, while they are present, in the present.

### **Spirituality as a Gain**

Some participants express growth in their spirituality as a gain. Faith, religious beliefs, and spiritual matters became more important in this time of oldest-old age for those to whom it had been important in earlier times of life. No one however, tells of radical change during their advanced age.

For Barbara, it is a matter of attending church and being with people. Her narrative reveals someone with a history of always going to church on Sunday and who still does. It is more about her social way of being connected with others, but not necessarily her God. She is indifferent about going to heaven or hell, and her religious beliefs do not appear to have importance. William tells of being an agnostic; “It’s an unknowable.” His cognitive way of approaching life and the world finds no evidence either way for the existence of God. Betty and Norma are life-long church goers. Norma no longer goes to church as she doesn’t want to bother others for a ride. Betty, in moments of illness or worry, struggles a bit with her religious beliefs and what they say about where she will “end up.” She goes to church on Sundays, as she proudly shared earlier, with her high heels on.



### ***“I Think It Has Changed”: John’s Exemplar***

If anyone demonstrated movement or change in their spirituality it is John. He finds hope in his belief that Christ will intervene in his life, and allow him to meet somebody to become his second wife. When asked how or if his spirituality had changed at this time of life, John replied

Oh yeah, I think it has changed because before my wife died I seldom thought about Christ. I feel that Christ has made a decision, made some decisions which I don’t understand why he’s made them, and don’t understand why he doesn’t make other decisions . . . and it’s all confusing because I lack patience, but (laughs) we’ll see what happens.

John’s gain has been the hope that through Christ’s wisdom, he will get what he desires.

### ***“It’s the Richest Thing”: Walt’s Exemplar***

For those with faith, religious belief, or spirituality that has been important to them in earlier years, it seems these aspects of life have taken on deeper and more significant meaning. A guided tour of Walt’s home office revealed a sanctuary of sorts, for a deeply spiritual man.

When you wake up in the morning, consecrate yourself to God. Make it your first thing and lay your plans before Him for the day, to be given up or followed through. So, I kinda like to have Him in charge before I hit the floor.

Lying in bed doing leg exercises “is when I listen (to God).” He sums it up later, “It’s really a mellow time now in terms of spiritual life because it’s the richest thing for me.”

Walt’s is a narrative of a faith that has grown to a place of primacy. It impacts the very way he moves through his day, his way of being in the world, being in relationships with his God and others, and how he projects himself in a temporal way into an eternal future.

### *A Lifelong Spirituality: Sarah's Exemplar*

Similar to Walt, Sarah knows a lifelong spirituality and family tradition of spiritual beliefs and religious faith. Threaded through her narratives are stories of her God speaking to her, and acting in her behalf during times of difficulty and when she needs encouragement. Praying to God is her natural response to daily life. Speaking about her Lord is as natural as talking about the weather. Recently, after experiencing very serious health issues Sarah asks "Lord, why is this happening to me?" She then remembered a time when God miraculously met her needs.

And this is what the Lord reminded me of that day. He said, "I showered blessings on you then and I'm still doing it." And I had to tell everybody what the Lord said to me. . . . And ever since I came home from the hospital I have been getting better. I said, "He said He would shower blessings on me and I'm getting better and better."

When asked towards the end of the final interview how she copes with the pain in her life, Betsy softly replies "I don't think I could have coped with the sicknesses, the deaths, the troubles that other people have had if I hadn't been taught to pray." Her parents taught her to pray and she believed them. "I don't care who would have a problem, if I have a problem, I would ask the Lord to help me."

For Sarah, like Walt, her belief and faith are vital to how she copes with her hard times, where she seeks answers for her questions, and how she lives in the world. Her gain in these oldest-old years as revealed in her narrative is that her life-long faith, and her growth and practice of her spiritual habits, continue to encourage her and provide hope during these challenges of growing very old.

### *And the Spirituality of Others...*

Very similar to Sarah's spiritual experience is Betsy's. Describing her religious beliefs she states "I believe in Jesus . . . and I love him. He's my life." Later she emphasizes this even more: "He's my life. He's my life and I don't know what I'd do without Him." These beliefs and sentiments of Betsy's are described elsewhere but there is a portion of her story best placed here in the gains of spirituality.

God is so amazing . . . He has time for us, He cares for us, every little detail. I can give you an instance. A friend of mine from church, her mother died. She gave me some shoes. I can't go out and buy shoes, especially those kind, \$100 and more kind of shoes . . . and she gave me not only one, she gave me two pair. Two pair, not even worn . . . they fit me perfect . . . they fit me perfect (tearful) . . . 6 ½ and even wide (she whispers) so that's the kind of God we have. . . . And they're the exact thing that I would want . . . .

During this time of more aloneness than she would prefer, with more weakness, frailty, and falls, Sarah feels loved and cared for by her God—clearly a gain for her.

Rebekah, Alma, Louis, Norma, and Betty also speak to the importance of faith in their lives. Each has their own distinct relationship with their God that has been forged through a lifetime of faith practices, religious beliefs, and spiritual experiences. As with their relationships with people, their relationship with God has a past, a present, and a future. In their belief system, the relationship with their God is the one that they have hope for in the future. As they are nearing the end of their lives, the hope they have grown into over a lifetime, is a gain that provides for overcoming their current challenges of very old age and offers an eternal future.

### **No Gains: "I Can't Think of Anything..."**

Whether it was a bad day, or a heartfelt response, or both, when John was asked if he could recall a recent time when it has felt good to be his age, he quickly responded "I

don't think so." When I asked him to think about it a bit more he replied "You see I'm at this age and I'm also without my wife, and I don't know which is which . . . am I disabled because of age, or am I disabled because of my wife?" John is insightful about his predicament. Being without his wife is the same as being old. There is no happiness, no gain in that. His lifeworld is filled with loss. It is his present. His old age is defined by great sadness. When asked where he finds strength to keep going day to day, his reply is provocative. "Just doing. . . . Just doing it. It's not because of desire, because I can't get satisfaction. . . . It's like breathing (laughs), you do it because without it you wouldn't live." Without experiencing current reward or good feelings, John's strength to go on is in automatic drive of "just doing." It is as automatic as breathing.

Madeline was also struggling, especially after her serious and debilitating fall. Her rewards were difficult to find. When asked about something positive that she has gained by living a long life, her reply was quick and short. "I don't know any positive . . . But I just try to get along . . . I'm just hoping it'll get better." But during the last interview when she was feeling better, Madeline gave a similar reply to the question about what has felt good or rewarding about being this age. "I can't think of anything . . . but I don't mind being this age." This woman, who did not want to complain, could not think of something rewarding in her oldest-old lifeworld.

While overall Alma was thriving with continued interests and social relationships, she made some remarkable statements. When asked if there was something recent that felt good or rewarding about being her age, she first mentioned her surprise party. This led to her wondering about how much longer she would "be around." She then added "I really don't find too many people near my age that are just going, 'Oh good, isn't this

great! (Laughs and claps hands).” A few minutes later, she is asked what stands out as being discouraging. After talking about her fall she adds,

I think anybody gets discouraged sometimes you know? But I don't allow myself to stay there. . . . If I didn't have a belief in the Lord, I think I'd get a gun (laughs) . . . and get rid of it [her life].

With these words, Alma paints quite a picture. The gains and losses do not always balance. It can be very hard to stay on the tightrope walk of aging. Growing very old is a challenge to even the most resilient. Billy Graham's words come to mind here, “I had been taught all of my life how to die, but no one had ever taught me how to grow old (2011, p. 93).”

### **Conclusion**

While the focus in this chapter has been on the gains of living a very long life, there is not the sense that any of the participants are keeping track or count of the gains and losses they are experiencing. Of course the awareness of each is there on a daily basis. They are living into what is possible, their possibilities, even though their possibilities have become more limited. Several participants were clear that there are times that are very difficult, “one would have an easy time feeling sorry for oneself.” Yet these narratives tell of a tendency to the positive, to being mindful of those aspects of life that still bring satisfaction, and rewards for living. Even though the losses increase, these oldest-old search for the positives. There are indeed times when positives are hard to find, when possibilities appear elusive. It has become evident that losses related to the embodied self are increasing and gains acquired from being in the world are diminishing. Identifying and knowing what these gains are, what possibilities remain however few, can be critical, even life-giving for the oldest-old.

These participants each told of the increased role of family members in old age. The gain is in experiencing family as loving, responsible, dependable, and present as the old needed more from them. Appreciation grows. Even seeing family members as a reflection of one's younger self is a gain. Longevity allows for deepening love and pleasure from these relationships. These oldest-old recognize that they have had time, more time than most, to forgive, to heal relationships, and to offer unconditional love to family. The awareness that the end of life is approaching seems to heighten the awareness and appreciation for what is good and necessary. Perhaps this growing sense that tomorrow may not come, provides the gift of recognition of that which is good, in the midst of so much that is difficult. This is possibility. Keeping the oldest-old in our midst may offer us all this perspective. In helping the younger stay reminded that aging and death are the natural order of things on this earth, perhaps our aging can keep us cognizant that we don't have forever to right wrongs, even self-forgiveness and wrongs done to others. We need each other. These participants have identified the gain of that recognition.

Reciprocally loving family relationships were common to all 13 participants. While it is unknown if this has contributed to why they have lived long, they see these relationships at the center of what is positive now. However, beyond this sample there are certainly oldest-old persons who have no family members, or with which they have broken relationships. The search for that which is good would need to look elsewhere for gain and reward. Strong life circumstances appear to grow even stronger. Relationships deepen. This is shown to be true for memories as well. A good life brings good memories. There is a tendency to especially recall the good memories and "work" to

leave the bad memories behind. Louis did not want to dwell on his regrets. Rebekah was selective in choosing to only retain the good memories, wanting to avoid regret. There is perhaps a functional choice to re-color our past, to support the need for happy memories that support living in the present without regret or bitterness.

There are however, also those for which a struggle to identify any gain is heard. John is able to admit, he couldn't see any. His being in the world is completely entwined with the loss of his wife, three years ago. He moves forward day to day, reflexively. "It's like breathing." Madeline seems to hope in the same manner. Being unable to identify anything positive, she tries to get along by "hoping it'll get better." A person can meet their match on any given day in very old age. One devastating loss or event, can place seeing anything positive out of reach. It is a fragile time of life, possibilities wane. The vulnerability and unpredictability of this experience of aging, can make the walk across the tightrope both lonely and wobbly.

In the identification of gains, as in losses, it was clear that some participants had given previous thought to these ideas, and others had not. Those with recent health or life change events, offered more thoughtful responses. It appears that remembering their gains, the positives in their lives had been on their minds. Focusing on the positive, the gains, rewards, and small pleasures is revealed as a tool for coping with the losses, the difficulties, the overwhelming changes and challenges. Two women, Barbara and Norma, who for the time have enjoyed stable, albeit diminished health, seem to have been surprised by the question. Their first thoughts were that getting through the day and whatever it had to offer was reward enough. Through further exploring, they also spoke to the rewards of the happiness of family, and the attention and love they receive.

Knowing the primacy of family and friends, the tendency toward retaining good memories over bad, the importance of remembering former things, the way memories may offer continued relationships, and the need to feel important, relevant, and even celebrated, can provide purposeful ways of caring and love. This can make bearable and possibly satisfying, this difficult time at the end of life. Yet, those providing the care and love, are confronted with the reality that in these oldest-old years, there are times when pleasure, gain, and happiness appear elusive; pain, depression, and fatigue prevail. The need to fix cannot camouflage the pain. And we will only wound those we care for by trying to do so. We all are confronted by the suffering. Discovering the unique needs at this time of life, those left behind in former times, and those still hoped for, is a loving way to respond to the very old among us.

Gains acquired in life function as the counterbalance for loss and pain. The human spirit seeks hope, a reason to be. Again, “it’s like breathing . . . just doing.” Because without it the spirit couldn’t survive. Identifying gains and rewards in life points to hope. As options for gain become fewer, those that endure become more valuable, more primary for breathing. Each individual walks this realization in their distinct manner. Some, with underlying support from family, spiritual resources, financial resources, and living environment, seem to float through their days effortlessly during times of stability. Others, perhaps due to a more introspective or philosophical nature, work a bit harder to hold an awareness of what is positive in their gaze. The journey of oldest-old age appears as a precarious tightrope walk. Deliberate steps are taken. The balance bar of gain, reward, hope and all that is positive is held firmly. Sometimes it is



balanced even and steady, sometimes it tips to one side and the risk of falling is painfully experienced and feared. Stability is often regained and the journey continues.

This sample of participants, without exception, is made up of unique and inspiring individuals. With honesty, integrity, and even positivity they have shared their life narrative of living long and of growing very old. These stories have told of experiences that were emotional, thoughtful, experiential, spiritual, physical, and social. Having lived long bodily in the world in a physical body that is deteriorating, and participating in social relationships that can be lost or grow in value, they see the end of life approaching. They know the time ahead is short. This knowledge along with habits of living, thought, and heart offer support and stability to this balancing of the losses and gains in this time of oldest-old age. The next chapter will explore these habits that provide needed resilience and necessary resources for coping with the sure but unpredictable and inevitable changes of the very old life.

## CHAPTER EIGHT

### HABITS AND ATTITUDES OF THE MIND AND HEART

“Thus we submit that wisdom and integrity are active, lifelong developing processes,  
as are all the strengths included in the life cycle stages.

They are definitely ongoing, should we dare to hope  
contagious, unending, perhaps everlasting?”

*(Joan M. Erickson, 1997, p. 9)*

This morning when I woke and knew that I had had a fair night,  
that my pains were not too bad,

I lay waiting for the uplifting moment when I pull back the curtains, see the sky,  
and I surprised myself by saying out loud: My dear, dear days.

*(Florida Scott Maxwell, 1968, p. 39)*

This is a difficult chapter to write. Listening to these varied and unique narratives of coping, surviving, and thriving, it is realized that these oldest-old have much to say about their lived experience of aging. The aim is to understand how the very old maintain a manageable and meaningful lifeworld while living encumbered by their aging bodies, and experiencing the varied losses and gains brought to them by living long. After listening to these participants, there is a prevailing sense that they share similar life skills that have been carried with them to this time of life. Although growth and change are evident, it seems the primary attitudes and life skills used and the body balanced while walking across the tightrope of aging have been learned and practiced over a lifetime. The younger among us have much to learn through listening to and learning from these wise and resilient participants. It may be prudent to practice these habits of heart and mind for the hoped-for years to come.

Living into oldest-old age was not anticipated. All participants expressed that they never expected to live this long, or that they never gave it a thought—and now here

they are. As Rebekah expressed “I’ve had very little preparation for this time of life.”

Billy Graham expressed this same sentiment.

All my life I was taught how to die as a Christian, but no one ever taught me how I ought to live in the years before I die. I wish they had because I am an old man now, and believe me, it’s not easy (Graham, 2011, p. vii).

Lifelong habits of being in the world, ways of thinking, living with and through heartbreak, pain, and suffering, ways of relating to others, of viewing oneself and personal growth, are carried by these participants through old age. Many spoke of using life’s lessons as they live into their very late years.

### **Habits of Thought: Dwelling on the Good**

#### ***Douglas’s Exemplar: “I Like Thinking of Good Things”***

After a brief reflection about friends who have died, Douglas describes his habits of thinking: “But you can’t dwell on that because life goes on.” He is forward-looking. “I always say that yesterday’s gone. You can’t do one thing about it. Tomorrow may not come. Today is the day. This is the day to live.” He goes on to reveal more of his natural, even habitual ways of thinking. “I don’t like to think of bad things in my life. I like to think of good things. . . . I make it a habit trying to be nice to people, always have.” In this short section of his narrative, Douglas reveals why it is that his family wants to be around him daily, and why these interviews are quite enjoyable. He is a positive, funny man, who is engaging, interesting, and keeps his audience laughing. And he is authentic. “You can’t dwell on that . . . today is the day . . . I like to think of good things.” As he tells his life story, it is clear that Douglas has practiced these tenets for most of his life. The fact that his childhood family was abandoned by his father is barely touched on as he tells his history. The three stories of men who invested in him, and who

he sees as giving him advantages in life, is where he dwells in his life story. People were good to him. This is what he remembers and what he gives back to people in his life.

These themes return several times during Douglas's interviews. Stressing his convictions as we talk again about the losses of his wife and son, he is emphatic. "But you can't dwell on that either because that's the thing, you can't do a thing about it." His habit of not dwelling on what you can't change is expressed here as his commitment to staying positive. "But you have to think positive. You must." The word "must" is a strong word. For him there is no option; one must remain positive. This begs the question of "or what?" He goes on to answer that question in saying "one would have a very, very easy time feeling sorry for yourself." Douglas knows this is not where he wants to live. "No, I think I've always loved life. In fact, I said 'Love life, love people, and laugh a lot. And humor's a great part of it, a very, very great part of it.'"

### **A Habit of Positivity**

Rebekah expressed this positivity in her own unique way, with her characteristic conviction.

Being old is not a death sentence. It's what you put into it. If you want to be miserable, you can be miserable. If you want to be happy, you can be happy. And my quote on that is: "Happiness, they don't sell it, you can't buy it; it is something that's acquired." And I have come to that place. . . . The negativity of life can kill you off, and I tell them [others living in her community] look, be positive.

She also sees the importance of reflecting on a happy past, and a future. In talking about the importance of memories and a future she expresses the following:

You've got to have joyful moments in your life that outweigh any negativity that would bring unhappiness to you . . . something to look back on and smile, and be happy over . . . and set a goal . . . this keeps your mind looking for something to look forward to.

Instead of the words “positive” and “negative,” William’s habit of living, while similar in effect, uses different terms. In his twenties, while learning to live with lifelong disabilities, he realized a life changing epiphany which continues to serve him well. It could be said, it is his way of life, his habit of living.

I can remember the day I was in graduate school, and I decided that I’ve been looking at all that’s been going wrong, and I really realized that people don’t like losers. So, I’m going to appear a winner. And if you appear to be a winner long enough, it diffuses through your whole body and mind . . . you act like a winner.

William has been and still is a winner. And in his own words “If you’re a survivor, you have to survive.” He is thriving in old age, but he would not want to mislead anyone. “It’s not easy.” William is also honest.

### **A Habit of Living for Today**

This attitude that “today is the day,” expressed above by Douglas, was also revealed in the narratives of others. In her final interview, Madeline was much improved after her devastating fall. When asked what might have prepared her for this time of life, she expressed a similar attitude or habit of thinking.

You just take things as they come, and deal with ‘em. . . . You don’t dwell on the past. It doesn’t do any good. . . . I don’t think too much in the future because I don’t know how much longer I’m gonna live. And so, I take every day as it comes.

Norma also states “you know, I just take it a day at a time” as she reflects on her good health, despite mobility issues. Betty, in her characteristic way, adds a bit more emotion as she relates a similar habit. In response to the same question of how she copes with changes in her life, Betty shares:

Just take one day at a time and make the most of it . . . one day at a time and one thing at a time. And some way or the other it all gets done. . . .

Tears don't mend nothing. And that's what I found out. You can't cry . . . things don't get fixed that way. . . . The four walls don't hear me (laughs)!

Barbara tells of a recent conversation with one of her daughters who mentioned a picture on the wall that she would want "someday." "And I said, 'Well you might as well take it today because who knows, I could be gone tomorrow' (laughs)." She ends this story with her characteristic laugh. Who does know? She conveys the recognition of all participants—there is no guarantee of tomorrow.

### **"There's No Profit in It"**

Betty alludes to an attitude that Alma expresses very clearly during a talk about discouragement. "I think anybody gets discouraged sometimes, you know? But I don't allow myself to stay there. . . . There's no profit in it." She then relates the story of a friend who is "sitting and stewing" about his situation and she declares, "So what is the point? Get on with it!" For Alma, there is no benefit of staying discouraged, no profit – move on! She agrees with Betty's claim that the four walls don't hear us; things don't get fixed by talking to our walls.

Others also expressed this idea of Alma's, that there is no profit in dwelling on all that is negative, hurtful, painful, or frustrating. As Louis said several times, if he allows himself the indulgence of regret or feeling sorry for oneself, "I don't stay there long. . . ." As Douglas said, "You can't dwell on that." In Alma's words: "There is no profit in it."

As interviews continued, this statement of "no profit in it" became noticeable in the attitudes and habits of responses for each participant.

### ***Barbara's Exemplar: "Just Go With the Flow"***

While not expressing it directly, Barbara offers an exemplar of this same attitude or thought habit. When answering a question about how it is to be 98 years old, her reply

is simple and without emotion. “I realize that I can’t do the things that I used to do, and I just have to go with the flow.” Barbara has remarkable health yet has made major adjustments due to her aging self. She is asked if she gets frustrated with her memory, as she had just talked about. “I suppose so. But everybody forgets something. I just go with the flow you know.” After relating a recent incident when she was unable to button the cuff of her blouse, she was again asked if she grew frustrated. “Well I suppose, but the feeling is that life goes on, there’s nothing much you can do to change some things, . . . so why let it bother you?” Yes, indeed. Why let it? She would find agreement in this among her peers. Perhaps this is also about possibilities. Barbara has found possibilities for coping where they meaningfully exist for her, in knowing life goes on.

Barbara had a few more phrases that were repeated over the course of the interviews that expand this go-with-the-flow attitude. After telling of the death of her father in early childhood she commented “I don’t think we recognized it as difficult. We just plugged along. Life went on.” Describing the loss of her first husband and a beloved aunt while in her 40s, “There you go again, you do what you have to do. . . .I didn’t think anything about it.” “You make do.” “We did the best with what we had.” “Life goes on.” “I just kept going.” “Keep doing what you’ve always been doing, why not? . . . If you haven’t broken your leg, why not keep going?” At the end of our interviews, she jokes and says “You’ve probably figured out that I did not take a class in philosophy. I never thought about thinking about things.” Yet, it is apparent, Barbara has gone with the flow and during this time of advanced old age, she is largely enjoying her life, friends, and family.

Despite my best effort to elicit from Barbara a more passionate response of resistance, or a glimmer of fight or questioning against painful times of life both the past and in the present, none came. Questions and prodding revealed more of the “go with the flow” approach. Even though I attempted to guide the conversation to a level of emotion and feeling, Barbara responded with a rationale, practical, cognitive view—“people do not live forever.” It was only in talking about the deaths in her step family that she expressed a bit of emotion. Yet, her comment stays in the cognitive realm when she relates that when these two men were “cut down at such a young age, it seemed wrong.”

While the vivid passion that the author Florida Scott Maxwell (1968) expresses while experiencing the losses and surprises of aging, is not evident in Barbara’s narrative, Barbara’s way is authentic. She lives the way she always has; her heart and thought habits remain. It is hard to argue with this approach when at age 98 she continues to enjoy life and people in the lifeworld she has created. Barbara admits that “I never thought about thinking about things.” She’s a self-identified non-philosophizer.

Barbara has lost two husbands, all of her family of origin, some younger family members, and many friends. When she is asked how she has coped with all the changes in her life she serendipitously provided a metaphor for aging. “Well, there again, I say go with the flow. If you’re going to go in the automobile across the country, you prepare a little bit, and enjoy the ride (laughs), and take your turn driving.” She is sounding a bit philosophical here.

Prepare for the trip. For the alert, astute, and willing learner, life can prepare the traveler for the trip in to old age. Enjoy the trip and do your part. There seems to be some consensus among the participants that “your part” may include going with the flow,



being flexible, and adapting to the changes. Make ready for the “trip” or journey through old age by developing the habits of “living for this day” and focusing on the positive. In other words, dwell on the good and don’t take tomorrow for granted.

Admittedly there was an expectation that more resistance to the impact of old age would be expressed, there was in fact very little expressions of this found. Alma expressed a feisty resistance to the idea that her children should be making any decisions for her. Yet overall her expression of “There’s no profit in it” related earlier, better expresses her overall view that staying discouraged does not help; it is better to “get on with it!” Betty, expressed a bit more passion around the possibility of relinquishing driving and independence. Her feisty personality expresses more emotion and resistance to these changes and less of the “go with the flow” for Barbara. However, even Betty acknowledges “You can’t dwell on your aches and pains . . . I don’t let it get me down, so far . . . I can spring back.” Like Barbara, she keeps going. These habits may be required preparation for the journey into and through these oldest-old years of life.

### **Habits of the Heart: Living With Gratitude**

This continued look into the “how” one lives and manages the challenges of aging, reveals a commonality among many in the realm of gratitude. The majority of these oldest-old participants experience their days through eyes, or a heart if-you-will, of gratitude. There is a particular focus on what they appreciate and for what they are thankful. It seems that this focus can be on very small things not thought of in younger years.

Norma expresses appreciation that she can “still do for myself. That I don’t have to depend on anybody to do things for me. I can go to the bathroom, and take my

shower, and you know, I take care of myself.” So grateful is she that she repeated it two other times, “I’m thankful that I can take care of myself.” And “I feel grateful for my health.” These formerly simple abilities that she has retained after many losses, have become more complex. Yet, she is grateful. Norma’s expectations have narrowed to what is possible for her to accomplish, possibilities that still draw her and to which she can still chose. Comparing herself to a friend who has lost her eyesight she adds “When I see things like that I think, ‘My God, you know, I’m sure blessed.’” Comparing oneself to others often draws one to a place of gratitude.

Similarly, Betty, when asked to compare her health to others her age states “Compared to my friends, I’m healthy. The Lord, I think He’s looking over me. I’m thankful.” Despite having type two diabetes, hypertension, hypercholesterolemia, and macular degeneration, Betty sees her health as good when she considers the health of her friends. This tendency to compare oneself to others was used by all participants in the positive sense. No one stated that compared to others their health was bad. Comparison in this way, always was used to emphasize being in a better, or more favorable situation or circumstance. Comparison seems to function as a tool of coping and gratitude. Perception is what matters. “At least I am better off than . . . .”

Describing her first thoughts of the day, Alma reveals her thankfulness. “I like to thank the Lord I had a good sleep or made it through the night.” Her first thoughts are of gratitude for sleeping and living. With this morning habit, she begins her day. These expressions seem to have another commonality. They focus on the continued health and functioning of the body. This is indicative of the everyday challenges to well-being that

the very old body can present. While the “I can” becomes increasingly limited, the body still retains abilities for which to be grateful.

Rebekah expresses a new perspective of gratitude as a turning point for her acceptance of being old.

Once you get to the point where you can realize that you still have your health, you still have your strength, and as I pray continuously . . . thank you Lord for my eyes to see, feet to walk, mouth to talk, and that I can still move my hands in praise . . . it made a total difference . . . .

Focusing on what she still has, not what she has lost, allows her to embrace her life at 90 years of age.

As Louis moved through the narrative of his life history, it became apparent that he has experience with feeling grateful. Louis is grateful for each stage of his life, for his loving parents, for his musical talent and education, his career, his own wife and family. He most articulately relates the balancing between the loss and the gain, and the work that it can sometimes take.

It’s a recognition that as we get older, we’re gonna suffer some of these things, and when I sink into one of these minor depressions . . . , I seem to bounce back pretty quickly and say to myself, “Come on now, this is silly, what you’re saying is ridiculous,” you know, because it is. I mean, I could be so much worse off . . . and I have so much to be thankful for. Here I am in a nice place to live, clean surroundings, good food, good friends, no undo pressures to get bills paid, or anything like this. And so, there is so much to be thankful for. And I am thankful. I kind of remind myself, and about the time I start to complain to myself the most, that’s when I get over it pretty quickly. . . . Yeah, you can rise above it then and say “Well, come on now,” you know? (laughs).

This interview is where the image of a tightrope walker with the balance bar first came to mind. The image has remained helpful in illustrating the walk in this journey through this time of old age. There is the self-correction that Louis describes. It is his habit. He starts to “sink” or tip towards depression and feelings of self-pity. His habit is to self-

correct. “This is silly,” and he is jolted “back to reality.” For Louis, his reality, his lifeworld is one of having much to be thankful for. His reality is also being walker-dependent, fall-prone, and living with chronic pain. Louis’s candor reveals the struggle therein. Yet he chooses to be a person of thankfulness, and this is where he ends up.

### **Wisdom Gained**

As a 93 year old, Joan Erikson tells of her urgency to add to and complete the lifelong work of her and her husband Erik Erikson, before she is no longer able (Erikson, 1997). She re-visits the use of the words wisdom and integrity as the syntonic side, the tasks that support growth, of the dystonic challenges of despair and disgust that they had selected for the last crisis in human growth and development. Digging deeply into the Oxford English Dictionary, Joan Erikson examines the root words of each term and comes to a satisfied conclusion that these are appropriate choices for use in this ninth stage. She claims that “wisdom rests in the capacity to see, look, and remember, as well as to listen, hear, and remember. Integrity . . . demands tact, contact, and touch” (Erikson, 1997, p. 112). It seems that a combination of remembering what has been seen and heard over a lifetime and learning how to apply it to our lives and relationships with tact as we touch the lives of others, sums up her view of the tasks of aging.

Attig (2015) sees wisdom ultimately as “a virtue of humility, discernment, imagination, and adaptability in making claims to truth and seeking value and meaning in living” (p. 2). In describing wise persons, he sees them as persons who “weigh ideas mindfully, concerning themselves with their truth value and applicability to the realities they encounter” (Attig, 2015, p. 2). An abbreviated view of wisdom then could be, remembering what one has seen and heard that has been experienced to be true and

helpful as one applies these insights to relationships and circumstances in one's lifeworld and ways of living. This understanding brings the notion of wisdom to a place that fits what was found in some of the life experiences of the oldest-old in this study.

It is significant to mention, participants were not asked what wisdom they hold that has helped them in this time of life. What is presented here as wisdom, is that which is seen to be so through the experience of thematic analysis and interpretation of that revealed through the narratives of these giving and honest oldest-old people.

### *Forgiveness of Self and of Others*

Soft spirited Betsy, brought up forgiveness in a conversation about what has brought happiness to her life. She draws on possibilities from her tradition of religious thought that would not be available for others without these religious beliefs. "It's so important to have forgiveness for people in your life. It's so important. So important, you can just keep that in your heart all your life." Betsy has learned to forgive.

It's been very important. . . . Scriptures say so plainly if you don't forgive, God will not forgive me. So I don't want to keep anything, nothing in my heart, little, big, all the big things I've gotten rid of, but it's the little things that break relationships.

Later she emphasizes that forgiving others is

. . . very important, because otherwise, where is your peace? Where with our relationship with others, where is it? There is none, unless we do learn to forgive because people are people. They're gonna blow it, and we're not perfect. Nobody [with emphasis] is perfect. I'm not perfect. I wish I were . . . but it's so important.

Betsy recognizes relationships are broken if there is no forgiveness. One will not live with peace unless one can forgive.

Betty also expresses a trust in forgiveness from others.

I found this out at my age now, that there's always a way to mend things. There's always a way, it'll be okay. Because you know, it's not that I robbed somebody, or killed somebody, or anything like that. Something that can always be fixed. It might take a little time.

She seems to trust that relationships will mend; they will work themselves out.

Louis addresses a need for self-forgiveness and a resentment-free, regret-free time of life.

I feel great satisfaction. Over the course of my life and what I achieved, you can sorta forget some regretful things that you did perhaps, mistakes that you made, and I have some things that I'm not proud of at all, . . . I kinda review things that happened in these various parts of my life, I find that I tend to forget or overlook the unpleasant parts and concentrate on the wonderful things that happened. And I think that's fortunate that you don't be resentful, either way, about things that've happened, you know? It doesn't accomplish anything.

This goes along with a focus on the positive. What does holding onto resentment or regret accomplish? According to Louis and others, it doesn't accomplish anything.

These participants have the wisdom to see where to put their energy—forgiving others, and themselves. In this late time of life, there is no profit in holding on to hurts. As we have seen previously, Sarah is working hard to forgive her now deceased husband. It is a bit harder when the one who has imparted hurt is no longer alive. For her, Betty's philosophy of "there's always a way to mend things" is not applicable, unless she chooses Betsy's course of forgiveness.

### *Walt's Way of Humility*

Living in humility is usually seen as a way of the wise. Over the course of his highly successful career, Walt has developed habits of the heart and mind that maintain a humble spirit. He relates a saying told him by a mentor early in his career. "If you want

to know how important you are, take a bowl of water and insert a needle in it. The hole the needle leaves when you pull it back out, is how important you are.”

Walt has created a “Solo Dio Gloria” file where he keeps correspondence that is professionally significant to him. It is the ‘Glory to God Alone’ file. Like Betsy, he finds meaning in the possibilities of his religious tradition. He lives his faith in a manner that sees his God using him in the world, not by his own doing. This way of living has endeared him to many, many people who respect him. In this wisdom he has gained the love of many.

### *Longevity Offers Wise Insight*

In her final interview Madeline was asked what has worked best for her in coping with difficult things in life.

Well, I think my attitude toward it is that, it’s not the end of the world, and it’ll get better. Things will pass. I think I have that attitude quite a bit . . . you just take things as they come.

Living long has allowed for Madeline something akin to patience and perspective.

Things don’t stay difficult forever; life doesn’t go on forever. This is acceptance of what is real.

Douglas, an avid sports fan, admitted that he used to get very upset and stay upset, if his favorite sports teams lost. But there has been a change.

When I was young, with [my favorite teams], I’d be upset for a couple of days. And anymore, it’s just a game. You’re gonna win some and you’re gonna lose some. You finally realize that you can’t win ‘em all. Yeah. And that’s a good way to look at it, because you aren’t gonna win ‘em all. You would be sad most of your life if you thought you would. Time takes care of everything.

Once again, here are patience and perspective. Living through hard and painful times has taught Douglas that things come and things go. “You can’t win ‘em all.” And he hasn’t

won them all. He has lost his wife and a son. He is walker-bound, and has experienced many falls. Similar to what was related above, when asked what he would tell others about getting older, he spells out his way of focusing on the positive. “Love life, love people, laugh a lot. Look at the bright side. That’s the thing to look at.” In talking about being 100 years old he shares an additional thought “I say you have to grow older but you don’t have to grow old. If you’re healthy and grow old, shame on you.” Douglas, the oldest of the participants, lives by his own standard. He authentically conveys love of life, people, and humor. It serves him well.

Like Douglas, Rebekah expresses numerous insights on aging that have helped her. She also wisely recognizes, like Douglas, that some responsibility for attitude lies with the oldest-old themselves. She says to other older people “You really have to make sure you maintain a group of friends someplace, other than your children, so that you have somebody that you can call and talk to and somebody’s shoulder to cry on.” She has a close sister. “The main thing in getting old, make sure somebody cares.” And further, “one of the things is your attitude. You’ve got to maintain a good attitude, an attitude of friendliness.” Rebekah lives by her own advice. Each individual in this study, was the type of person that others enjoy being around, which is possibly why they were referred to the researcher. As Erikson (1997) suggests, these oldest-old seem to remember what they have seen and heard over their lifetime. They each seemed to have recognition that being someone that matters to others, someone who people want to be around, is vital to their wellbeing, living wisely, with integrity.



### **Reconciling the Losses: “You Survive Those Things”**

The oldest-old are well acquainted with loss. They know loss in their bodies, and loss of people from their lives, loss of abilities, and even dreams. They know suffering both in their own lives and in the lives of people that matter to them. There is a recognition that this is to be expected and there are no illusions about these realities. Early in her life, Alma experienced the losses of three family members, through three distinct tragic events. She learned in childhood that life goes on. After relating these events in her life history, she comments in a subdued way, “I’ve had some tragedies in my life.” Then, “Anyhow, you survive those things somehow. You recuperate.” Events such as these can be very instructive. Alma learned that recuperation and life after tragedy is possible. She has practiced this lesson again and again in her life. The practice continues.

William has had practice too. He simply comments “I’ve had so many losses over the years, I’ve learned how to manage them.” Having confidence that one has and can manage loss offers hope that the future is manageable as well. When talking about friends lost in recent years, it is evident he has no illusions about what life at this age holds, “but no, you expect to lose them.” Loss is an expectation when you are 92. When you expect something, it is not so difficult when it occurs; you are not taken by surprise.

Loss in relation to the aging body was directly expressed as an expectation by several participants. No one related surprise about their disabilities and health issues. Several, in fact, expressed surprise at how well they are, relative to others they know. Some acknowledge their place in life and what is expected to come along with it. In relating his concerns about his eye issues, Douglas simply states “but you stop and figure

at 100, what can you expect? You know, you're gonna have something (laughs).” There is no expectation that things should be different. Living long carries with it the expectation that you are “gonna have something.” This expectation leaves the door wide open to welcome in gratitude.

Louis uses words that are even stronger. When asked what has allowed him to cope with these bodily changes, he gives a deep sigh and offers “I think it’s faith, and I think it’s a recognition that as we get older, we’re gonna suffer some of these things.” While admitting that he gets discouraged, he also tells of not staying discouraged. The habit of recognizing that things could be much worse protects against dwelling on how difficult things are. Again, his door is open to gratitude.

I do have a genuine recognition of where I am, and if I catch myself complaining, and I do complain to myself (laughs), then I’m generally very quick to recognize what’s happening, and jolt myself back to reality. And thankfulness . . . which I always end up with.

Louis has no illusion that his life now, in old age, should be pain or difficulty free. As he describes it, in moments of weakness he may give in to self-pity, but he “jolts” himself out of it. In recognizing that suffering “some of these things” is a part of old age, his habit is to stop complaining, and be thankful, because this is where he wants to live.

With all of the current talk about successful aging, these participants still know the reality of difficulty, loss, and pain, yet they habitually know how to retain gratitude for what is good in their lives. They are telling us that oldest-old age is very hard, as should be expected, and that they may get caught up in discouragement during confrontations with declining health, frailties of body and mind, and losses affecting the spirit and the soul. Increasing longevity and medical interventions often make this decline a slow one. There is no expectation that one will not suffer or “have something.”

Yet these people tell of a self-discipline, learned from earlier hard times, of turning towards the positive and striving to remain grateful. There is no profit in dwelling in the loss and pain. Life, with its losses, is to be lived with gratitude.

### **Habits of Spirituality and Faith**

In Louis's narrative just above, his first thought regarding what allows him to cope is "I think it's faith." In an earlier interview he describes a fear of being incapacitated, and that he "would much prefer if the good Lord would take me, not put me through that kind of existence." He goes on to express certain religious beliefs that he has some confusion about, yet "I'm 100% Christian." He is a prayerful man whose church attendance is a weekly habit. His faith is key to his ability to manage his challenges at this time of life.

Betty has other habits from her lifelong religious practices. In describing her daily routines she includes her prayer traditions.

One in the morning, a rosary, and a rosary at night. 'Dear God, please let me have a peaceful night' . . . I'm not a fanatic, but as a Catholic I pray, you know. It's a habit. And I don't like to miss mass on Sundays because it seems like my week goes better. I don't have as many aches and pains. I don't know. Things go smoother, you know.

Betty's words reveal that she not only prays to her God, but also that nights are not always peaceful and that aches and pains can make for a difficult week. Yet, she seeks help, a peaceful night and a smoother week, through her habits of faith.

The habits of Walt and Sarah, as revealed through their narratives, were portrayed in the consideration of the gains of spirituality in the previous chapter. They described habits of faith, prayer, and religious beliefs that began in childhood, and have been a

source of strength and hope throughout life. Prayer has been Sarah's primary habit of coping.

I would ask the Lord to help me. . . . That's what He has done down through my life, and when I think about things that I have . . . problems that I have come in my life, . . . that's the only thing that has brought me through.

It seems her reflexive response to pain, suffering, confusion, is to turn to prayer. She is finding hope and support in life in the same place she always has, in the place her parents taught her, in prayer.

Walt's morning habit of waking early and laying his day out before the Lord and listening, his view of being a channel for God's work, habits of prayer, study, and thought all indicate a core of faith and spirituality. For both Sarah and Walt, one is left with the impression that their faith journey carries the primary sustaining hope in their past, their present, and their future.

Aging is a faith journey for others as well. Betsy states clearly, "I believe in Jesus . . . And I love Him. He's my life." "He's just become so dear." Her daily habits include prayer, singing in worship in the quiet of her own home, and asking "the Lord to help me, to keep me from falling. Jesus is my strength. I keep asking Him to keep my feet going." When asked directly how she copes with all her challenges, "What's worked best for me is just to learn that it's Jesus business, not mine."

Rebekah holds a similar belief. When she was asked about where her coping ability comes from, her answer is direct. "That coping ability is in the recognition of knowing that all of this came only from the Lord, without God I can do nothing. And so, my real approach to health and life is Divine, Divine."

Alma sees her preparation for this time also as a matter of her spirituality.

The only thing I can say is that I'm very thankful to be a believer . . . but my faith has grown stronger, I've made some big changes as we go along and I just try to let the Lord direct me and be open to His guidance, His spirit, and not worry about it.

Betsy, Rebekah, and Alma, tell of being comforted, strengthened, and guided by their God. Their ability to live in oldest-old age and cope and live with the losses and gains this time of life present to them, lies in their habits and attitudes of their faith.

These oldest-old are from a generation in the United States that were largely raised with religious beliefs and a tradition of going to church. Ten of the 13 participants expressed prayer and religious beliefs as a means of coping during this time of oldest-old age. Only William spoke directly to being agnostic; he succinctly stated "It is an unknowable." Instead of being more future oriented, William is involved in his present and seems to find meaning in talking and reminiscing about his past. His detail for past memories is quite remarkable and it is apparent he spends time with these memories. His future does not hold possibilities that are meaningful to him, yet his past is rich with happy and meaningful memories. Barbara and Norma offered little expression of the importance of spirituality or faith issues in their lives currently. They are neither as past oriented as William, nor as future oriented as those more spirituality minded. These two women are present-oriented and drawn to their day to day calendars of events. The future is neither anticipated nor dreaded.

It is apparent in these other ten narratives that these beliefs and traditions can grow over a lifetime, providing possibilities for ways of coping with the challenges, loss, and suffering endured at any point, as well as an avenue, or a focus for expression of gratitude and thankfulness. As there is some current evidence pointing to the fact that younger Americans are more un-churched, and less faith-minded than previous

generations, one is left wondering what outside of themselves, will provide future generations the means to endure and hope during this time of oldest-old age.

### **Growth: Adaptability, Patience, Persistence**

Lest it be thought that these habits of heart and mind are only lifelong patterns, narratives were also told of growth and learning new ways while living in old age.

#### ***Betsy's Exemplar: "It's a Thing of Learning"***

These words of Betsy's were first described in chapter four, in regards to her body's physical changes. Here, they offer testimony to personal growth experienced in response to the demands and changes this oldest-old time of life seems to require of Betsy. These words bear repeating, "... like I said, adapt to a new way of being and doing." She talks more about what this means. "It's having to get used to a lot of things that are different. And the different thinking, you have to think differently, and being adaptable, adaptability, persistence. I have to learn patience (laughs)." And a bit further on in the conversation,

It's a thing of learning. You know we think we learn so much, but boy, we have to learn a lot all the time . . . what I've learned is not to expect a lot, and just to go along as the Lord leads me.

She related all this while interjecting it with laughter, but it is clear that old age is requiring much of her. Barely able to walk, always requiring a walker, recovering from a serious illness, yet still having not regained her former strength, Betsy's response is to adapt, and not expect a lot. She is working hard at making this way of being and doing manageable. Yet she is used to hard work; she knows how to do that. She knows how to pray and seek leading from her Lord. These life habits are allowing for growth in

adaptability, patience, and tenacity in the face of ongoing and increasing obstacles and disability of aging.

### *Other Expressions of Growth*

While it was evident through both observation and listening, that each participant was continuing to learn new ways to be and do in response to their aging selves, a few participants noted specific areas of growth. Alma expressed her goal of continuing to grow personally and spiritually. She also told of a particular area of growth.

I think I have probably less insistence that something go this way and not that way. . . . I try to remember that I am the Lord's property, let Him take care of His property, don't boss and dictate, so that's kinda my new philosophy.

This is a new philosophy, a new way of being and doing for Alma.

Rebekah has also experienced tremendous change in learning a different way of being and doing, as is seen in her struggle with independence and recognition that "I'm old." She speaks to another part of the growth involved for her in this process.

I also realized that this is a phase of life. . . . It helped me a lot to realize that there are stages and seasons that we have to go through. . . . Since I've been here, this is the change that has really made me realize that being old is not a death sentence. . . . It's what you put into it.

Despite feeling put out to rest by her daughter and pastor, she has grown into an appreciation for where she is living, what she can contribute, and the importance of her attitude as she continues into this season of her life. She sees it as largely depending on her, what she puts in to it. Rebekah's perspective has changed. "You have to get over the fact that it's [life] not over, it's just beginning." In a later interview she tells it this way: "And it's just now I really realize how beautiful life can be."

Rebekah is a resilient woman. She describes depression and reconciliation with her growing recognition of what life after 90 years will mean. Instead of the decline that depression can bring, Rebekah recognized the opportunity to choose growth—and she chose it. Her ability to do this, in fact has been demonstrated throughout her life.

Choosing growth is a habit for her.

William also offers an interesting insight regarding change. Most of my life . . . I tried to do something different. So, if I get into a pattern, I consciously try to change it. *But now*, [emphasis mine], I try to develop patterns that're the same. . . . You consciously try to have some correspondence between your goals and what's realizable, so they're much more limited.

His approach to living has changed tremendously, from one of adventure and change, to one of predictability and management. In light of his increasing physical and mental limitations, William, who is goal oriented, speaks of setting goals for himself that he can actually meet. The implied truth here is that living the way he used to is not an option. At this time of life, under these circumstances, with his current and every increasing challenges, a new strategy is needed to offset the losses of advancing old age. He articulately describes the conscious response to this. Through wisdom and growth, he is able to adjust goals to those that are commensurate with his abilities. He does this in a much more cognitive manner that is congruent with his temperament and training.

In a different manner, Louis speaks to growth he recognizes as desirable but has not accomplished. “I haven't graduated from saying ‘Well, I'm lucky to be like I am,’ you know. You feel that too, but you've gotta feel regrets here and there.” Perhaps, as in Williams view, this goal isn't recognizable. Louis may feel regret at times. However, his area of growth has been in his relationships with his family. “I think the relationships, that's been a growth that's occurred . . . I'm just more and more thankful.” From his



perspective, his children have become adult children that are attentive and loving. They were very involved with him when their mother was sick, and after her death, as Louis tells it, they seem to provide the right amount of attention and care, even from a distance.

For each of these participants, growth is a way of being in this world of oldest-old age. Growth, as portrayed in these experiences of aging, involves one's self-concept, one's rules of life, one's relationships, and one's ways of being and doing in the world. For the old it can be both a choice and a necessity. With cognitive ability and memory intact, human potential for growth is a lifelong.

### **Conclusion**

These narratives about living in the years of oldest-old age, allow for a revelatory gaze into the daily lives of each participant. Early in the interview process, there sprouted a gradual recognition that each individual had a certain pattern of thinking about their situations, or responsive thought habits that helped them either stay positive or regain positivity in the midst of ongoing difficulties. As their captivating life histories were told, and there were more and more opportunities for listening, it became apparent that these habits of thinking, feeling, responding, even growing and changing had long been established in their lives. These very old people have developed habits over the course of their long lives that are productive, helpful, spiritually uplifting, and even life-giving during this time of ongoing challenge and change. As the body increasingly demands more of their time, attention, and energy, they have their well-practiced and reliable responses that come to their service. They are survivors, and as William stated "survivors know how to survive." As has been identified in this chapter, these survival tactics are shared by most. Habits used involve being positive, dwelling on and

remembering good things, living for today, being adaptable, and having a posture of gratitude. Remembering time-given insights of wisdom, forgiving self and others, being humble, continuing in spiritual practices, and learning new ways were other habits of the mind and heart revealed in these narratives.

Lest these participants be painted too heroic, too in control, it should be added that in some way, all participants spoke to times of being overwhelmed, discouraged, fearful, lazy, and/or depressed. They were cautious about allowing aging to be seen as easy, or as less difficult than it truly is. When the balance bar leans too far to one side there is a fall to discouragement. Yet, the intriguing almost universal response is not to give up and surrender to self-pity, at least for very long, but to self-correct in some habitual manner. Focus on the positive, on today, on what one has to be grateful for, on good memories, and for some, on prayer.

During the interviews, participants were able to talk about whatever was on their minds. They held a captive audience of one. There were no attempts to gain sympathy or indulge in self-pity, by anyone. While answering each question, they gave thoughtful and seemingly honest responses. They told it like it was. However, they did not dwell long in stories of difficulty, loss, disappointments, or fears. Time spent talking about negative life events, either past or present, was minimal. Conversations were easily turned by these narrators to the positive. The “I don’t stay there for long” prevailed. This was in spite of instance after instance of physical ailments, disabilities, falls, vision loss, memory loss, and loss of loved ones. There were times when the interviews were emotional, when the losses, challenges, or infirmities were overwhelming, and a heavy

sadness was felt. But at least for now, recovery to some prior level was found, and positivity reigned. No one took advantage of the ear that was listening.

It is tempting to say, “Go ahead. Complain. It’s ok, I understand.” Members of a younger generation, who believe in venting and self-expression might encourage this. But as these oldest-old would ask, “what does it profit?” Might we learn from these who are older and probably wiser, that this is not the best course for living out our days? This oldest-old generation knows hardship. They come into oldest-old age with habits of thought and emotion that help them cope with the challenges that subsequent generations may not have. While living to these very old ages may in fact be a surprise, perhaps they are better prepared than later generations will be in spite of the anticipation of increased longevity. After much listening, what is heard is that these days are distinctly difficult, but they will not stay dwelling on the difficult. There is no profit. Instead there is a choice to be thankful for “my dear, dear days” (Scott Maxwell, 1968, p. 39).

After listening to these oldest-old, one wonders about the wisdom of the words of the Welsh poet Dylan Thomas (2010, “Do not go gentle”): “Do not go gentle into that good night, Old age should burn and rage at close of day; Rage, rage against the dying of the light.” There is no rage heard from these participants. There is perhaps a quiet fight. Perhaps the fight witnessed here is a fight of remaining positive and treasuring the sweet days, not lamenting the shortage of them. Perhaps the easy way would be to live with anger and burn with rage. Very old age, as has been seen is a time of progressive resignation and acceptance of loss, change, and disability. Yet these resilient participants choose to “not stay there.”

It is also possible that this small sample of 13, just happen to be of similar sentiment and thought. Perhaps this is the zeitgeist, the spirit of the age, for them. The wars, the depression, the personal tragedies, may keep expectations reasonable, and create an appreciation for small things. Perhaps they have had a lot of practice looking for the bright side of life. We must be mindful that they have demonstrated that the attitudes that they bring in to oldest-old age have been with them much of their adult life. Others that have raged against life along the way, would most likely continue to rage into their final hours. Those that live passionately and intensely may live into old age with passion and intensity, and die in like manner. And perhaps our most honoring response is to support each individual in their life long approach to life, in its progress and in its end. This would require us to recognize that there are innumerable responses to old age and its accompanying disabilities and losses. “To each his own.” “To each, her own.”

While medicine and society seem committed to extending lives, it is imperative that we be equally supportive of these lives in ways that promote dignity and well-being not helplessness. These oldest-old are perhaps saying “In spite of how I appear on the outside, I am not helpless. I have choices. And even though I may have difficult days, today I choose an attitude of positivity and gratitude and living for this day.”

Jurgen Moltman (1983) offers a provocative view of health appropriate to what has been learned from these participants.

True health is the strength to live, the strength to suffer, and the strength to die. Health is not a condition of my body: it is the power of my soul to cope with the varying condition of that body (p. 142).

What is evident in the narratives listened to here is that these participants are working hard to retain this view of health and their power to choose it. “This is the day to live.”

Meaning can be found exactly there. The following chapter will explore where these oldest-old find purpose and meaning in their own unique worlds.

## CHAPTER NINE

### WHERE PURPOSE AND MEANING ARE FOUND

Age is proof you got from there to here.  
Alas, so many that you loved did not complete the journey.  
You mourn them, yes, and always will, but age is such a triumph over youth,  
Again, because you moved across the years to *here*.  
Leaving *there* where it belongs  
For youth to come along and re-discover

*(Rod McKuen, 1999)*

“Hope prevents us from clinging to what we have  
and frees us to move away from the safe place  
and enter unknown and fearful territory.”

*(Henri Nouwen, 1979, p. 77)*

It is good to remember at this point, the previously stated understanding that “time creates a story” (Benner & Wrubel, 1989, p. 64). We are in the now, as influenced by the past, and as imagined in the future. Because of our temporality, or living into the future, we are always becoming. Yet the whole of this life-time must be considered as we learn about meaning and purpose from narratives of those who have lived long.

Meaning has been found to be highly unique to each person in this study. While commonalities and shared meanings do exist, the individual stories create a deep sense of where purpose and meaning are found in the context of a whole and long life. As these stories are shared, it is hoped that the distinct experience of each one will be preserved while the epitome of the oldest-old will also be revealed.

#### **Doing What You Have Always Done and Doing It Better: Paradigm of Walt**

“You’ve done your best work since you were 70.” This comment was both an observation and a compliment Walt received from his boss several years ago. At 92, Walt persists in going to work four days a week at an institution that continues to value his presence. On Fridays, he plays 18 holes of golf. He is an academic, a practitioner,

and a published author who has advanced degrees in his field. Walt, highly philosophical and reflective, has developed habits of thinking and ways of the heart that have kept him beloved at his institution. His professional rewards have been reaped longer than most people, resulting in a legacy that will continue even when his life is over. Yet, behind this is a fear that if he stops, his mind may fade and his life will soon be over. He is almost clinging to life. More than once he mentioned reading “some research” about a shortened life span after retirement. As described in Chapter 4, Walt is torn between the satisfaction, rewards, and lure of his legacy that pushes him on despite his fatigue, his wife’s changed health status, and her increasing need for him to be home.

Walt relates that he tried to retire three times. He smiles in a manner that conveys deep satisfaction as he describes how he was lured back by organizational leaders through enticing positions and sincere compliments about his work. His paradigm is also one of remaining engaged. When asked if he does not believe in retirement, he replies “No, I don’t. Cleaning spots off the driveway? No thanks (laughs).” It was with his third “attempt,” that the president of the organization actually told Walt that he couldn’t retire until she did. The president is now retired. When asked what he dreaded about retirement, his response was

I tell people I was born 30 years too soon . . . but here’s the catcher. I discovered early on in some of those retirements, a study that said if you retire, [if] you don’t have something that grabs you, you don’t feel needed or wanted or loved in particular, you have about 18 months to live because your immune system shuts down, you’re open to whatever is going around . . . it’s problematic in some ways with my wife’s waning and stuff. We both know that. She can say, we’re not as together as we used to be and I’m seeing that’s true.

Walt has established a program which has a deep and ongoing influence on the culture of the organization as well as the training of influential people who pass it on to

others. He has made a tremendous impact in ways that will outlast him. “And now they treat me like a legend.”

In this same interview, Walt spoke of writing his memoirs and of a new book he has in mind which just formed itself in his thoughts at “4:00 am this morning.” He continues to live into his familiar possibilities. Yet, he also has a way of weaving stories of his aging experience in and out of his stories of personal satisfaction from his professional life and the purpose he has found. I wonder if this is because he realizes this may not continue to be a possibility for much longer.

During our second interview I asked Walt if there had been any recent instance when it felt good or rewarding to be this age.

Every day that I’m at work . . . I usually run into people I’ve known for years that’re back here. Like this week. There’s a former worker. Our birthdays are the same. So, we go out once a year and have our birthday. And she was telling me about a client she’d had recently and nobody thought he was worth anything. Turns out he’d been a chief tail gunner in the war, and had the Purple Heart and all that stuff. And she said she just asked him questions like I taught her. But I run into my trainees all the time who say, “I use it every day.” So, when she told me that, it was just a reassurance that what was very difficult in the beginning has now become a culture in the organization, and is very, very soul satisfying.

“Very, very soul satisfying.” Walt has frequent assurances that his life and work have made a difference and will continue to do so. Soul satisfying . . . deep, deep affirmation that he has lived a life that has mattered. It is hard for him to leave this behind. Yet Walt, as a professional and a deeply spiritual man, has enough insight into human frailties to recognize that he will not be around his organization forever. In response to the question about losing something important to him at this age, he replies:

Well, I think becoming an icon is totally rewarding. But that icon soon fades with people who’ve never heard of you. So, other than in a book, or your name, or your picture . . . When you’re gone, you’re gone. And a



part of the thing that's ameliorated that is to know that everything I've ever been and done is in the books of Heaven. . . . It's really a mellow time now in terms of spiritual life because it's the richest thing for me, and just trying to watch and even respect every one too, by going down the hall and somebody's trudging with a broom, and I say, "You do beautiful work." And see them straighten their shoulders and all. Sort of the random acts of kindness.

Walt has a tremendous sense of satisfaction balanced with an awareness of the finitude of life and limits of the memories of others. What provides deep meaning and purpose for Walt is the eternal quality of his good works. He believes in a God that sees and remembers. His work has added meaning in the face of eternity and a God who cares about such things. Walt's beliefs and spirituality are foundational to his sense of meaning and purpose at this time of life, and life beyond life.

The third interview starts with Walt relating the marvelous birthday party that was given for him. He then describes how in a written document from a colleague, he received further confirmation of the permanent impact that his work and influence have left on his organization: "Could you ever imagine in your wildest dreams?" He felt the reward of long and hard work acknowledged. When I asked what it felt like to read about this, he replied "Oh, tears. . . ." And then, fairly abruptly Walt changes the topic: "But my body began to talk to me. Almost one morning my knees were stiff. . . ." So, here is his reality check in the midst of rejoicing, and another example of his way of weaving the story of aging into the story of meaning and purpose.

Toward the end of the interview he answers the question "What has brought you satisfaction at this time of life?" Walt's quick short response was "My work." He then described the satisfaction of having raised up a successor and the "immediate relief" it brought when he officially handed over the work to his protégé. Being able to see the

work taken to the next level by a new and younger person who was chosen, mentored, and trained by him, has brought great meaning and satisfaction.

I think one of the brightest, beautiful things that happens now is, and I get introduced this way, “Walt is a legend.” God is legendary, but people smile. They don’t even know me, but they know me by name. And so I’ve made a deliberate habit, although I haven’t done it for a while now. . . I would go to each of the administrators and talk with them about *them*. And pray with them and find them in tears . . . and the joy that comes from that, of ministering to people who aren’t used to being ministered to. The great fun is being a channel. The day I discovered in my life that I was not a source but a channel, my life changed . . . a channel for God.

So here is where profound purpose and meaning lies for Walt. To be a channel for God, or God’s hands at work in the world, was the epiphany that changed his life; an epiphany which has been life-giving, even life sustaining. Walt’s unique experience has been his humble beginning which led to his long and rich professional life. He continues to be fully engaged with his world. His spirituality encompasses his professional life which together continue into his 93<sup>rd</sup> year to provide deep meaning, purpose, satisfaction, and many, many life-giving memories. However, there is a sense that Walt is coming to terms with the reality that this time is limited. Old age is having its way and he is acknowledging that. Continuing to do what he has always done, may soon be an impossibility. This knowledge makes this time all the more meaningful.

### **The Spiritual Provision of Meaning and Purpose**

Walt is not the only participant for whom religious beliefs and on-going spirituality have provided life-sustaining meaning and purpose. Others found this through their unique way of experiencing their spirituality at this time of life.

### *Alma's Driving Force: Finishing a Personal Work*

Alma, also a very religious person of life-long faith, has her own unique story of how spirituality and religious beliefs bring her purpose and meaning at this late time of life. At the end of our first interview, Alma was asked if there is anything she still wants to accomplish in life. Her answer was quick and definitive.

Yes. I wrote a 70 page paper on this, and I came to realize recently that the administrators [leaders in her religious denomination] that were there in 1977 and 1985 are no longer there, they're probably retired and a lot of 'em dead. I mean, I've out survived two [denominational leaders] (laughs). Anyway, the first of May we had an outdoor concert here. I went to the thing and I was backed up in the shade, and one of the PhD teachers came, a man that I had appreciated, and I had seen in a video series where he was a participant in a discussion group. And I've wanted to talk to him about life insurance. And anyway, whether I should've done it or not, I did it. I wouldn't say I was very well prepared, you know.

With passion in her voice, Alma described her Biblical view on life insurance and her denominational perspective. At an earlier time in her life, she spent many years researching and writing up a position paper on this topic.

My church was fine for about 90 years . . . but for the last 50 years, we've gone to the world, . . . and I feel anguish for those people, and you know . . . there's a new crop of administrators. I just cannot go to my grave without making another attempt. And so, I can funnel it down [shorten her first paper]. It won't need to be 70 pages. I can funnel it down and hit some important points. We have missed such a blessing and it seems such a tragedy. I want to write it up and [submit it].

Talking forcefully and with conviction, Alma explains a brief history of life insurance, her views on it, and the fraud she sees it to be. She became very animated and spoke with strength and conviction as she related the conflict between business and the church. And then her resolve was evident.

I want to get it written up and sent to some very key personnel in my church. And I would lay down my life before I would give up my conviction because I have the evidence, I feel overwhelming evidence, and

my husband helped me . . . I just leave it up to the Lord, and if He wants it done, it will be done. Even if I lose my eyesight. . . I'm not gonna back off.

For Alma, there is still a spiritual and scholarly work to be done. She is still engaged in meaning pursuits; living into meaningful possibilities. Using strong, even forceful language, she is not giving up on a deeply held spiritual belief that has deep meaning for her. This is her purpose, and it is bringing meaning to her at this time of old age. This late time of life is pressing her with urgency. When body functioning is waning, and independence is teetering, this purpose in her own intellectual and spiritual direction and property is animating and provides energy and reason to press on.

During the third interview, when Alma was directly asked “What gives you purpose and meaning at this time of life?” her response was succinctly spiritual. “To be as healthy as I can be, and to keep growing, and getting more and more into the Word [Biblical scriptures].” She speaks of her body and her soul, and she speaks of growth. Even at 91, Alma is growing spiritually and intellectually. It is life-giving for her.

***Betsy's Sustaining Faith: When You Can no Longer Do What You've Always Done***

Betsy is very transparent, honest, and genuine. Her kyphosis is apparent. She cannot walk around without a walker. Her head hangs low when she's thinking. Betsy is frail. Her belief in God and Jesus Christ runs very deep; it sustains her, and gives her hope. Betsy conveys both a sadness and a deep peace. Placing her hands over her heart as she speaks of her Lord, her eyes often tear up.

A Hispanic-American woman, Betsy never learned to speak Spanish until she and her husband spent a great portion of their adult lives as missionaries in Mexico. She

reveals her current purpose and where she finds meaning as she responds to questions about loss and disappointment.

What has been discouraging more than anything is not being able to go, like to go down to Mexico, I want to go. . . . That's the only thing that discourages me. But I've had to realize I can't and so what I do is pray, and so (laughs), that's what the Lord has me here for, that's what he has for me and it's been like I said, adapt to a new way of being and doing.

In direct response to my question about what gives her meaning and purpose in her life she replies:

Well, I believe right now that the Lord is preparing me for what's coming ahead. He's coming soon, I believe He's coming, and there's gonna be hard times before that, and He's preparing me to "be still and know that I am God." I'm gonna be here when Jesus comes back. That's what I believe. That's what He's preparing me for now . . . until He comes back.

Life seems to be a struggle for Betsy, yet she strives to live as her Lord would have her at this time. Being old, living alone, and being dependent is getting tiresome. But, her faith is fresh and life giving to her. As she relates, her purpose is to pray and to allow her Lord to prepare her. This is the meaningful pursuit, the life giving possibility that remains for her. Much of her day is spent in prayer, reading her Bible, and singing songs in worship to her Lord. What Betsy has done before is no longer possible. She is doing new things; she is adapting to new possibilities and very spiritual way of being and doing.

### ***John's Spirituality: Faith Brings Hope***

Of all the participants in this study, John is the individual who is struggling the most with depression, complicated by the continued grief from the loss of his wife. He speaks of her as being in his dreams nightly, and being on his mind daily. His unexpected disappointment in his old age is to be living without his wife, who died a sudden and unanticipated death. John's spirituality is his source of hope, through which

he finds meaning and purpose. When I ask directly where he finds strength to keep going day by day, he quickly replies “Just doing. Just doing it. It’s not because of desire, because I can’t get satisfaction. It’s like breathing (laughs) you do it because without it you wouldn’t live.” He is asked further about where he finds purpose or meaning in his life right now.

J: I don’t know if this is answering your question or not, but it’s in Christ and I pray that he has the power to serve the circumstances when those circumstances get to the point where it’s right for me.

I: Please tell me about the hope that you have in that?

J: Well, I just hope that I meet somebody. And every place that I go I’m looking for that person and constantly evaluate, will she fit that situation? I don’t think that’s very healthy. The hope is that He [Christ] will intervene and make things right. I know that it’s his election that He hasn’t made them right and for a good reason He hasn’t, and I don’t know what those reasons are.

In the previous interview I had asked John if there were things in his life he would still like to accomplish?

J: I’d like to be a better Christian. I think my religious life is lacking, and I’m done with all my counseling, but I still don’t regard Jesus in the way that I should.

I: And that’s become very important to you?

J: Very important. My main objective now is to live the kind of life that would be acceptable for me to be back with my wife.

During our interviews, John’s struggles were evident. At first he speaks of going through the motions: “Just doing . . . it’s like breathing.” It seems to be his reflexive response to being alive. Yet as the conversation continues, John’s thoughts take a decidedly spiritual turn. John’s spirituality and faith beliefs are bringing him hope for a future. His purpose and meaning now is to live a life such that his Lord will reunite him with his wife in heaven, or bring him a woman companion and new wife. Living and growing spirituality is providing both meaning and purpose even in his grief. John has a

definite future orientation both for this life and his heavenly expectations. Sustaining hope, growing in his spiritual life, and gaining a new companion are what are providing him purpose for each day. His children have also provided him a care provider, or paid companion, who demonstrates genuine interest in John's wellbeing.

Walt, Betsy, and Alma have all been active and strong spiritual people throughout their adult lives, with spiritual practices and beliefs that continue to bring them purpose and meaning. Walt and Alma are continuing work that has been meaningful for years, yet now has renewed urgency and commitment. Betsy's narrative speaks to her inability to continue her meaningful missionary work but to her ability to find deep purpose and meaning in her private spiritual practices and "new ways of being and doing." John's experience is one of a spiritual response to his grief and loneliness that has provided a source of hope in his unexpected circumstances in old age, an incentive for personal growth, and a purpose in living well each day.

It is interesting to note that the participants who are highly spiritual, have had this orientation for most of their lives. Those for whom religion and spiritual practices are unessential at this time of life, have lived throughout their lives with religion as a minimal influence. The single agnostic, and those that are simply church-goers remain in a similar belief system and life pattern even now. Very old age does not seem to bring with it profound change in religious beliefs or the meaning one finds in one's faith and spiritual practice.

### **Busy With Everyday Life**

For some participants, purpose and meaning revolve around just getting through each day and doing what they need to do. It was indeed a surprise to hear expressions of

satisfaction, fulfillment, and even happiness found by some of the participants in just taking care of business and doing what needs to be done that day.

### *Norma's Way of Contentment*

In our first interview I became intrigued by Norma's lack of need. I wondered if this is reflective of a life without other ways of remaining engaged in meaningful pursuits. Social class and culture may point to the importance or lack of importance of meaningful endeavors or purpose outside of one's family. Yet, her peacefulness and contentment were evident. When asked, "What do you continue to look forward to?" She replied, "I've nothing, just, everything is normal right now and I hope it stays like that. . . . I just hope I can stay here as long as I live." She indicated that she had nothing more that she wanted to do or accomplish and added, "I've had a good life. You know, I don't have any regrets. I did the best I could." In our next interview, Norma's response to the question of what gives her meaning and purpose every day was simple: "Well, just to get up (laughs) and do whatever I have to do, you know."

In our final interview, Norma's response to the same question was similar, equally simple, and spoken with contentment. "Well, if I have something to do you know, appointments or like today I went to get my hair done, and I look forward to whatever . . . whatever I have to do that day."

Being the oldest in a family of nine children, Norma had a large role in raising her siblings. With her own three children and her husband, she was the traditional mother and homemaker. Norma cared for others as her primary role almost all of her life. From when her first sister was born until her husband died four years ago, she daily took care of others. At one point she related that "Now, I can go to bed when I want, and get up



when I want. I don't have to worry about nobody." She has no regrets, she has nothing else to accomplish, and she has no further strivings. Her social world has narrowed to family, as life-long friends have died. Norma's children and grandchildren are vitally important to her and seem to be the unspoken providers of social ways of being engaged, deep meaning, and purpose. Remaining in her home, which was built long ago by her husband, is her primary desire. Every day that she is able to do that, is meaningful to her.

### *Barbara's Good Life*

Barbara, at age 98, enjoys excellent health and continues to drive short distances in her community. She cared for her second husband for about two years as his health declined from Parkinson's. He then died 11 years ago after eight months in a nursing home. Continuing to live alone in their home, she keeps a calendar of her many activities and enjoys a calm, steady daily routine. Her responses are very practical and to-the-point. When asked what gives her purpose and meaning at this time of life, her reply is simple.

Get up in the morning, have breakfast, go to your meetings or not, whichever, and talk on the phone with people you know. Keep doing what you've always been doing, why not? You know if you've broken your leg you're gonna be shelved for a while, but if you haven't broken your leg, why not keep going? (Laughs).

Earlier in the same interview, Barbara had related the surprising pleasure and happiness she has experienced from her former husband's children. When they married they were both widowed. She had her four children and he had his four children. Since his death, she continues to enjoy her relationship with her own children and grandchildren as well as her stepchildren and step-grandchildren. This has been a "big,

giant plus” in her life. In response to my question about what brings her happiness at this time of life, she replies “People, yeah people in general.” She comments:

B: Life has been good, and maybe it’s my fault.

I: Your fault?

B: Because I wanted it, I expect it to be good.

I: So life has been very good?

B: Yeah, and I have a difficult time answering your questions because I haven’t thought much about that. Just life goes on.

Life goes on and Barbara enjoys the moments. She is involved in doing what has been written on her calendar each day. In comparison to the more spiritually oriented participants who are more future oriented, Barbara is not concerned about the past nor too much about the future. When asked how she would describe her life right now, her reply is “Oh, it’s been good. I’ve enjoyed life. I’m not sorry that it’s coming to an end but who knows, I may live another few years.” When asked if she is getting tired of it all, her replied was “No, not really, no ‘cause I have good friends. . . .” People provide meaning for Barbara. She related many stories of friendships in her retirement village and loving relationships with her large number of family members. She is socially engaged.

In response to a question about a recent experience in which it felt good to be her age, Barbara enjoyed telling me a story about a comment she made at a club meeting.

Well, when people at our Club remarked about what I had said. We had a special meeting, and everybody was asked to say something, some little thing. So, I said “It’s great to be here. It’s great to be anywhere” (laughs). And so, one of the men copied that comment. Afterward, he apologized. He said, “I hope I didn’t steal your thunder” (laughs).

Barbara’s narrative seems to say that sometimes just being connected and socially engaged in one’s daily lifeworld is enough to provide meaning and purpose. Being at peace with oneself, enjoying each day, and being involved with the people in your life, make for a good life at 98 years of age.

### *Betty's Taking Care of Business*

Betty's sense of humor is one of the things that stands out about her. While there was a lot of laughter during the interviews, the seriousness of her concerns behind the humor are significant. Of all participants, Betty's narrative reveals the most anxiety about getting older. Each day she maintains her independence, is meaningful to her. She is asked what she looks forward to each day. Her quick response: "Taking my bath and getting the hell out of here!" (Laughs). She knows this is threatened by her potential vision loss due to progressing macular degeneration. "Is there anything you still want to accomplish?" Her reply hints her fear: "I hope I never quit driving till I die." To Betty, driving is very symbolic of her independence of being in control of her days. Enjoying driving now provides purpose and meaning to her days as she knows it may soon no longer be a possibility. When asked how she would describe her life to others she energetically replies,

Hard work and you can make it. . . . And you know, when I have something to do, like my refrigerator filter . . . it went out about two days ago. And so after I got out of the beauty shop, I just went on ahead over there. I don't like to leave things for tomorrow, I don't like to leave things go. And another thing too, on the 40 years that I've been going to a doctor, I never have missed an appointment (knocks on table). Never. Never. And I don't like to be late. I don't like to be late.

Doing things that need to be done on a daily basis, taking care of her business promptly, provide meaning for Betty. She's a practical woman.

The first time Betty is asked what provides purpose and meaning for her, what gets her up every day, she again offers a practical response. "I get tired of being in bed (laughs). . . . And I get hungry! (Laughs). Because you know, I can't do what I used to. There's just no way I can do it anymore." Betty is experiencing many "I cannots." She

is constrained by what are no longer possibilities and wants to maximize what are the continued “I cans.” It is possible that ability to drive is symbolic of both the I cans and the growing I cannots.

At the end of our final time together, she is asked what gives her purpose and meaning in life, and what keeps her going. Her answer: “Cause I gotta get up and you know, doctor’s appointment or lab or go to the store. More or less I have a schedule you know.” While her response here does not quite articulate the actual question of meaning, Betty’s story absolutely does. Taking care of business and maintaining her independence are where much meaning resides for this lively woman.

It is worth noting a difference in present versus future orientation between the highly spiritual and those that are not. Barbara, Norma, and Betty seem to live more in the moment, in each particular day. For those that have a more spiritual emphasis in their lives, Walt, Alma, Betsy, and John, there is a tendency toward a future or eternal focus. In both cases, meaning and purpose are found.

Barbara, Norma, and Betty each expressed finding their daily meaning in successfully living each day in their own way. To be clear, all three of them have families that are present, loving, and involved in their lives. Each has a certain security in that. Only Betty is concerned that her family is very busy and consumed by their own lives, implying that they may not have time for her. And, while all live alone, they also have active social lives. There are other participants, however, that spoke to the primary role of relationships with family and friends, and involvement in the world around them, as a sources of meaning and purpose.

### **Contributing to Family, Friends, and the Surrounding World**

Each participant tells of somehow experiencing meaning and purpose through relationships with family and/or friends, other involvement with the surrounding world. However, five persons offer distinct ways that vividly convey where their meaning and purpose are found. Heidegger emphasizes that our distinctly human way of being is through engagement with our world (Dreyfus, 1991), and while the immediate world may be smaller and still shrinking, the very old continue being-in-the-world in relationships in old age. For some participants, family was at the core of all that brought meaning and purpose. Perhaps for them, narrowing possibilities for meaningful engagement in the world have shrunk to family members. For others, the position was shared with more personal resources, or possibilities that are still present from earlier times of life.

#### ***Sarah's Role at the Very Center***

Being in the family home, it is clear how deeply Sarah is treasured by her daughters. She is a thoughtful, dear woman who is easy to be with and to listen to. There is a peacefulness felt in her presence. Her weak yet tenacious voice seems to reflect a life of hard work, a life that has seen pain and hard times, yet a life that has given, and given, and given. Her perspective suggests that she has lived and continues to live a life that matters to others. Sarah is treasured. Her family realizes she will not be with them very much longer. Sarah's past provides significant context for her present. She relates a history of family caregiving for ill family members. This was made evident in caring for parents; caring for her father when very young, and her own mother after a long and debilitating illness. Her mother lived with Sarah and her husband, and four children in their two bedroom house for many years. As she tells her story, it is clear that Sarah

finds meaning in caring for others. Her pain and joy, her sadness and happiness, loss and gain are about relationships and caring for and about other people.

Sarah's time is filled with people, being deeply engaged with family; there is no aloneness, loneliness, or social isolation. She lives in her own home with five family members; others live close by. Sarah is one of only two participants in this study that lives with children. In her case, there is also grandchildren and a great grand-child. She has moved from being the caregiver to the being the cared for. Yet, there are still opportunities to contribute, which she sees clearly and holds dearly. As a deeply spiritual woman, she is thankful to be able to share her wisdom regarding spiritual matters. Although Sarah is speaking about giving up some financial independence, she relates a teaching moment.

My daughter is in charge of my spending. . . And I try [each month] to select one [charity] I feel most needs support. And I checked 'em if they're in California. And my daughter said "Why do you do that?" And I said "Because scripture says that you have to give and you have to help somebody that you can help," you know, you have to help somebody even if you don't know that the money is really going to the right place. But you have to pray for that, this money's going for these poor children or these poor people that are gonna be fed or whatever. And I had to explain that to her and she said, "Oh."

While she has retained the authority regarding her financial decision making, she also sees it as setting an example and using it as a spiritual teaching for her daughter. This giving of money may also provide Sarah with meaning when her world is shrinking down to home and her family.

But, what becomes clear in later interviews is the meaning and purpose of her role in the life of her family. "I lay there in bed at night and pray for all my nieces and nephews." As Sarah was the youngest child in a family of 17 children, this is a time

consuming job. But it is evident that she sees her role as the family matriarch who prays for them all. Sarah continues to relate her special place in the family as the sole survivor of her generation.

We're having a family reunion in August and we're planning, we're hoping that we can get most of 'em to come here. Hmm hmm. Yeah, I have all these nieces and nephews that have been calling me. It's like nobody but auntie, we don't have anybody but auntie. . . . Even so many come to see me that have lived around here all this time. And their children are coming to see me and they're calling me, and I thought "Gee whiz, all these relatives."

Sarah is clearly pleased to be at the center of family attention. The meaning of 'nobody but auntie' and the purpose of providing this connection to the family is easy to understand. At least for now, she is the queen.

Our last interview reveals even more of this part of Sarah's story of purpose and meaning as she responds to the question of what her life is like at age 88.

[Big sigh] It's different. Sometime I can't remember exactly what I want to say, it won't come out the way I want it to. But it's not bad, I'm enjoying it because it seems like people enjoy being around me. I try to spread peacefulness with people because I don't like to see people depressed, unhappy, burdened, and if I can do something to cheer them up then I feel I have accomplished something. . . . My daughter-in-law called me yesterday and she said that she has been asked to speak at an event. And when I finished talking to her, she said "Oh, Nana, I feel so much better." And I thought "Oh, I've accomplished something."

Sarah recognizes when she contributes to others. She is able to be an encourager from her chair. Her mind is sharp, her memory is clear. Sarah's faith, positive attitude and loving concern for others dominates. Family members seek her out; they demonstrate her true value. Perhaps age, having slowed her physically, has made her even more available to them. Sarah, then told of being able to make peach cobbler.

I can't clean and cook as much as I used to. We had Easter dinner and my family loves peach cobbler. And I have this pan about this big. Great big!

[She describes how it was all eaten except one small ‘pile’ for her.] It’s the little things like that.

While the “I cannots” grow, these little things provide meaning, pleasure, and satisfaction. Later in the interview, Sarah relates another story of meaning in her life.

Even Easter at our church, I make—get those plastic eggs, and I put candy and change. I save change and then I put in change, and these are little kids, and candy. So when I went on Easter Sunday I had my bag of Easter candy and things and I thought, well at our church they don’t hide eggs, they hide crosses and however many crosses you find, you get that many eggs. So they had fun, and I had eggs here at the house for my grands and great grands. It was really nice.

Later I ask, “What brings you the most satisfaction and happiness at this time of life?”

Sarah’s response is “Having my children and grandchildren and family members around because they call me—‘Well, I just wanted to hear your voice.’” She realizes her role in the family, and enjoys her ability to support others. Of course, it is also family that brings her disappointment and sadness: “Anytime someone is unhappy or something is going wrong with someone.” She hurts when they hurt. Sarah is at the center of family life, and family life is at the center of Sarah’s life creating a purpose and meaning for her old age.

### ***Douglas’s View: Love Life, Love People, and Laugh a Lot***

Douglas is an amazing example of choosing the positive on which to focus, and to make the most of opportunities, to create opportunities, and to not look back. At 100 years, he presents with a smile on his face that makes me smile; positive and upbeat, with a great memory. The first interview occurred shortly after his family threw him a grand 100-year birthday party. Being celebrated in this way, being appreciated and honored by more than 250 guests was very meaningful to Douglas. Knowing he has touched many



lives in such a positive way, was affirming for what continues to provide him with purpose.

His 100 years of life have brought Douglas to a time when all his children, who also live in very close proximity, are retired and are willingly involved in his life on a weekly, or even daily basis. His grandchildren are also very present in his life. In responding to a question about how he stays so positive, he reveals where meaning is found for him.

You have to think positive. You must. Yeah, because you've got things to do and you show your family how to live. And if you feel important to a degree, you will, I suppose, until you die—because of family relationships. I imagine if the kids had moved all over and I never got to see 'em, then that would be different. You'd have a very, very, easy time to feel sorry for yourself.

His family celebrated him, his church celebrated him, and in a local publication, his town celebrated him. Douglas had been celebrated and felt very loved and important to those who are most significant to him.

During his very early adult years, Douglas had three different men give him a “hand-up” when he needed it. Each man making a significant difference in his life. He remembered them with sincere appreciation. Throughout his long life, Douglas has tried to be that person in the lives of others. In a later interview, he described how his son took him out to Glendale to the bakery that made his gigantic and delicious birthday cake for his party, for free. Douglas has never met this friend of his son's, and he insisted on buying lunch for all the bakery staff to express his appreciation. He talked at one point about buying small Christmas presents for all the workers of a local restaurant where he eats lunch. And with pride, Douglas spoke of the upcoming wedding of a great-grandson. “You can bet I'll be putting money on this wedding.” Feeling significant and

appreciated, and making others feel significant and appreciated is where Douglas derives both pleasure and meaning during a time of life when other ways of having purpose are scant. Having comfortable financial resources, this is also how he “invests” in others.

### *William’s Vicarious Living*

William, like Douglas, has had his prior ways of living with purpose and meaning greatly curtailed. With his long-term neurological disability, the recent loss of his wife, and his retirement from his prestigious profession, his sources of purpose and meaning have greatly changed. Yet, at age 90, he did receive a very gratifying and prestigious professional award which he and two colleagues won for their work in engineering.

When asked what it is like to be 92, he replies:

Well, many years ago, I set my goal to live to be 68. And I don’t know why, I think maybe because I didn’t think I’d live to the year 2000. But I thought maybe 1990 was in reach. And it turned out to be. And because I have so much family support and because I have such good social connections here, it’s been very pleasurable. For a widower here [upscale senior residential community], which is a female dominated location, it’s more difficult. So, I have to make an effort, but it’s not impossible. And so, I think I mentioned that two colleagues and I got something called the \_\_\_\_\_ Prize recently. Well, I got that I guess when I was 90, and my two coworkers who really deserved the honor, had died. So, I think my slogan is “rewards come to those who wait.”

William is obviously pleased to have received this national award, which brings with it affirmation of years of work well done. He is also very pleased to have lived long enough to actually be present at the ceremony, unlike his colleagues. For this high-achieving man, this was a particularly meaningful event that he was able to share with his family, and his former employer.

While William’s living situation provides many diversions and activities in the form of lectures, seminars, and committee work for mental stimulation and even fun, he

speaks to other sources of meaning. One purpose, which has been described in an earlier chapter, is knowing his body and keeping it as fit as possible. This is critical for his physical well-being. William also has made a significant shift in his life-style and source of meaning. All during his adult life he “kept his bags packed” as he describes it. He was always waiting for the next adventure, the next challenge. Now his strategy has become the opposite; he strives to keep things the same, steadier. He acknowledges that his opportunities are much more limited; he has a realistic sense of what is possible.

I consciously try to have some correspondence between my goals and what’s realizable. And so, they’re much more limited. So, my older daughter who as I say does everything [like I did], I live vicariously through her and especially my four granddaughters who’re of the same nature (laughs).

William had previously described the uncanny likeness between him and his daughter and contrasted the two of them with his sons who have remained living in the same town in which they grew up. Of course loving them all, watching his daughter and granddaughters live lives of adventure and challenge similar to his is deeply satisfying and provides him with meaning during this time of his own limited options. His legacy lives on; they are his offspring. He seems quite content with this.

Getting his “affairs in order” is William’s current outstanding practical purpose. Speaking of lessons learned earlier in life from his adventurous nature, he touches on this practical concern.

I learned to think ahead and in more detail and rely more on my own resources. And you know, you really don’t do that until you’re forced into a position where all the other resources are cut off. And that has all been very helpful. For example right now, I’ve been working as hard as I can to get my children ready to operate when I’m deceased. And so, they of course have no understanding of the problem, and my affairs are somewhat chaotic. So, a week after I die, they’re going to have scores of questions, and I’m not gonna be there to answer.

For their sake, he is now working with one of his sons, and one of his daughters to take care of his affairs. William's concern is for his family. He is thinking of their wellbeing, and making that a priority right now. This caring for one's family has proven to be a common source of purpose for parents, even when one is very old, and one's children are well into middle age. William's role as father and grandfather provides meaning and purpose; he is still the dad, still the grandfather. This is evident at the very end of our last interview as he responds to the question of what brings him meaning and purpose now.

W: Well, you know, I can still be helpful to my family. And so, (laughs) I do that. [He relates a time of giving his daughter advice]. Then I said, "So that is my fatherly advice," and she wrote back and thanked me for the fatherly advice.

I: So you still contribute.

W: Well, yeah, I do. And of course, the granddaughters all being somewhat scholarly and having scholarly interests, we have that in common. And so, being egalitarian, I consider myself on their level . . . grandparents don't have the generation-gap problems. In fact, one of my favorite expressions that I heard recently- what grandparents and grandchildren have, [why they] get along so well is because they have a common enemy (laughs).

I: Anything else that gives you particular meaning?

W: Well, I interact with the media. So I get enjoyment out of the PBS news hour, the Masterpiece Theater offerings. And of course, I share that interest with my children. So, we have that. And then my kindle . . . we all get the same books to read. For example, there was an email from her [his daughter] this morning listing an Amazon book.

Being someone who values learning, he can continue finding meaning through this lifelong endeavor. While not living close to any of his family, William's technology-savvy life keeps him in touch with them. They obviously value him, his opinion, and seek to stay connected. Technology is not what provides meaning, it is a conduit for family communication. It keeps their worlds and interests in common and provides connection, purpose, and meaningful sharing for this father with his children, and this grandfather with his grandchildren. William feels valued and connected; his opinion

matters. His existence matters to those that most matter to him. And even more meaningfully, William feels that he has said all he needs to say to his family. He relates one last story at the end of our final time together: “My oldest granddaughter, (laughs), some years ago said, “Grandpa, do you have any advice to give me? And I told her, ‘Plastics’ (laughs).” William has had a good life without regret, full of accomplishment and purpose, rich in meaning. He continues to have a purposeful and meaningful life with and “vicariously” through his family.

### ***Rebekah’s Purpose Rediscovered***

While Rebekah is certainly in relationship with her sister and her daughter, her narrative of finding purpose at this time of her life as related in Chapter 5, was difficult, emotional, and long. She has lost all the beloved projects at her church that brought her both purpose and meaning. As she sees it, through prayer and guidance from her God and with the help of her pastor, church friends, caregiver, and daughter, she has emerged from this painful transition. As an outside listener, I hear Rebekah’s deeply ingrained resilience in finding new possibilities in this new lifeworld. Rebekah is now full of gratitude and is a leader in her new senior community. She has meaningfully engaged in the lives of others living around her. New meaning has been found in believing that she had to give up all that she loved in her former life, to move on to her next God-given role. “It was like somebody had cut my whole life away.” For Rebekah, God has done this work in her and this possibility brings deep meaning in her in late life.

One of the things of getting older is that you have to get over the fact that it’s not over, it’s just beginning. And then I know too, that God always has a plan for your life, even if you’re not ready to accept it.

As she told her story of her transition into her new life, Rebekah shared her thought that “You may shed a lot of tears over it, but in the end you have to think of this: Why am I still here? There is a purpose for me still being here.” Rebekah has found it. Her current narrative, her new life with new possibilities, is one of investing in this community, and in a very personal way in the lives of others. Seeking to encourage others in this time of their lives, she helps them discover their purpose and their way of being in their shared community. Rebekah’s investment is evident as she relates a conversation earlier in the week with a friend of hers who is dying.

R: I said, ‘There’s life as long as you believe there’s life.’ So that’s one of the things that has helped me.

I: You’ve really changed her life . . .

R: And she’s changed mine too, because the desire to live is the greatest thing there is. When you give up hope, there is nothing left.

Without saying it directly, Rebekah had found herself on the brink of hopelessness and despair. Now, she has found both the purpose and possibilities for her life and where meaning can be found. She invests in the lives of others. At the end of our last interview I ask Rebekah what gives her purpose and meaning during this time of life?

The joy of making other people as happy as I am. And I look at that as being such a fight, and especially when I see these people here that are so down and out and then I silently pray for them.

Rebekah has her sister and beloved daughter whom she cares for and feels loved by. But her investment and engagement in this community and the people who live around her has led her to a place of gratitude, happiness, meaning, and a deep sense of what she believes is God’s distinct purpose for her life. She was not ready to give up her former life of purpose in her church. Listening to her journey, it is easy to interpret what happened as others interfering and making life decisions for her. Even though her pastor

and daughter had loving intentions, Rebekah felt she was being pushed to give up everything she loved and became depressed. Her indomitable spirit, sought and found new purpose and deep meaning in the turn her life had taken. She found and chose her way to be in oldest-old age. With a less resilient person, this heavy—albeit loving hand—could have forced this woman and family to pay a heavy price in resentment and depression.

### *Louis's Unique Past in His Present*

Louis's narrative is brimming with a past overflowing into his present, and still presenting opportunity for his future. In the center is his loving and attentive family. Even though they live at a distance, his three children and his grandchildren bring him happiness. The importance of family to Louis was evident when he first mentioned them in the initial interview.

I had the opportunity recently, after I sold my house . . . I suddenly had quite a big deposit in the bank. What am I gonna do with it? And I thought well, instead of waiting for my death and then parceling the proceeds out, which will still be done, why not make some sizeable contributions to my three children and my grandchildren right now? And I did that. And so, they all got sizeable checks and they were all thrilled about it. . . . And I had the satisfaction of seeing this happen, you know. So, I'm glad I did that.

Being able to surprise and gift his family members in this way, particularly for a father of his generation who is a highly respected and successful man, brought not just satisfaction but added meaning and purpose to his long and prosperous life. Later in this same interview, Louis is asked what he continues to look forward to:

I'm looking forward to a more comfortable life and at least with the degree of freedom that I have now, with the friends I have now. And I guess I have a hope to live to 100, for some reason. I'm not sure why that is (laughs). I hope that's reasonable, but of course, things can change overnight . . . .

Louis's ability to contribute in a unique and meaningful way goes beyond his immediate family and creating a comfortable life for himself. As a highly decorated career military officer who served in World War II, and as a musician of some distinction, he is often asked to speak and relate his war experiences. This provides him with profound opportunities, filled with personal purpose and meaning, to contribute to and even entertain others. When asked about recent good or rewarding experiences, Louis relates the following:

My Veteran's Day talk. It's foremost in my mind now, of course I had a story to tell and I was telling it to people who had not heard this part of history, hardly anyone knows. I mean, World War II . . . very few of us had had the opportunity of being in a war as I was, to be in the first battle of the war. . . . And so, yes, that would be a perfect example of where I feel like I've contributed something and it's something important that I'm doing for this crowd.

This led to asking Louis about how it feels for him to go to the VFW on Sundays.

It's satisfying and I must say that I'm just showered with attention, and goodwill, and "Here's the general coming," and they have a special chair for me there that they bring up with arms on it so I'd be comfortable, and so, it's yeah, there's a little bit of an ego boost there.

At the very end of our last interview, as with all participants, Louis is asked if given a camera, what would he take a photograph of that symbolizes this time of his life. He takes a long pause and offers a thoughtful response.

I guess I would take a picture of myself making a talk to all the residents of where I'm living right now as I did on November 11<sup>th</sup>. To see 167 people hanging on my every word. . . . I have it here [the bugle] because I'm practicing every day in anticipation of another talk I'm giving on the 6<sup>th</sup> of January to a bunch of military aviators who still get together. (Laughs) I gotta kinda keep the lip in shape both on the trumpet and the bugle too.

Louis's quiet dignity and pride shine through as he relates this privilege of being recognized for his life's work. He sees continued purpose in teaching and reminding



others about the history and stories of the war. Later, he relates the meaning for him in seeing the enjoyment people get from his military stories and his trumpet playing. In spite of these unique avenues of contributing to others, he still has a vague, lingering sense of purposelessness that he is balancing. As a pertinent reminder, in an earlier chapter Louis share a thoughtful realization that at the end of the day “I’m really not accomplishing anything here to speak of.” As a man “loaded with responsibility” earlier in his life, meaning and purpose are a bit convoluted. Louis walks the tightrope of aging with the question of whether he has a purposeful and meaningful *enough* life.

Here is a man who had vast and at times serious and consequential responsibilities in leadership roles. He was accustomed to having each day be significant to himself and to others. This low-key role of retirement and aging with disability continues to impact his sense of fulfillment. He emphasizes that “I don’t spend long on it” to make clear that this is not where he allows his thoughts to dwell. Louis is a thankful man and is largely content with how things are for him. He is satisfied and even pleased with his current state of affairs. Being walker-bound, his freedoms have diminished, but his sharp mind is still very autonomous and competent. Secure resources have allowed for a very comfortable living situation; his children are supportive and involved despite their distance. With his positive personality, talent, and intelligence he attracts new friends. Louis still lives a life, a very old life, which is rich in purpose and meaning. More than ever, he recognizes the significance of this. Louis finds even more meaning in his present life through the comfort in his memories of his wife.

## **Pride and Comfort in Memories: Importance of Reflection and Reminiscence**

Long lives bring into oldest-old age an abundance of memories which can be significant, fun, seemingly insignificant, and of course also difficult and painful. While Louis has rich and satisfying memories from his youth, his military career, his music, and his family, there are other memories which bring both pride and pain.

In our first interview, Louis told his story of caring for his wife during her long and difficult illness. His range of emotions about this was evident. She died when he was 85.

She died in 2005 and I realized in 2004 that I really wasn't finding it possible to give her the degree of care, as a caregiver that she needed. So, I folded up my [music career] after a New Year's Eve job, and took care of her. And I'm so thankful that I did that because when I think about the things that I should have done for her, I can think of lots of things that I didn't really do too well, but I did well at this time when I became a caregiver. And I learned how to take care of all sorts of things. She was at home when she died, and I was with her, and I had been going to the hospital to visit her as often as I could. So we were very close. And I felt like I had really given her the type of care she deserved. And she needed a lot of care there at the end because in addition to her other problems, she had a rectal prolapse, and so that she had to wear a bag . . . a colostomy. And therefore I had to take care of that. Well, you know, this is a type of a job that brings out real love if you feel it. I was just glad to do it. . . . I felt whatever shortcomings I had shown over the years, I had shown some real strengths on this occasion. I came through for her.

During our second interview, Louis shared more about the how this memory has impacted him when he was asked about thoughts that go through his mind when he meets a new day.

Yes, I generally review a few things in my past, you know, about things I wish I had done a little differently . . . things I might've done for my wife who died here eight years ago that I didn't do. And yet, I feel really heartened by the fact that I was her exclusive caregiver for about the last year of her life, and they were rather difficult care giving duties . . . I do feel that I was a really good husband at that time in her life, and at other

times, maybe not quite as good as I should be. So, I sometimes go through some of this.

Louis talked more about praying for his wife, and then in a very transparent moment related his difficulty with self-forgiveness. Louis's narrative highlights the honest truth of relationships; we don't always get it right. Deaths of loved ones in old age are the same as when we are younger; we cannot go back and change our mistakes. Memories of this can be carried as a heavy burden; forgiveness of self can be a challenge.

Later in this same interview, Louis has more to say about memory. He had just related some regret he holds due to his physical restrictions, and was asked if he wonders about how he came to this place of disability.

No, I think it, in my case, I've gotta be honest, I feel a great satisfaction. Over the course of my life and what I achieved, you can sorta forget some regretful things that you did perhaps, mistakes that you made, and I have some things that I'm not proud of at all, but the overall effect, . . . I feel like I've had a wonderful life, and many wonderful opportunities, and had an opportunity to be around some wonderful people. . . . And when I review things that happened in these various parts of my life, I find that I tend to forget or overlook the unpleasant parts and concentrate on the wonderful things that happened. And I think that's just fortunate, you know, that you don't be resentful . . . about things that've happened, you know? It doesn't accomplish anything.

The notion that negative thinking, focusing on unhappiness, past difficulties, or regret doesn't accomplish anything was expressed by other participants. Alma's question, "What does it profit?" holds the same sentiment. Positive memories can bring comfort, pride, and meaning in one's life review.

Walt also made a highly significant statement regarding the value of memories in old age. At the end of a discussion on loss and gain he adds "But see, memories, the thing that can save you from a lot of morbidity, is memories." In his view, memories are preventative treatment for disease, perhaps disease of the heart and mind. He seems to be

saying that when one can no longer do, memories of doing and being are very therapeutic, even life-giving; they are meaning-giving and purpose-giving. Recognizing that he has impacted thousands of professionals causes a smile to cross his face and mine.

With similar sentiment, William also speaks to the role of reflection and memories.

Well, of course I can't generalize, but I would be quite surprised if most people don't spend quite a time in reflection. And you know, we have such large long-term memories and short short-term memories that there's more to reflect on. And of course, there's many opportunities to do that. And at my age, obviously I have less to look forward to. And so, more opportunity to look back and I do not do it on going to bed at night because I want to get right to sleep, which I do. But, my reflection is that, I'm sure it's more through luck than through good planning or decision making, but I would have to say that all my life and my married life with my wife, the decisions that I've made, that we've made, which at the time were very difficult to make, almost always turned out to be the right decisions. And of course, I'm sure a lot of it is luck because if I'd made other decisions, things would've been different and not necessarily as good . . . I have no regrets.

William's insightful observation that those in late life have much to look back on and much less to look forward to, make memories and reminiscence more pronounced and significant. One's temporality, one's place along the lifespan, encourages time spent in reflection. The attitudes, thought patterns, habits of the heart and mind as discussed earlier, will influence the impact memories, reflection, regret or satisfaction of past life has on meaning and purpose in the lives of the oldest-old. In our final interview, William offers another experience of meaning in memories. "You have the memories [of life with his wife]. And so, with time it becomes diffused. So life together and memories after, it's almost a continuity." So deeply meaningful and integrated in his life are his memories of past time with his wife, that his relationship with her is ongoing. Meaning in memories can provide a way of coping as they fuse the past and present together.

William seems to be saying that he is in a meaningful ongoing relationship with his wife, through memories.

The meaningfulness of memories is also evident for Madeline. Her pleasure and pride in her extensive world travel bring her satisfaction with her life and meaning even now. She realizes that she made the most of her retirement and her good health until age 85, when things began changing. Yet her pleasures and even distinction in this are meaningful still. As memories become more extensive over time, it is clear that remembering a life lived fully and to one's satisfaction can provide deep meaning during oldest-old age as abilities fade and options dwindle.

Similarly, Rebekah also related her thoughts regarding the importance of memory in providing meaning for the oldest-old. "So we got to have something to look forward to and I think it's so important to look back over your life." Rebekah's past also involved travel and highly meaningful work. She has decided to be deliberate about bringing back past joyful times.

I think I'll relive my vacations by taking out all of my different movies that I have and all the countries that I have visited, and go to movie night. . . . But, I just came to the conclusion you've got to have joyful moments in your life that outweigh any negativity that would bring unhappiness to you. . . . And these are the things that really come back to my life to make me be very happy. . . . There has to be something in your life that you can look back on and smile, and be happy over.

Understanding, meaning making, and purpose finding during these very late years of life seems to involve remembering former meaningful times. One's meaning and purpose seems to be observed as a whole, an entire life time, not only in the distinct time period of old age.

## Conclusion

Through their narratives, these oldest-old individuals have described experiencing meaning and purpose at this time in their long lives to involve remembering, even treasuring life as a whole, an entirety. Meaning making looks at the entirety of life, not only this “moment” of old age. Reflection and reminiscence provide profound meaning in the present moment, through enabling an ongoing sense of purpose and meaning from earlier times of life. Duggleby et al. (2012), in their study of older adults, chronic illness, and hope, see meaning and purpose as important aspects of hope; hope is seen as a choice. With aging, as through all of life, there is a dynamic aspect in the sources of hope, purpose, and meaning. These oldest-old have consistently expressed hope in their future, often that death will not be slow or difficult. However, hope, purpose, and meaning also have aspects of a focus on the past, and the now. The future is not taken for granted; it may not be theirs. The past is sure, and it has mattered. In the now it is sometimes found in just the ability to get through the day and stay well.

Considering Nouwen’s view of hope (1979) as that which allows us to move from the safety of the known into “unknown and fearful territory” (p. 77), these oldest-old seem to be willing, or as in Rebekah’s case even forced, to move away from active and former ways of achieving meaning and purpose. They have moved instead into a time of needing less from their present. As William stated “You consciously try to have some correspondence between your goals and what’s realizable.” Meaningful engagement with the world is found in what is seen as realizable. As in Heidegger’s notion of solicitude, we are drawn to doable and meaningful possibilities.

None of the participants expressed an expectation that they would live as long as they have; they are in unknown and unprepared-for territory. Known ways of experiencing purpose and meaningful engagements in our western world often involve doing, achieving, goal-setting, goal-reaching, producing, and even more doing. These are hallmarks of meaning and purpose for the young. For most participants, these former ways are no longer within reach. Bodies are setting limits, and perhaps so are cultural expectations. As revealed through their stories, only two participants are working to maintain these former ways of sustaining meaning and purpose, yet they acknowledge that life is changing as their bodies are changing, demanding more care, and capable of less. Other stories testify of those who are content with where their life journey has brought them. They recognize the change, and have entered this previously unknown territory of negotiating for meaning, purpose, and even hope in new and sometimes challenging ways. This negotiating, or find a way through this journey of very old age to a place of new and solicited meaning, may be a hallmark of aging.

Relationships, including a relationship with one's God, have taken on added meaning. The primacy of contributing to these relationships in meaningful ways is told to provide purpose and even hope for these oldest-old participants. Even memories of relationships bring meaning. Being in these relationships, is the larger part.

Anthropologist Sharon Kaufman (as cited in Gubrium and Holstein, 2000), informed by her research, held this view: "The old Americans I studied do not perceive meaning in aging itself; rather, they perceive meaning in being themselves in old age" (p. 4). While it is agreed that the focus is being oneself in old age, the term of negotiating meaning conveys more fully what is heard here. More than just perceiving,

they are finding one's way to meaning while being themselves in old age and it may look very different.

Remembering that lived time is the context through which one creates meaning for one's life and chooses one's own possibilities, these narratives suggest an additional capacity of the oldest-old. These very old people live in a place of faith; faith demonstrated in the value and meaning of one's life, in the entirety of one's life. Therefore, one can have hope and belief that one has mattered, and still matters to others, even in one's final days and with a failing body and mind. Hope and faith in the value and reality of a long, well-lived life has been chosen. Several participants spoke to the meaning of good memories. These are the reminders of the well-lived life and continue to provide meaning and purpose in the present.

It seems this unknown territory of meaning, purpose, and hope in oldest-old age is one of diminishing intensity. And perhaps this triad, so central to Heidegger's being, is not as accomplishment and "now" based as in younger years. It involves negotiating new, less intense ways of being themselves in oldest-old age; meaningful aging is doing, getting, or achieving less in the moment, and being satisfied with that. Perhaps less is needed in the now, because people learn to live within possibilities that exist, and because there has been a long collective lifetime of more.

Aging happens in a larger cultural story. Cultures have age-assigned roles, attitudes, and behaviors (Moody, 2010). Questions remain about whether this group of participants are merely living into these assigned roles, attitudes, and behaviors. Is it that they are learning to live with less because less is available? Are they learning to live with possibilities that remain available to them? Yet this is all a part of the everyday lifeworld



of the oldest-old. What is evident is that these oldest-old persons convey an attitude and perception of meaningful *enough* engagement in their everyday life world in the now.

Meaning and purpose of former years are available to provide meaning in the now; they are held close through memories and remembering. As William stated “you have the memories...and so, with time, it becomes diffused. So life together and memories after, it’s almost a continuity.” Those who can continue to do what they have always done, keep doing it; those who cannot don’t. Yet unless life is lost in a quick moment, a slow trajectory of aging is expected, and all eventually will enter into and dwell in this unknown territory where meaning and purpose look different, but purpose, meaning, and hope, may remain.

## CHAPTER TEN

### FRAMING THE NARRATIVES OF THE OLDEST-OLD:

#### WHAT LISTENING HAS OFFERED

The crucial task of age is balance, a veritable tightrope of balance; keeping just well enough, just brave enough, just gay and interested and starkly honest enough to remain a sentient human being.

On the day when we can boast none of this,

we must be able to wait until the balance is restored. . . .

The old can supply little ardour, just the small amount we manage to create each day by our careful balancing. . . .

*(Florida Scott Maxwell, 1968, p. 36)*

Phenomenological research begins with wonder . . .

*(Max van Manen, 2014, p. 27)*

For me, it did begin with wonder. What is this experience of being very old?

This concluding chapter hopes to convey what has been discovered in this effort to understand the experience of aging and how this understanding can be used to inform our approach to caring for our oldest-old. Just as this listener and writer comes to this research with a context, so does each reader—this has also been discovered. Everyone comes to these narratives and writing with their own context for aging. Whether by distant observation of or caring for the old, by bearing witness to a loved one's journey, or by recognizing that one's self is near or in this time of oldest-old age, reading these narratives touches one's soul. Out of our own context, our own lived experience, from our own past, present, and anticipated future, arises thoughts and feelings about old age as we read the experiences shared by these participants. Unless a life is cut short by accident or acute disease, there is an increasing likelihood many of us will live into very old age. However, we are mortal and one of the gifts we receive from these aged givers is the reminder of possibilities for ourselves as we walk the tightrope of aging. During

the journey to the end of our lives we too will desire to stay balanced on this same tightrope with the recognition of loss, gain, purpose, and meaning in our last years.

Each participant has shared intimately of this present time of life, of being among our oldest-old. They also shared honestly about their past. As it turned out, these individuals collectively have some similarities in their particular present life situation. Although each journey to the present was distinct and unique, no participants are currently in nursing homes, none are experiencing dementia, and none have been abandoned by family or friends, although they have lost many by death. While a few of them have substantial financial resources, most have enough, and none live in poverty. All have loving family involved in their lives; some have many, and others just a few. Most likely the prevailing presence of these positive life circumstances can be attributed to the method of sampling and the referral sources. Those who offered the referrals often knew their friend or family member as an “amazing,” “loving,” “intelligent,” “accomplished,” or otherwise fascinating person, willing to tell their stories and share their lives. And indeed, they have. These individuals offer insight into the possible ways to walk through very old age.

In this chapter I seek to offer insight, interpretation, cultural critique, and applicability of what has been learned through listening to these narratives and seeking understanding of the experience of living in oldest-old age. In taking a “listened to” view of aging, it is hoped that our medical, social, and cultural understandings of this phenomenon of living in very old age, will allow for effective and supportive ways of seeing our oldest-old through this last time of life and unto death.

## **Framing the Experience**

We all are situated in a lifeworld. According to van Manen (1990), phenomenological research “always begins in the lifeworld” (p. 7). As defined earlier, this is the world as we immediately experience it, pre-reflectively. It is the familiar, everyday lifeworld that makes a difference for possibilities in life, for a given way of life (Wrubel, 2009; Agre and Horswill, 1997). Some of this lifeworld is now understood to be unstated, even unrecognized personal, social, historical, cultural and societal influences that limit or expand personal possibilities while journeying through very old age. As previously stated, “Human lives are situated within meaningful activities, relationships, commitments, and involvements that set up both possibilities and constraints for living” (Benner, et al., 2009, p. 436). This notion of “situatedness” reflects an understanding that we are never totally free or totally constrained in choices of how we see, respond, act, and think (Benner, et al., 2009). According to Heidegger, (Dreyfus, 1991), “we are always in the world by way of being in some specific circumstances” (p. 163). Each participant is situated in their unique lifeworld.

### ***The Frame of the Times***

Some specific circumstances that influence possibilities for living are generational. For this group of old people, their life span has created obvious common experiences of living through the Depression during their younger years, a world war and two other wars in their young adult years, and then a vast array of technological and medical advances throughout their lifetime. Antibiotics and vaccines were not available in their childhood. Most experienced deaths of loved ones in their childhood homes which may not have even occurred in this contemporary era of vast medical marvels.

They know hard lives; they know loss; and they know gain. As stated before, they are survivors.

### *The Frame of Cultural Values*

In earlier chapters, we have seen the influence of the revered notion of being independent, without obligation, without being a burden. It has been suggested that in actuality we are always interdependent in our social being-in-the-world. The view offered here is that the American cultural perception, or misperception, of the independence-interdependence-dependence continuum, places a heavy burden on our oldest-old during a time of increasing vulnerability and dependency. These very old participants revealed both gratitude in maintained independence and anguish over lost, or of losing, independence. They reflect the cultural values. As has been heard, becoming dependent is a large part of what is at the very core of their concerns, the very heart of what is meaningful in their current situations. Issues of independency and dependency are reflected back to them in the eyes of their families, social circles, society, and their interactions or lack of interactions that surround them.

Related to this, is the desire to remain an autonomous decision maker. This capacity is also highly valued in our culture, and was heard broadly in the narratives. As aspects of dependence, loss of decision making ability and certainly financial decision making are undesirable for most people and are to be avoided if one is mentally competent. The desire to retain autonomy and decision making authority over one's affairs also impacts choices of our old persons and those people in their lives. It is an ongoing dynamic. Continuous choices regarding abilities to manage finances, see and write checks, and make medical and health decisions are made as a result of bodily and

cognitive changes. One man's relief that his son is managing his finances, is in contrast to a woman's pride in remaining financially independent, and another woman's monthly opportunity to make a charitable donation of her choosing. Each reflects the situatedness of the individual; each reflects meaning in the experience in aging.

### ***The Frame of Ageism***

Ageism is a cluster of "beliefs, attitudes, social institutions, and acts" (Whitbourne, 2008, p. 30) that influence responses, usually in a denigrating manner, to individuals or groups based on chronological age." In general, "Isms" are seen to work detrimentally on the targeted group. Participants in this study, while generally loved and respected, spoke in ways reflecting societal attitudes regarding old age. From the surprising experience of the courteous young woman opening the door for the old man, to the loving family saying "No mama, you can't do that," to the pressure from the pastor and church congregation saying it is time to rest, ageism is present even with loving intentions. These experiences reflected participant age and frailty in the eyes of others. There is the proverbial fine-line between loving and respectful support for the inability of the "I cannots," and placing premature limits on what are still the "I cans" of the very old. It can be shocking, even depressing, and lead to hurt or reluctant resignation. Yet, these are survivors still.

### ***The Frame of Mortality***

Attig (2015) takes a phenomenological approach to the realm of death, dying, and bereavement. His reflections of being "acquainted with the contour and depth, poignancy and power of the challenges of facing personal mortality, living while dying, and living meaningfully in the aftermath of loss" (p. 2), encourages a consideration of mortality as

part of the lifeworld influences of the very old. The oldest-old are both living and facing the end of life; they understand their personal mortality to be close at hand. They have told of the desire to live for this day, for tomorrow may not come. Aging bodies are shouting of their oldness, of their failing abilities and the growing I cannots, with reminders that although fully alive, death is an ever closer reality. Their stories tell of living in the aftermath of many, many losses of self and others. Losses of course, hold a myriad of meanings to the loser, but these participants have chosen to move forward and learn new ways of being. Our humanness, our being in the world has this impulse towards hope, meaning and purpose.

With all of this and more that is unspoken, even unidentified, creating the frame for the experience of old age, thematic analysis has allowed for a rich understanding of themes discovered that thread through the narratives of these oldest-old participants.

### **Themes of Meaning-Making**

Phenomenology is never about generalizing, but is always about the individual experience (van Manen, 1990). Still, thematic analysis has led to the recognition of common experiences brought on by being in the world as a person of very old age. Listening to the narratives of the human lifeworld, or the lived everyday experiences, through the eyes of these 13 oldest-old participants, common themes have been revealed as discussed in the earlier chapters. What has been richly seen as well, is the importance of the individual life context of living through a past, into the present, and as envisioned into the future. Both themes and personal life context have provided the exploratory material for understanding this lived experience of aging. As is every individual, each participant is a fully “conscious subject at the center of a unique world of experience,”

and has an awareness of self as a “singular and irreplaceable human being” (Attig, 2015, p. 3). Through embodied practical and caring interactions with our physical and social surroundings, we discover and make meaning in our lives. This meaning-making of these lived experiences of aging is the personal, the unique, and the provider of possibilities and constraints in living to the end of one’s life.

### ***Living With the Changing “I Can” and “I Cannot”***

Oldest-old age is revealed to be a time when the body speaks loudly of its age and longevity. By extension of Leder’s (1990) notion of the absent body, we can understand the uniqueness of this time of life. Seeing the body as the “most abiding and inescapable presence in our life” (p. 1), he however suggests that in health the body is far from our awareness; we largely live with corporeal absence. It is in illness, Leder proposes, that we become aware of our body. Extending Merleau-Ponty’s thoughts on our embodied way of being, Leder (1990) writes of the corporeal structure of the “I can” (p. 46) which dominates our experience of the body often without our specific intention. He also introduces the notion of “I cannot” (p. 48) to refer to the bodily functions not under our direct cognitive control. I cannot tell my liver how to function, or tell my intestines how to absorb the nutrients from the apple I have chewed and swallowed, nor do I have the knowledge to do so.

These notions of the “I can” and “I cannot” take on deep and rich meaning when used to gain understanding of losses of very old age. As Attig (2015) reminds us “We are grounded in, consciously aware of, and engaged with the world in and through our bodies” (p. 3). The very old body experiences many losses of function and ability. When the I cannots overwhelm the I cans our relationship with the world and even ourselves,



changes. The loudly speaking body pronounces many I cannots that speak to others and ourselves of being old.

The very old body is far from being absent from the awareness of the embodied self. Intentional accommodation and caring, very thought consuming movements or inability to move, demand attention. Our narrators tell of many I cannots. I cannot walk without a cane, walker, or wheelchair. I cannot move about without thinking of every step; I cannot move quickly or step backwards. I cannot see, I cannot hear. I cannot remember that name, or that word, or where that thought was taking me; I cannot do my puzzles. I cannot live without fatigue, or pain. I cannot open jars; I cannot knit, sew, or read. I cannot sleep through the night with this demanding bladder. I cannot be a missionary; I cannot travel. I cannot drive; I cannot go where I want, whenever I want. The list of I cannots seems endless. The list of I cans seems to shrink. A bad fall or a serious illness can add even more and make this all seem insurmountable. An “I cannot continue to live if this is what it will be like,” was also expressed. All of these I cannots have a profound impact on the social way of being, or the “I am,” of these oldest-old.

These I cannots also show up as having an impact on family members of the very old. There were stories of family fear, and community misunderstanding of these I cannots. A fearful family response can lead to prematurely taking over the decisions, being overprotective, or more strongly stated, of stripping the old of their choices, self-confidence, and dignity. While there are certainly times of disability when independent living and autonomous choice are no longer possible, these steps need to be taken carefully. Respectful attempts to communicate, problem solve, and develop a plan for continued safety and dignity can be made together, when possible, with consideration of

the needs, desires, and well-being of the oldest-old. Role-reversals were evident. Some were welcomed by the participant, and some were slowly accepted. These are delicate choices that can both stabilize and upset the careful balancing on the tightrope.

*Learning New Ways of Being: The Changing “I Am” and “I Am Not”*

As these bodily ways of being in the world change for the oldest-old, so do their social ways of being. Relationality refers to this way of being in the world in lived relations with those around us (van Manen, 1990). In these relationships we search for a sense of purpose, meaningfulness, reason to live, and for many an experience with the divine other. In this relational realm of the lived world, we can view the change in the “I am” in relation to independence-interdependence-dependence, the loss of spouses and others, and even the loss of professional or other meaning-giving roles.

Participants reveal the journey through old age as universally holding concerns of independence and dependence. The mounting I cannots signify changes from “I am” independent to “I am not.” The meaning attached to this change was demonstrated through varied expressions from tearful concern to resolution and acceptance. As discussed previously, the notion of independence is highly valued in our society, and is judged to demonstrate strength and worth. Analogous to this, dependence demonstrates weakness, frailty, and I am old. Gawande (2014) sees this veneration of the independent self to have overtaken the veneration of family care-giving for their old.

These symbols of independence and the symbols of dependence escaped no one’s attention. While most were no longer driving, they spoke with gratitude for the independence they had, however minimal. I am independent and living on my own contained the I cans of taking care of myself, feeding myself, and living in my home.

Other changes and challenges of old age that are revealed as meaningful in the narratives are I am a widow(er), I am alone, or I am lonely. Long held notions of identity become I am not; I am not a wife, a professional, or a traveler, or a missionary. The embodied self holds concerns as I am afraid of falling, of losing my eyesight. Or, I am in pain, I am weak, I am slow, I am old. Even the future holds I am and I am not such as I am afraid of how I might die; I am dreading dependence, or not driving, and more.

While many of these I am and I am nots as well as these I can and I cannots may occur at younger ages, what is distinct about these changes and challenges of old age are that there is little hope that things will improve; rather, there is an awareness that things may get more difficult. This is how it will be unto their final days. These things count as losses and they are increasing. The way of socially being in the world is highly impacted by these losses of I am. When one no longer knows anyone the same age, “I am the oldest.” When siblings have all died, “I am the only one left.” And when you no longer know anyone from high school or college, from your wedding, or any of your lunch buddies, the world becomes much smaller. Family relations increase in importance. I am the mother or I am the father matters and has deep meaning, even if now “I am the child.”

Spoken so clearly by Betsy, old age is a time of learning new ways of being and doing. The new ways of being are the I am. The new ways of doing are largely the I can. Of course this includes many I am nots and I cannots of ways that are changed or forever lost.

### ***Time Provides Meaning: Living in Temporal Ways of Being***

There is a difference between the objective knowing that all persons must die and the subjective knowing of “someday soon, I will die” (Attig, 2015). These very old

participants consistently told of this subjective knowing. This knowing provides an accepted and clear understanding of the limits of “my own lifetime.” Seeing these limits in full view, these participants have allowed this boundary to inform their self-understanding about what is meaningful, what matters, where to focus their energies, how to perceive their world, and how to remember their past. For Heidegger “death is the ultimate and most fundamental meaning-giving possibility” (as cited in Johnson, 2000, p. 138). Meaning for the oldest-old, whether reflected on or not, is considerably influenced by the approach of death, the end of life. While in younger years of life mortality can be largely ignored, in old age it cannot be kept at a safe distance.

With the end of life being certain, and time left for life being uncertain, the appreciation of relationships appears among these participants to be primary. Rebekah’s words of “make sure somebody cares” show great wisdom. Not to overuse a well-worn phrase, it does “take a village.” Living in positive relationships provides the love, support, and source of purpose and meaning for being in the world. They are reminders of meaning that can get lost when one is weary and the days are rough, when the walk on the tightrope is treacherous and balance cannot be found.

These oldest-old have lived a very long time, longer than most around them. While they did not expect or even prepare for it, this moment of old age allows a unique perspective on their long life. Through listening for what is meaningful in the now, a slowly evolving awareness revealed that the past now matters more than the future, and even more than the present. In large part, the work is done. Being at the end of life has allowed for the acceptance that now is a time when slow is okay, less may be better, doing matters less and being matters more. Life is viewed as an entirety, not as a now,

and the future is not assumed. For most participants, there is a commitment to each day of life, and a gratitude for it. But listening also revealed very difficult days, where perhaps the work involved in continuing life did not seem worth the effort. The nearness of death is both a subtle and a continuing presence in the midst of living in old age. Being temporally in the world brings this opportunity to affirm one's past and present being in the world, and that one's individual, unique life has mattered.

Recognizing mortality also seems to bring understanding and meaning in the declines of the body. No one told of being surprised at the failing body or mind, at losses of ability, or what disabilities of old age has brought them. Some expected worse. Statements of "What do you expect?" and "You're gonna have some of these things," tell that old age provides the answer to the questions of the "why is this happening?" "Because I am old" is enough of an answer. Temporal being, approaching mortality explains the old body. It is here, because "I am old." And because this is recognized, and because the end is near, the careful walk across the tightrope balancing the ever increasing losses with some appreciated gains, is the journey of old age.

### *Remaining Essentially the Same*

While the increasing variability and uniqueness between people as they live and age longer has been noted, there is another observation that is equally relevant. Given that this is a small sample of 13, there would normally be some caution in saying this with too much conviction. However, Vaillant (2002) made the same observation in his longitudinal Study of Adult Development and aging well, with his three combined cohorts totaling 824 individuals. While growth and change is probable throughout life,

people essentially and basically remain the same. As stated by Vaillant (2012) “people change, but they also stay the same. And the other way around” (p. 13).

Learning new ways of being and doing, changes of the I am and I am not and the I can and I cannot all point to ways of adapting and coping with the challenges that old age has wrought on bodies, minds, abilities, and life circumstances. Betsy has learned patience; Douglas has learned that you cannot win every game. Yet, the narrators in this study offer no evidence of old age “changing” them in great ways. In fact, it was quite the opposite. They became even more like themselves, if that can be understood. None of the narratives described anything that even remotely told of radical life, personality, or temperament changes. While evidence of refinement is noted, no one described significant changes to self or beliefs that have occurred due to living long. What was described, as noted earlier, was a growing commitment to values, worldviews, truths, and life philosophies of sorts that had long been established. Much of this was seen previously in the narratives telling of long established habits of living.

### **Considering Phenomenology, Theory, and Aging**

Hermeneutic phenomenology, as seen by van Manen (1990), is a human science which studies persons. Each person is seen as unique and irreplaceable; each having a unique and personal lived experience with a certain phenomenon. The phenomenon explored here is aging, specifically aging as an oldest-old person. A phenomenologist seeks to express phenomena in a rich, even raw language. Distinct from this approach to understanding are other forms of research that begin with theory. A theorist observes and interprets the world through a previously acquired framework or lens of understanding (van Manen, 2014). Phenomenology resists this approach, seeking instead to examine

the self-given-ness of the experience of interest. It is “more a method of questioning than answering, realizing that insights come to us in that mode of musing, reflective questioning, and being obsessed with sources and meanings of lived meaning” (van Manen, 2014, p. 27). Through this mode, the aim of phenomenology is to question the assumptions, abstractions, and suppositions of theory. It is acknowledged however that most theory starts from human experience with something, from somewhere, and therefore may offer insights into phenomenological questioning. With this in mind, van Manen suggests “rather than using theory as a scaffold for building an interpretive structure, phenomenology uses theory as a foil for examining what it glosses” (2014, p. 66). With this suggestion in mind, and knowing that there are a myriad of aging theories, the “foil” used here will be the view of Successful Aging (Baltes & Baltes, 1990; Baltes & Carstensen, 1996; Rowe & Kahn, 1997; Vaillant, 2002) and Erikson’s (1997) revised psychosocial theory of the life cycle.

### *Successful Aging as a Foil*

As discussed in chapter two, the “successful aging” perspective is having a profound influence on current research on aging. This view acknowledges old age as a time of life which affords productivity and continued psychosocial growth, running counter to previous views that it is a time of frailty and senility (Rowe & Kahn, 1997). While having the measure of successful aging as life satisfaction and a sense of well-being, Moody (2010) stresses that this idea should never be based on the denial of the realities of loss and decline in the final stage of life. A variant on this theme is the notion of “positive aging” as seen by Vaillant (2002), who presents a more moderate position

that requires reflection on how the oldest-old react to the inevitable changes of health and disability that aging can bring. Aging is seen as both joyous and miserable.

This notion of successful aging implies that there is also the opposite—unsuccessful aging. Even the notion of positive aging suggests the corresponding notion of negative aging. If the opposite is not available, then these terms would be meaningless. As has been described in the narratives offered by these oldest-old, their experience is one of a variable course. It is not either/or, it is both. These old people have their good days and their bad days; times of stability and times of decline. Some testify to days of uncertainty, wondering if living is the better choice.

Closer to the reality of the lived experience of oldest-old age seems to be that of parallel movement of losses and gains, negative and positive, with the acknowledgment that change toward decline is inevitable. Does successful aging eventually become unsuccessful aging? Through the balancing of these dual courses, the metaphor of the careful walk across the tightrope is imagined as reflective of this experience. It is the attitude, the inner negotiations, the will-power, the habits of positivity and gratitude, that prevent the “I cannots” and the “I am nots” from leading to depression, sadness, or despair. This is seen to be the work of very old age. While what is interpreted as positive or negative, what holds deep significance or minor significance, what counts as loss or only an inconvenience, and what is seen as gain or not, holds highly personal possibilities and constraints. This is all experienced in an individual and distinct situatedness of a singular lifeworld, giving variable and personal meaning in the unique lived experience of each individual oldest-old person.



While beyond the scope of these few paragraphs, the notion of successful aging seems wholly inadequate to describe this variable journey which holds invariable decline or sudden death on the horizon. Our society and its fixation on notions of productivity and success may well be hindering well-being for our oldest-old. Medicine is relentlessly pushing out the boundaries of longevity and extending the years of good or adequate health. But, absent a sudden death during a time of good health, the inevitable decline will come indeed. We are mortal, and who knows this better than our oldest-old?

### *And the Ninth Stage*

Precisely because the Ninth Stage of the Life Cycle (Erikson, 1997) was developed and written by oldest-old persons, it offers another narrative of oldest-old age, thus another lived experience. To some it may seem to take a negative perspective with its dystonic-syntonic developmental tasks. As Erikson (1997) states “Old age in one’s eighties and nineties brings with it new demands, reevaluations, and daily difficulties. These concerns can only be adequately discussed, and confronted, by designating a new ninth stage to clarify the challenges” (p. 105). As one living it, Joan Erikson can be seen, for practical purposes of this phenomenological study, as being a participant. Does she sound like a successful ager? As a 93 year old author it is hard to argue that she is not; she continues to be productive and successful in her work. Yet, her honest struggle and accompanying despair is apparent. “Despair, which haunts the eighth stage [of development], is a close companion in the ninth because it is almost impossible to know what emergencies and losses of physical ability are imminent” (p. 205-106). It is clear that Erikson is not feeling successful or positive on a daily, or even a moment by moment basis, in her experience of being in her Ninth Stage and oldest-old years.

Accepting the total of Erikson's stages of psychosocial development aside, the deep conviction of the 90-plus year old Erik and Joan Erikson is clear. With informed lived experience they hold that a new stage of development is needed to accurately reflect the tasks of the oldest-old. This is a distinct age. Distinct from the younger-old (ages 65-74) and the old-old (ages 75-84), the oldest-old (85 and older) (Whitbourne, 2008) are challenged by losses of independence and control, personal value and confidence, not to mention the ever aging body with its loudly speaking demands and ever increasing disabilities. Even the most resilient, as many of these participants are, have their bad days, their moments of self-pity, their moments of lost confidence, and their moments of wonder and fear.

#### **How It Fits—Research, Policy, Practice**

“By asking whether phenomenology may do something *with us*, Heidegger hints at the formative value of phenomenology” (van Manen, 2014, p. 69). Here, van Manen hints at the meaning and purpose of phenomenology to form our thinking and our pathos about certain human experiences. In some instances the purpose of phenomenology may be purely to understand the lived experience of a certain phenomenon, or answer philosophical questions of human-being-in-the world. However, through wonder about certain phenomena in the realm of health and wellness the desire to understand related human experiences, the intent goes further. It is to have this gained understanding form our thinking and our pathos as we shape our healthcare practices and learn to care for individuals. Phenomenology speaks to our personal and professional lives (van Manen, 2014, 69). This additional intent is to use our changed selves to make changes in the lives of others. Changed insights and understandings, changed knowledge and

convictions can be used to make a difference in our own being-in-the-world, our interpersonal world, our professional world, and our social world.

This researcher's journey into phenomenology has indeed created personal change. Time spent with these 13 oldest-old participants has changed me. Their honest sharing and intimate stories have changed my understanding of living with losses and gains of oldest-old age. I have worked to be a good steward of their time, of their words, and of their lived-experience of aging. To place their narratives and stories into the world of aging research, policy, and practice is an honor. Offering the reader their voices and my interpretation of the experiences of the oldest-old in our care and in our society is humbling.

### *Fitting Into Research*

As observed by the prolific aging researcher Paul Baltes (Baltes & Mayer, 1999), “There are probably few research areas in which scientists’ and society’s beliefs about what is desirable and essential influence the selection of research questions and interpretation of findings as strongly as in gerontology” (p. 476). The questions we ask, the research methods we choose, and the interpretations we offer come from a perspective, a worldview, a theory, and a history—a way of being in the world. While the research and theory literature on aging is extensive, it was found in the original review of the literature that studies focused exclusively on the oldest-old are rare. No studies were found that sought to explore living with losses and gains at this time of life. This then, is one of a few studies in the United States that focuses on the oldest-old and loss.

This study, with these questions, answers, and interpretations from the narrative data of 13 very old participants, moves us toward an understanding of the experience of growing very old and living with the losses and gains that inevitably come. Singular, unique, possible human experiences are offered. Others may also have them, and some may not. Rather than theoretical and objective data that can be generalized to others, these data offer possibilities experienced by one that may be experienced by others.

The similarities within this study sample suggests two possible directions for future research. One possible path is to follow these same participants with additional interviews to understand the lived experience as a progressive journey of aging over an extended period of time. A second path would be to listen to other population groups, those in nursing homes, those living in poverty, those living with family. Each direction would enable new, unexplored understanding of further possibilities about living with the losses and gains of oldest-old age.

### ***Fitting Into Policy***

Just two weeks before the writing of this chapter, the White House Conference on Aging (The White House, 2015) was held. It was heralded as an important first step in conducting a national dialogue on aging, while being cognizant that this segment of the population is on the verge of a vast increase in numbers. Discussions included such topics as caregiving, financial security, technology and the importance of supporting the aging population in the United States. These types of conversations are essential and vitally necessary for the well-being of our oldest citizens and our society as a whole. Yet, this dialogue needs to bring change on its coattails in order to be felt by those who need it

most—our very old and their families. While the potential and possibilities for more humane policy development is vast, a couple of suggestions are offered.

It is hard to measure the impact of theories and models of aging on policy development and the real lives of our elderly. Yet, following Joan Erikson's lead, and designating a new life stage, phase, or population designation of oldest-old can only be helpful. The importance is not to be bound to chronological age, but specific realities of the lived experience of the very old that are distinct from the younger old. Differences between 65 years of age and 85 or 95 years of age are profoundly significant in establishing policy for how society will support and care for them. How much better for all is it to recognize that in general, those people 85 years of age and older are facing distinct and growing physical, emotional, psychological, and spiritual challenges. Yet, to also recognize that they know positive ways of coping, and that meaning and purpose are found through contributing to the family, friends, and the community around them. This study is an example of research that can inform the understanding of various possibilities, experiences, and meanings of living into old age. Erikson's work (1997), coming from personal experience and passion, is a place to start. Creating a new stage of human development that avoids over generalizing can allow for recognition of increased individuality in our old, and encourages us to know the unique person, and what matters, and is meaningful to them.

A second policy issue, is one of encouraging and supporting both the very old and their families in the ideas of multi-generational living. Much of society, even healthcare providers, would like to turn their backs on the reality of our mortality, yet it is ever present. Denying or hiding realities of aging works against our understanding. The

mystery of life processes are slowly revealed to us as aging is understood and affirmed as a process of human growth (Nouwen & Gaffney, 1997). “The elderly are our prophets, they remind us that what we see so clearly in them is a process in which we all share” (p. 16). We are aging unto mortality. Perhaps this boundary would, as Heidegger suggested, offer meaning-giving possibilities to being-in-the-world (Dreyfus, 1991).

Physician/author Atul Gawande (2014), laments medicine’s and society’s reluctance to honestly approach and examine the experience of aging and dying. As he states it, this collective avoidance has only increased “the harm we inflict on people and denied them the basic comforts they most need” (p. 9). We do not want to sacrifice our aged and our dying by our refusal to recognize our life cycle, mortality, and finitude.

Being as independent as possible without being a burden, is a highly meaningful aspect of old age. Our cultural preference for being independent and unobligated to others, creates a tension when considering family care for the oldest family members. Joan Erikson (1997, p. 118), puts it succinctly:

Every human being is headed for old age, with all its joys and sorrows.

But how can we learn from our elders how to prepare for the end of life, which we all must face alone, if our role models do not live among us?

How, indeed. “Without the presence of old people, we might forget we are even aging” (Nouwen & Gaffney, 1997, p. 16). This separation can deny our human solidarity by making aging a societal problem, instead of our most basic common process. Through methods of phenomenological research and listening to these voices of experience, the very old can become our teachers again as they narrate their stories of the possibilities of becoming old, including the delicate and deliberate acts of balance.

### *Fitting Into Practice*

While medicine and society seem committed to extending lives, it is imperative that we be equally supportive of these lives in ways that promote dignity, well-being, and a life of meaning. Considering the caring roles of nursing and the curing role of medicine, what happens when the sure thing, comes to pass? While independence is the ideal, what is as inevitable is that eventually, in the absence of a quick death, disability and infirmity will advance on the oldest-old and independence will not only be unwise, but even impossible. How will they cope? How will their family cope? When cure is no longer a possibility, caring takes the dominant role. Whether in a care facility or in a family home, or as a friend or loved one, nurses are the providers and teachers of caring. They also are often those who bear witness to the difficult walk of very old age and all it can mean.

Nurses know how to care for the individual, the unique individual with particular needs and even particular possibilities. Nurses realize that people live in the context of their own distinct history, present, and hope and plan for a future. Nurses know how to provide care in ways that speak caring and are perceived as caring by the recipient. To these caring practices, phenomenological research offers insight into the experience of the singular person. Meaning is found in the lived experiences of aging, whether they be losses or gains, positive occurrences or negative. They are always to be seen in the context of something, one's life as a whole, this time of old age, one's family and culture. There is meaning in the nurse's practical involvement as well. We are in relationship as care givers. In addition, as Heidegger suggests, there is meaning in objects encountered in this context as well (Johnson, 2000). There is meaning in the cane, the walker, the

wheelchair, the grab bars in the bathroom, the lift for the toilet, or the commode and in the emergency alert bracelet. The place of comfort in one's home environment is rich with meaning. Recognizing this meaning filled context and aging or illness experience, allows the astute nurse to enter into the caring relationships acknowledging the meaning and the significance of the health or illness context.

The phenomenological approach and what has been revealed in this study also gives attention and respect to stories and narratives. Through listening to stories of the individual we come to know them. We learn what provides meaning, and to consider how this particular individual will negotiate and cope with the challenges with which they are being confronted. Remembering we all age in context of relationships, whether it is in their presence or their absence, we can offer support to ongoing relationships and the memories of others.

These sensitivities can help guide family members in providing personal and satisfying care and support for their loved one. It is quite possible that the family feels they know every idiosyncratic trait of their loved one, especially if they are the spouse or a child. A vitally salient understanding for all involved is the recognition that each family member, friend, and care provider also experiences the aging person from his or her own personal context. This context involves perceptions regarding the aging of themselves and of the other. Encouraging a sensitivity on behalf of the family to how the situation holds meaning to the aging loved one is part of caring. Knowing the aging loved one is paramount. Nurses have opportunity to model and teach this.



### **And in Closing . . .**

While these oldest-old have demonstrated that on most days they can balance on this “veritable tightrope,” we do not want to yoke them with the burden of needing to live and die successfully. In our society obsessed with success, must they also demonstrate success in aging and dying?

And finally, as further medical extension of life expands slowly onward, it is likely that added bodily dysfunction and mental disability will become even more a part of the journey. These efforts, these inquiries, and these wonderings about how the very old live and find meaning in these experiences need to be continued. We need to care about our very old and realize that we too, will most likely inherit their place as the oldest-old. Moltman’s words offer inspiration and clarity for the journey at hand.

True health is the strength to live, the strength to suffer, and the strength to die. Health is not a condition of my body: it is the power of my soul to cope with the varying condition of that body (1983, p. 142).

These participants, each in their own unique way, have demonstrated the power of the human soul, to cope, be grateful, and find meaning in the varying challenges their bodies and mind present to them. Will future generations possess habits of heart and mind to walk “the *veritable* tightrope of balance” without despair? We need to continue to wonder and seek understanding in this increasingly common experience of becoming very old. There is wonder still . . . .

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**APPENDIX A**

**INTERVIEW SCHEDULE – SESSION ONE**

**Demographic Interview**

ID # \_\_\_\_\_

Age: \_\_\_\_\_ Gender : \_\_\_\_\_ Ethnicity: \_\_\_\_\_

Place of Birth: \_\_\_\_\_ Where do you say you grew up: \_\_\_\_\_

Number of Children in Family of Origin: \_\_\_\_\_ Birth Order placement: \_\_\_\_\_

Age of participant when parents died: Mother \_\_\_\_\_ ; Mother's age at death \_\_\_\_\_

Father \_\_\_\_\_ ; Father's age at death \_\_\_\_\_

Marriage history (when married, divorced, widowed, re-married, etc.):

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Did you have children? \_\_\_\_\_

Number of children: \_\_\_\_\_

Do they live near you? \_\_\_\_\_ How often do you see them? \_\_\_\_\_

How would you describe your relationship with them? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

How would you describe your religious or spiritual affiliation or beliefs? \_\_\_\_\_

What is your highest level (grade) of education: \_\_\_\_\_

Occupation(s): \_\_\_\_\_

When Retired?: \_\_\_\_\_ What was it like to retire? \_\_\_\_\_

What did you look forward to? \_\_\_\_\_

What did you dread? \_\_\_\_\_

\_\_\_\_\_

What concerns, if any, do you have about your financial situation? \_\_\_\_\_

\_\_\_\_\_

Would you describe your income and finances as adequate, more than adequate, or less than adequate? \_\_\_\_\_

Living situation:

Alone in own home: \_\_\_\_\_

Live in own home with (circle if appropriate)

Spouse/Partner    Family member    Friend

Live in retirement home: \_\_\_\_\_

Live in home of family member: \_\_\_\_\_ Specify: \_\_\_\_\_

How long have you lived in this current situation? \_\_\_\_\_

Health Status:

How would you rate your health? Is it    Excellent    Good    Fair    Poor (circle response)

Comments: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

How is it compared to others your age?

Excellent    Good    Fair    Poor (circle response)

Comments: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Are you being treated for any health conditions?    Yes                      No    (circle)

If so, what are these conditions?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

## APPENDIX B

### INTERVIEW SCHEDULE – SESSION ONE

#### Life History

Life History Questions: These questions will be shaped by the life story that unfolds and by what is appropriate to the story.

**Introduction:** I would like to spend some time just getting to know you. To understand how life is like for you now, I would like to hear a bit about your life story and about what stands out now in your memory about different times of your life.

- a. Could you tell me briefly about your childhood?  
What was your life like during those years?  
Could you describe a meaningful time in your childhood?  
Could you describe a difficult time in your childhood?
- b. What about your young adult years? From 20 to 40 years old?
- c. Now think about your mid-life years...From 40 to 65 year old? What stands out now in your memory about mid-life?
- d. In your later years of life from 65 until 85 . . .

The following questions may be prompts for any of the above age groups:

- What events stand out as significant or meaningful during this time that may continue to impact your life now?
  - Can you describe a difficult time that occurred during this time that you recall?
  - What new health issues developed during this time that were significant at that time and/or continue to impact your life now?
  - During this time did you give much thought to growing older? What did you anticipate older age would be like?
- e. We are up to the present, the time period since age 85.  
What do you continue to look forward to?  
What would you still like to accomplish?  
What do you dread or worry about?  
What are your thoughts about the end of life?  
When in your life have significant loved ones died (eg. parents, spouses, or children)?  
What were the circumstances?

f. I would like to ask about your current health.

Can you tell me about any health issues that have had a significant impact on this time of life?

What other health issues do you have?

What medications, if any, are you currently taking?

How would you rate your health compared to others you know that are about your age?

How would you describe your life to others?



## APPENDIX C

### INTERVIEW SCHEDULE – SESSION 2

#### Typical Day

In order to understand what your typical day is like, I would like to ask what yesterday was like for you, beginning with yesterday morning. Is that ok with you?

Morning: Think about yesterday morning....

- Please tell me about when you woke up and what your morning was like . . .

Possible prompts if necessary to stimulate recall:

- What is your morning routine?
- When did you first wake up? And when did you get out of bed?
- How well did you sleep?
- Do you remember any first thoughts?
- How easy is it to get out of bed?
- What do you think about when you meet a new day?

Mid-day: Think about your mid-day and afternoon....

- What was your mid-day like?

Possible prompts:

- What errands or appointments did you have, if any?
- Tell me about your “to do” list?
- What did you eat for lunch? Where did you eat?
- When did you take a nap or rest? Watch TV? Work on projects or hobbies?
- How was this different from your typical day?

Evening: Think about yesterday evening...

- What was last night like for you?

Possible prompts:

- Who, if anyone, did you see or talk to yesterday?
- What did you have for dinner? Where did you eat it?
- What is your night or bedtime routine?
- How did you sleep last night?

Potential final questions to understand what daily life is like for the Participant:

- Did this reflect your typical day?
- Is there anything else you would like to add that would help me understand your day, what makes it pleasant and what makes it difficult?
- Was there anything that made yesterday untypical or special?
- How is your weekend different?

Thank you for your time. I would like to return for our second conversation within the next week. Is that acceptable to you? When would be a good day and time? Where would you like me to visit you?

## APPENDIX D

### INTERVIEW SCHEDULE – SESSIONS 1, 2, & 3

#### Experiences of Aging

**Week 1:** I have learned a little about your life story. Now I would like to talk about and explore some specific instances or experiences that you've recently had that will help me understand what living at your age now is like for you.

**Week 2:** I have learned a little about your daily life and routine, now I would like to return to our conversation about specific instances or experiences that will also help me understand what living right now is like for you.

**Week 3:** I would like to open our last time together with the chance for me to hear any more specific experiences you have had that will help me understand your life. (Focused questions)

#### Introductory questions:

*-What can you tell me about what it is like for you to be \_\_\_\_? (insert interviewee's age)*

*-How is it different than what you expected?*

*-What changes have you experienced as you have grown older?*

#### Focused questions:

1. (Good/rewarding and Bad/discouraging)

*-Can you tell me a particular and recent instance when it has felt good or rewarding to be this age?*

*-Can you now recall a recent instance that it has felt bad or discouraging to be this age?*

2. (Losses and Gains)

*-Can you tell me a recent time that stands out in your mind because it shows what it was like to have lost something important to you (a dream, an ability, a body function, a beloved person) at this time of your life?*

*- Which losses have been the most difficult? Have any been surprising?*

*-Can you tell me a recent time that stands out in your mind because it shows what it was like to have gained something positive (an experience, a discovery, an item, a skill at this time of your life)?*

*-Which gains have been the most positive? Have any been surprising?*

3. (Satisfaction/happiness and Disappointment/sadness)

*-What has brought you satisfaction or happiness at this time of life?*

*-Can you recall a specific instance or time that is an example of that?*

*-What has brought you disappointment or sadness at this time of life?*

*- Can you recall a specific instance or time that is an example of that?*

4. (Coping)

- Tell me how you have coped with these changes? What has worked best for you?*
- How has your life prepared you for this time?*

5. (Purpose and Meaning)

- What gives you purpose and meaning at this time of your life?*
- If I gave you a camera and asked you to take a photograph of something in your home that symbolized this time of life for you, what would it be?*
- Can you tell me why?*

Example of prompts to keep the participant close to the actual instance/experience & to explore the experience to the fullest:

- What was that like for you?
- Can you tell me more about that?
- Did you tell anyone about that?
- Can you give an example?
- How did that feel to you?

**Interview 3 Summary Questions:**

- What more would you like to tell me that would help me understand your experiences of loss and gain, disappointment and surprise at this time of life?*
- What would you like others to know about this experience of living a long life?*

## APPENDIX E

### INFORMED CONSENT

**Title:** The Lived Experience of Aging: Listening to the Oldest-Old

**PRINCIPAL**

**INVESTIGATOR:**

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**1. WHY IS THIS STUDY BEING DONE?**

The purpose of the study is to listen to persons in the oldest-old years of life, in order to gain understanding of the aging experience and its meaning from those growing very, very old. An additional purpose is to describe and interpret the lived experiences of losses and gains of advanced old age. You are invited to participate in this research study because you are known to the researcher as someone over 85 years of age and able to describe daily experiences related to aging.

**2. HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?**

Approximately 12 individuals will participate in this study.

**3. HOW LONG WILL THE STUDY GO ON?**

Your participation in this study may last up to two months and will involve three separate interviews spaced approximately 3 to 4 weeks apart. Each interview will take approximately 60 to 90 minutes of your time.

**4. HOW WILL I BE INVOLVED?**

You can participate in this study if you are 85 years of age or older, speak and understand English, live in a community setting, and are able to inform the researcher of your daily experiences in a narrative interview.

You cannot participate in this study if you do not think that you can share experiences of your daily life and some of your life history, or are uncomfortable with being audio recorded.

Participation in this study involves the following:

- Arranging a location for the interviews with the researcher at a time and place that is private, safe, and comfortable for you to talk
- Having each interview audio recorded and later transcribed into narrative written text

- Participating in three separate interviews that will last approximately 60 to 90 minutes each, spaced 3 to 4 weeks apart; or additional but shorter interviews to allow completion of each of the four interview guides
- Responding to four different interview guides with questions regarding your life history, and your current life experiences
- Responding to the interview questions in the Demographic Interview, the Life History Interview, the Typical Day interview, and the Experiences of Aging Interview.
- For example, I will ask “Can you tell me a recent time that stands out in your mind because it shows what it was like to have lost something important to you at this time of life?”

#### **5. WHAT ARE THE REASONABLY FORSEEABLE RISKS OR DISCOMFORTS I MIGHT HAVE?**

There are minimal risks to you for participating in this study. Sometimes individuals may feel uncomfortable being asked questions about their life experiences. Some questions may result in difficult or confusing memories, thoughts, or feelings. Appropriate community resources will be offered to assist you in coping with these situations should they arise.

If at any time during the interview you find that you do not wish to participate you may refuse to continue. If you do not wish to answer a specific question you may decline.

#### **6. WILL THERE BE ANY BENEFIT TO ME OR OTHERS?**

Although you will not benefit personally from this study, your participation has the potential to help nurses and other healthcare professionals know how to better serve people in your special circumstances. In addition, the information learned from this study will benefit others in the future.

#### **7. WHAT ARE MY RIGHTS AS A SUBJECT?**

Participation in this study is entirely voluntary. Your decision whether or not to participate or withdraw at any time from the study will not affect your ongoing relationship to the researcher or anyone else.

#### **8. WHAT HAPPENS IF I WANT TO STOP TAKING PART IN THIS STUDY?**

You are free to withdraw from this study at any time. If you decide to withdraw from this study you should notify the researcher team immediately. The researcher may also end your participation in this study if your safety and welfare are at risk.

#### **9. WHAT OTHER CHOICES DO I HAVE?**

The only alternative to participation in this study is not to participate.

## **10. HOW WILL INFORMATION ABOUT ME BE KEPT CONFIDENTIAL?**

Efforts will be made to keep your personal information confidential. You will be assigned a unique research number. All of your identifying information including the consent forms will be kept separate from the audio recordings, field notes, and transcriptions and locked in a secure locked file. Recordings will be transcribed using your unique research number and with no names or other identifying information included. After each transcription is completed, the transcript will be reviewed for completeness and to ensure that any identifying information is removed.

All electronic transcriptions will be kept in a separate electronic file that is password protected. Hard copies of the data including transcribed interviews, field notes, written observations and reflections, will be kept in a separate locked file and identified only by research number. All files will be kept in a secure research space.

We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. You will not be identified by name in any publications describing the results of this study. Upon completion of the study the audio recordings will be deleted.

## **11. WHAT COSTS ARE INVOLVED?**

There is no cost to you for participating in this study.

## **12. WILL I BE PAID TO PARTICIPATE IN THIS STUDY?**

You will not be paid to participate in this research study.

## **13. WILL THE STUDY STAFF RECEIVE PAYMENT?**

No payment is being received by the study staff.

## **14. WHO DO I CALL IF I HAVE QUESTIONS?**

Call 909-558-4647 or e-mail [patientrelations@llu.edu](mailto:patientrelations@llu.edu) for information and assistance with complaints or concerns about your rights in this study.

## **15. SUBJECT'S STATEMENT OF CONSENT**

- I have read the contents of the consent form and have listened to the verbal explanation given by the investigator.
- My questions concerning this study have been answered to my satisfaction.
- Signing this consent document does not waive my rights nor does it release the investigators, institution or sponsors from their responsibilities.
- I hereby give voluntary consent to participate in this study.

I understand I will be given a copy of this consent form after signing it.

\_\_\_\_\_  
Signature of Subject

\_\_\_\_\_  
Printed Name of Subject

\_\_\_\_\_  
Date

**18. INVESTIGATOR'S STATEMENT**

I have reviewed the contents of this consent form with the person signing above. I have explained potential risks and benefits of the study.

\_\_\_\_\_  
Signature of Investigator

\_\_\_\_\_  
Printed Name of Investigator

\_\_\_\_\_  
Date