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End-of-Life Caregiving and Meaning Reconstruction : Experiences of Adult Children Providing Home-Based End-of-Life Care for a Parent

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END-OF-LIFE CAREGIVING AND MEANING RECONSTRUCTION:

EXPERIENCES OF ADULT CHILDREN PROVIDING HOME-BASED END-OF-

LIFE CARE FOR A PARENT

A DISSERTATION

Submitted to the Faculty of

Montclair State University in partial fulfillment

of the requirements

for the degree of Doctor of Philosophy

by

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DISSERTATION APPROVAL

We hereby approve the Dissertation

END-OF-LIFE CAREGIVING AND MEANING RECONSTRUCTION:

EXPERIENCES OF ADULT CHILDREN PROVIDING HOME-BASED END-OF-

LIFE CARE FOR A PARENT

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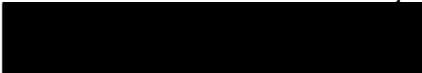Department of Counseling &
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ABSTRACT

END-OF-LIFE CAREGIVING AND MEANING RECONSTRUCTION:

EXPERIENCES OF ADULT CHILDREN PROVIDING HOME-BASED END-OF-

LIFE CARE FOR A PARENT

by Kim Marie Tassinari

Caring for a terminally ill parent is a tremendous responsibility and a job for which most adult children are unprepared, especially if care is provided in the home. As the *silver tsunami* or the graying of America, fast approaches, many families will be faced with the tremendous responsibility of caring for a parent. Few researchers, however, have examined the experiences of adult children who have provided end-of-life (EOL) care in the home. Moreover, there is a paucity of research from the counseling profession that explores how individuals construct meaning after EOL caregiving experiences with their parents or how they make meaning after a loss. The purpose of this study, therefore, was to explore the experiences of and meanings made, if any, by adult children who have provided home-based end-of-life care for a terminally ill parent. In this qualitative interview study, I employed two rounds of interviews and one focus group interview to explore the experiences of adult children who had provided care to their parents in either their home or their parent's home during the end stages of life. Data analysis revealed three overarching themes: *unchartered territory*, *transitions of uncertainty*, and *multiplicity of meaning*. Participants in this study assumed the role as primary caregiver, each encountering difficult journeys along the way. In fact, all participants reported high levels of distress, uncertainty, and emphasized the importance of having supports in

place. Despite the difficulties encountered, participants also reported that caregiving was

an unexpected gift. Findings suggest that counselor educators should prepare for the rise

in family caregiving by bringing awareness to the counseling profession on the needs of

future caregivers and advocate for coursework that educates counselors-in-training on

caregiving, grief, and loss issues. Implications for counseling practices and directions for

future research are further discussed in chapter five.

ACKNOWLEDGEMENTS

DEDICATION

I dedicate this work to my cherished parents, Virginia and Carl, who are no longer with us. They taught me the value of hard work, perseverance, and grit and worked extremely hard to provide our family with a stable life and a platform so that we could do better and achieve greater things. I know they would be "beaming with pride" – as my mother would always say. I am so appreciative and forever grateful to my parents for their love, support, encouragement, and devotedness to our family throughout the years. Cheers to you, Mom and Dad!

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CHAPTER ONE

Introduction

Providing home-based end-of-life care for a parent may be a profound experience. For some adult children caregivers, the experience can be extremely daunting, leaving loved ones emotionally and physically exhausted and in search of answers to existential questions during both the caregiving experience and then during bereavement. For others, it can be profoundly rewarding and meaningful. As the population in the United States ages, caregiving will also increase and most individuals are unprepared for such an endeavor, especially adult children who assume the role of the primary caregiver for a terminally ill parent (Higginson, Sarmento, Calanzani, Benalia, & Gomes, 2013; Talley & Crews, 2007).

Researchers have indicated that most adults do not expect to undertake full-time caregiving responsibilities and are often unprepared and lack the skills and support necessary to care for a terminally ill loved one (Aoun, Kristjanson, Currow, & Hudson, 2005). Furthermore, researchers have found that the emotional depths experienced by caregivers who provide home-based care are complex (Grbich, Parker, & Maddocks, 2001). Moreover, bereavement adjustment, or the ability of an individual to return to a new state of being after a loss, may be compromised for those who have had difficulty finding meaning after a loss (Neimeyer, 2001). Gillies and Neimeyer (2006) reported that bereaved individuals who can make sense of or find meaning after a loss might

experience an adaptive outcome of grief or positive adaptation to bereavement. Few researchers, however, have qualitatively investigated the experiences of adult children who have provided home-based end-of-life caregiving (cared for a terminally ill parent in a home setting) and the meaning making structures they used, or how those adults made meaning in bereavement. For this study, the terms "adult children home-based caregivers" or "adult children" refer to individuals who have assumed the role as primary caregiver and are or were responsible for providing emotional and physical support to a terminally ill parent (Stajduhar, 2013).

Background

There are approximately 44 million caregivers (19 % of the population) in the United States currently providing care to an adult age 50 and older (National Alliance for Caregiving [NAC], 2009). Researchers (McMillan, 2005; NAC, 2015) have noted that caregivers between the ages of 45-55 have reported higher levels of caregiver burden when compared to caregivers from other age groups. Of note, most adult caregivers within the 45-55 age group are working women who in addition to caring for a parent, are caring for their own nuclear families (Bedini & Gladwell, 2014; Hammer & Neal, 2008; Penrod, Hupcey, Shipley, Loeb, & Baney, 2014; Pope, 2013; Roberto & Jarrott, 2008). Additionally, the physical and emotional impact, high levels of stress and burden, and lack of self-care often lead to more health related issues for this population of caregivers (Pinquart & Sörensen, 2006). As the older adult population increases, these issues will become increasingly important to the mental health professionals who work with the adult population.

End-of-Life Care

Many adults will provide end-of-life (EOL) care for a parent at some point in their

lives (Roberto & Jarrott, 2008). While there is a fair amount of research on caregiving,

there is a dearth of research specifically on home-based end-of-life care. EOL caregiving

involves all tasks associated with providing care to those with an advanced, progressive,

incurable illness to help them live as well as possible until the individual dies (Stajduhar,

Funk, Toye, Grande Aoun, & Todd, 2010). EOL is a critical period during the caregiving

trajectory due to the emotional intensity of watching a loved one decline. Although most

health care professionals provide caregivers and their families with instructions and

information on the expectations of dealing with illness, the experience of caring for a

dying parent is emotionally and physically challenging (Blum & Sherman, 2010; Phillip

& Reed, 2010).

Illness trajectory, or the course of illness, most often determines the course of

caregiving (Blum & Sherman, 2010; Northfield & Nebauer, 2010). Chronic conditions

such as cancer, diabetes, cardiovascular disease, arthritis, hypertension, osteoporosis, and

dementia are not uncommon in older adults (Roberto & Jarrott, 2008; Talley & Crews,

2007). Other physical ailments such as injuries due to falls, disabilities, and impairments

due to illness and frailty, typically referred to as geriatric syndromes, are also common in

older adulthood (Stephens & Franks, 2009). Various conditions will require a certain

protocol of care that will ultimately impact the caregiving experience. EOL caregiving

requires primary caregivers to make important decisions regarding treatment, including

whether or not to continue with treatment, and transition to palliative or comfort care

(Harrington, Mitchell, Jones, Swetenham, & Currow, 2012). When a cure is no longer an

option, many families will face the difficult decision of changing the course of treatment

from curative to palliative care (Ward-Griffin, McWilliam, & Oudshoorn, 2012). As

impending death approaches during these end stages, however, adult children caregivers

will often face a deep sense of loss as they watch their parent's health decline and as

parents lose function (Gill & Morgan, 2012). Anticipatory grief, defined by Rando

(1986) as "a phenomenon that involves mourning, coping, interaction, planning, and

psychosocial reorganization that are stimulated as a result of impending loss of a loved

one" (p. 24), also tends to escalate (Holley & Mast, 2009; Waldrop, 2007). Anticipatory

grief is a key concept in fully understanding the emotional depths experienced by primary

caregivers. While there has been much focus in the literature on the needs of the care

recipient, primary caregivers also require care and support to facilitate end-of-life care.

Home-based EOL Caregiving

Home-based caregiving, for my study defined as care that one provides in a home

setting (i.e., the caregiver's home or the parent's home), has been increasing over the last

decade resulting in an increasing number of family caregivers (Williams, 2002). Though

home-based care is the preference for many terminally ill individuals (Aoun et al., 2005;

Stadjuhar et al., 2010), many families lack requisite skills and are unprepared to facilate

care in the home (Gomes, Calanzani, Gysels, Hall, & Higginson, 2013; Gomes,

Calanzani, & Higginson, 2012; Higginson & Sen-Gupta, 2000; Zarit & Reamy, 2013).

Previous research has informed us that providing end-of-life care for a loved one can feel

overwhelming and stressful, and has resulted in chronic illness for caregivers themselves

(Schulz, et al., 2003) and, in extreme cases, has been correlated with increased risks of mortality (Pinquart & Sörensen, 2006). However, there has been little to no research to help professional counselors and other mental health and health care professionals understand how home-based care may impact caregivers. In this qualitative study, I investigated the experiences of home-based caregiviers with the goal of helping professional counselors, other mental health practitioners, and health care providers understand further the complexies of caring for a dying parent in the home.

Meaning Reconstruction in Bereavement

Several researchers (e.g., Brandstätter et al., 2014; Gillies & Neimeyer, 2006; Neimeyer, 2001) have purported the importance of meaning reconstruction in bereavement. While adult children may expect their parents to die, such a loss is significant and can often result in existential questioning (Nadeau, 1998) and a search for meaning (Davis, Wortman, Lehman, & Silver, 2000; Neimeyer, 2001). Contemporary grief theorists (e.g., Brandstätter et al., 2014; Gillies & Neimeyer, 2006; Neimeyer, 2001) have maintained the importance of meaning-making after a loss as it helps to facilitate a positive adaptation in bereavement. In fact, research indicates that finding a sense of meaning and purpose after experiencing a loss may be healing (Neimeyer, 2001) and that therapeutic approaches such as narrative work have been found to support bereaved individuals who struggle with loss (Neimeyer, 2001).

Viktor Frankl (1959) developed the theory of logotherapy (logos derived from the Greek word "meaning") and postulated that finding meaning and purpose in life is paramount. Frankl (1959), through his horrific experiences as a Holocaust survivor

during World War II, found that people are capable of translating tragedy into triumph

through the process of finding meaning and a search for purpose in life. Irvin Yalom

(1980) also maintained the importance of finding meaning in our experiences and

emphasized meaninglessness as one of the four ultimate concerns for all human beings.

Theorists have supported the importance of active engagement and immersing oneself in

a purposeful search for meaning (Davis & Nolen-Hoeksema, 2001; Gillies & Neimeyer,

2006; Yalom, 1980). However, the meaning structures (i.e., how an individual constructs

meaning; analogous to Janoff-Bulman's [1992] "assumptive worlds" or Thomson and

Janigian's [1998] "life schemes") of bereaved individuals can become impaired after loss.

Naturally, bereaved individuals will strive for comprehensibility in death (Nadeau, 1998;

Neimeyer, 2001; Neimeyer, Klass, & Dennis, 2014). Previous authors (Brandstätter et

al., 2014; Bray, 2013; Neimeyer, 2001) have underscored the importance of meaning

reconstruction (i.e., constructing meaning through three processes: sense-making, benefit-

finding and identity reconstruction) in bereavement as a way to facilitate the meaning-

making process in loss. I discuss meaning reconstruction further in chapter two of this

document.

     Lack of meaning in bereavement. Meaning reconstruction has been found to

play an important role in the first two years of bereavement (Gillies & Neimeyer, 2006;

Holland, Currier, & Neimeyer, 2006). Finding meaning in loss, however, is not always

attainable. For example, a loss that is sudden or traumatic (e.g., suicide, homicide, or an

accident) may be difficult for survivors to make sense of or find meaning in (Currier,

Holland, & Neimeyer, 2006; Park & Ai, 2006). Furthermore, researchers have found a

connection between complicated grief and a protracted search for understanding over time (Bonanno, 2004; Davis, Nolen-Hoeksema, & Larsen, 1998). In other words, when an individual suffers a difficult loss and one that is incomprehensible, they are more likely to suffer from complicated grief (Holland et al., 2006; Thomson & Janigian, 1988). Any loss in itself presents challenges and disrupts one's emotional world (Nadeau, 1998) and the death of a family member, especially a parent, is a significant loss. After the loss of a parent, adult children will often reevaluate many aspects of their lives, particularly their attitudes regarding themselves, their families, and how to move forward in life without their parent (Neimeyer, Prigerson, & Davies, 2002). The inability to make sense of or find meaning in a loss can result in an increased level of distress in post-loss adjustment (Gillies & Neimeyer, 2006; Holland et al., 2006).

Statement of Problem

The population of older adults in the United States has increased and will continue to rise, which has also resulted in a rise in family caregiving (NAC, 2009; World Health Organization [WHO], 2012). Moreover, home-based caregiving is increasing, putting family caregivers at risk of assuming a role for which many are often unprepared (Higginson & Sen-Gupta, 2000; Zarit & Reamy, 2013). While home-based care may be the preference for most dying individuals (Gomes et al., 2012, Gomes, Calanzani, Gysels, & Hall, 2013), family caregivers lack preparedness (Aoun et al., 2005) and, therefore, encounter a host of issues as they provide home-based care (Phillips & Reed, 2010). Many of the tasks that are involved in providing care in the home, such as physical and emotional support, can be burdensome (Aoun et al., 2005). In addition to

managing care for their parent, most adult caregivers are middle-aged and are often

caring for their immediate families (McMillan, 2005; NAC, 2009). As a result, middle-

aged caregivers experience higher levels of stress and burden compared to the typical

middle-aged adult (Roberto & Jarrott, 2008; Waldrop & Meeker, 2011). Caregiver

burden is impactful, resulting in an array of physical and emotional symptoms (Gaugler,

Eppinger, King, Sandberg, & Regine, 2013; Gillies & Neimeyer, 2006; Holley & Mast,

2009; Lin, Chen, & Li, 2013; Waldrop, 2007). Moreover, caring for a dying parent in the

home can add to already high stress levels (Higginson et al., 2013; Stajduar, 2013).

En d-of-life caregiving is the final transition in the end-stages of providing care.

Primary caregivers and their families tend to share a great deal of angst and pain as they

watch a loved one lose function while entering the dying phase. Emotions tend to

intensify during the end stages. Such heightened emotions often cause family caregivers

to experience high levels of stress and anxiety, depression (Pinquart & Sörensen, 2006;

Redinbaugh, Baum, Tarbell, & Arnold, 2003; Stajduhar, 2013), and anticipatory grief and

sadness (McMillan, 2005; Waldrop, 2007; Waldrop, Kramer, Skretny, Milch, & Finn,

2005). Many adult children who have provided care for a dying parent will continue to

experience grief and loss after the death of their parent, well into bereavement. In

addition to grieving for the lost loved one, for some individuals, their grief may be

associated with the loss of their role as a caregiver (Lin et al., 2013). Furthermore,

caregivers who have had poor physical and psychological health while providing care for

a loved one tend to be at risk for more depressive symptoms after their loved one's death

(Phillip & Reed, 2010). Moreover, caregiving can impact the physical and emotional

well-being of caregivers, causing serious health issues (Pinquart & Sörensen, 2006). For

this reason, it is advantageous for the counseling profession to explore further the

complexities that surround end-of life caregiving and how strength based approaches

such as meaning reconstruction can benefit caregivers.

Adult children who have attended to the care of a terminally ill parent will often

reevaluate their lives after a loss and begin an active search for meaning (Nadeau, 1998;

Neimeyer, 2001). Individuals who have difficulty in adapting to loss may experience a

crisis in meaning (Neimeyer & Anderson, 2002). Also, researchers have noted that a

majority of caregivers continue to experience chronic depression and poor psychological

health (Hudson & Payne, 2011; Schulz, Hebert, & Boerner, 2008). It is clear that

providing end-of-life care for a terminally ill parent is a critical time during the

caregiving trajectory, which can have lasting effects for the caregiver. There is, however,

a lack of professional literature and research from the counseling profession that explores

home-based end-of-life caregiving, particularly, the complexities that surround caring for

a terminally ill parent, and how an adult child caregiver constructs meaning after a loss,

namely, meaning reconstruction.

Purpose of the Study and Research Questions

The purpose of this study was to explore how adult children experience the home-

based end of life care of a parent and how they attribute meaning, if at all, after the loss

of a parent. I employed a basic qualitative study that examined how caregivers

experience end-of-life care and meaning making. It was my intention to bring to light the

importance of this topic, to give voice to caregivers who have provided care for a dying

parent, and to provide information that can inform the practice of professional counselors

working with adult caregivers and adults who may become caregivers.

Research Questions

Following are the two research questions that guided this study:

1) What was the experience of adult children who assumed the role as primary

    caregiver during home-based end-of-life caregiving of their parent?

2) How do adult children caregivers attribute meaning after post intensive

    caregiving of a parent?

Significance of Study

While much has been written about caregiving in general, some of the research

that is often cited is now dated, and there are few studies that address the impact on

caregivers as they provide end-of-life care, particularly home-based care for a parent.

Moreover, much of the published research on this topic is in the fields of nursing,

gerontology, and psychology with an orientation toward pathology or problems

encountered in the caregiving experience. There is a paucity of research examining the

needs of adults who serve as caregivers for a parent and their adjustment to bereavement

from developmental and strength-based counseling theories such as the meaning

reconstruction theory of bereavement (Neimeyer, 2001) and the potential benefits of

meaning making during the bereavement process. One goal of this study was to

contribute to this gap in counseling research literature.

Although most adult children caregivers fare well while providing care for and

then losing a dying parent, some individuals experience a deep sense of loss (Gill &

Morgan, 2012), prolonged grief (Parkes & Prigerson, 2010), and loss of meaning or existential angst (Koop & Strang, 2003; Ling et al., 2013; Neimeyer & Anderson, 2002). Navigating through these difficulties may require the support of counselors. It is important for counselors who work with older adults and those caring for family members to understand the critical nature of end-of-life caregiving and the experiences of caregivers.

As baby boomers (individuals born between 1946-1964, a cohort that comprises 25% of the population; Colby & Ortman, 2014) cross into older adulthood, more families will find themselves having to care for a loved one, including a parent. The rise in family caregiving will result in more stressed caregivers seeking support from counselors. The counseling profession, therefore, must prepare future counselors to work with distressed caregivers and their families on issues related to caregiving and grief, loss and bereavement.

Only recently have grief theorists reexamined bereavement from a developmental perspective and have found that mourning and meaning are interlaced (Neimeyer, 2001; 2006). When human beings experience a tremendous loss such as the loss of a parent, a seismic event in one's life, individuals will naturally seek to comprehend the incomprehensibleness of loss (Neimeyer, 2001; Neimeyer et al., 2014). This study was designed to utilize a current model of bereavement to explore meaning-making after EOL caregiving experiences with a parent and expand upon the current professional literature of meaning-making in loss.

Conceptual Framework

The theoretical framework on which I based my research study is the meaning reconstruction theory of bereavement (Neimeyer, 2001). Through the lens of meaning reconstruction theory of bereavement, theorists view people as active meaning-makers, especially in post-loss adjustment (Frankl, 1959; Gillies & Neimeyer, 2006; Janoff-Bulman, 1992; Nadeau, 1998; Neimeyer, 1998). The grieving process is uniquely experienced, which can present challenges to the bereaved especially when grief involves a significant loss (e.g., the loss of a parent). For the most part, many bereaved individuals cope well and are resilient (Bonanno, 2004). Neimeyer (2001), however, noted that few researchers have been able to discern the emotional phases in bereavement adjustment.

Neimeyer (2001) argued that conventional models of grief indirectly disempower bereaved individuals by implying that to grieve one must passively negotiate a sequence of psychological transitions catapulted by external events (e.g., caregiving), negating the importance of the affective aspects of adaption. Similarly, Neimeyer, Klass, and Dennis (2014) purported that society tends to police bereavement and suggests how one should properly grieve, implying that the grieving process is an individual matter. In fact, some researchers (e.g., Nadeau, 1998; Neimeyer, 2001; Neimeyer et al., 2014) have rejected the idea that grief is processed individually, and argue that individuals experience the grieving process collectively within a social and relational context. Neimeyer (2001), through the meaning reconstruction theory of bereavement, offered a model that empowers the bereaved individual to grieve collectively in a social and relational context.

Meaning reconstruction occurs in three contexts: sense making, benefit-finding, and identity reconstruction (Neimeyer, 2001).

Sense Making

Losing a parent can feel like a seismic event for the adult child and may present challenges depending on the nature of the loss. When EOL adult children caregivers and family members are about to lose their parent, it can feel like a crisis, and after a loss surviving family members are faced with existential issues surrounding the loss (Nadeau, 1998; Neimeyer & Sands, 2011). As a result, family members often find themselves in a state of disequilibrium. This imbalance drives the meaning making process where loved ones try to make sense of their loss (Nadeau, 1998). Researchers have found that people experience the most difficult losses when the grieving individual is unable to make sense of loss (Nadeau, 1998; Neimeyer, 2001; Thomson & Janigian, 1988). Furthermore, low levels of meaning-making, that is, the inability to make sense of or derive benefit (e.g., silver lining) from a loss, have been associated with the greatest level of complicated grief (Holland et al., 2006).

Benefit Finding

While it may seem paradoxical to find a personal benefit or a silver lining (e.g., renewed relationships, enhanced empathy, or a sense of purpose) in loss, such benefits can lead to significant changes and improve bereavement adjustment (Davis et al., 1998; Thomson, 2012). Also of note is that people do not typically recognize benefits immediately after a loss (Nadeau, 1998). The process of grieving is painful and difficult, especially after a significant loss. The ability to find benefit, therefore, may occur

months or possibly a year or more after a loss (Gillies & Neimeyer, 2006). For this

reason, in my research study, I explored adult children caregiving and meaning making

experiences one to three years after a loss.

Identity Change

Meaning reconstruction theorists acknowledge that the grieving process is

intimate and personal (Neimeyer, 2001). One's beliefs, practical skills, resources, and

relational dispositions shape the grieving process and define our very sense of self and

who we are as human beings in a social context (Thompson, 2012). While people may

expect to experience pain and anguish in loss, it is not entirely negative (Calhoun &

Tedeschi, 2013). Rather, grief can become transformational and result in positive

changes, which authors (Calhoun & Tedeschi, 2013; Tedeschi & Calhoun, 2004;

Tedeschi, Calhoun & Park, 1998) have referred to as *posttraumatic growth*. People who

experience positive growth will report a change in social relationships, an increase in

empathy, and becoming emotionally closer to others (Gillies & Neimeyer, 2006).

Meaning reconstruction is a social constructivist approach that uses narration as a

means to facilitate meaning-making in bereavement (Holland et al., 2006; Neimeyer,

2001; Neimeyer et al., 2014). Exploring home-based EOL caregiving as it relates to

meaning reconstruction highlights the possible benefits of facilitating meaning making in

bereavement, and offers insight into a new way of helping bereaved caregivers make

sense of the incomprehensibility of losing a parent from a terminal illness.

Chapter Summary

Many adults will assume the role as a caregiver of their parent, a developmental occurrence often experienced around mid-life. Most dying individuals and families prefer home-based care at the end stages of life (Aoun et al., 2005; Stajduhar et al., 2010). Researchers, however, have found that many adult children lack the necessary skills and supports to facilitate home-based end-of-life care (Aoun et al., 2005; Gomes et al., 2012, 2013). Furthermore, adult children who continue to suffer a loss may be at risk for complicated grief and other depressive symptoms. Meaning reconstruction after a loss may be a key component of bereavement adjustment, an area that may prove fruitful for counselor research (Neimeyer & Anderson, 2002). It is my hope that the findings of my research study will illuminate the importance of addressing caregiver needs and how counselors can address the role and benefits of meaning making in bereavement.

Organization of the Dissertation

There are five chapters in this qualitative dissertation. In this chapter, I presented the background and conceptual framework of this study. I included the need for this research study, questions that guided my study, and the significance of the study. In chapter two, I present a review of literature that pertains to the current research study. In chapter three I outline the study's methodology, which included sample selection and procedures I used to collect and analyze data. In chapter four, I present the findings based on data collection, analysis, and interpretations. In chapter five, I discuss the implications of results for the counseling field, the limitations of the study, and offer suggestions for further research studies.

Definitions of Key Terminology

Caregiver. NAC (2009) defined caregivers as those who provide unpaid care to individuals with special needs of a child or dependent adult. A primary caregiver is a person who takes on the responsibility of care for the care recipient (Zarit, 2009).

End-of-life caregiving. End-of-life caregiving involves all tasks associated with providing care to those with advanced, progressive, incurable illness to help them live as well as possible until the individual dies (Stajduhar, et al., 2010).

Home-based care. Home-based care refers to the location in which individuals provide care. Care may be provided in the home of the care recipient or the caregiver. In home-based care, family caregivers are primarily responsible for most aspects of care regardless of whether hospice and palliative home care services are involved (Stajduhar et al., 2010).

Meaning reconstruction. Meaning reconstruction is a process that entails two complementary movements: "to conserve what was viable in one's pre-loss sense of self and life, and to construct a new way of being-in-the-world when this attempt at assimilating the loss into old meanings fails" (Neimeyer & Anderson, 2002, p. 61). The foundation of meaning reconstruction is based on major activities in which individuals engage such as sense-making, benefit-finding, and identity change (Gillies & Neimeyer, 2006). Counselors commonly use narrative strategies in the meaning reconstruction process, which may include telling the story of loss that encompasses one's external voice rich in sensory detail, and the internal or reflexive voice that explores associated feelings and meanings (Neimeyer & Anderson, 2002).

Bereavement. According to Neimeyer and Anderson (2002), *"*Bereavement is, among other things, a crisis in meaning" (p. 61).

CHAPTER TWO

Literature Review

My study was about adults who provided home-based end-of-life care for their parents. While death is an expected life event in older adulthood, many adult caregivers are unprepared, unskilled, and lack the necessary support to care for loved ones, especially those who are terminally ill (Aoun et al., 2005). Becoming an adult caregiver of a parent requires many adjustments, although temporary, and the physical and emotional toll of caring for a terminally ill parent cannot be understated (Aoun et al., 2005; Grbich et al., 2001). There are approximately four million caregivers (19% of the United States population) providing care to adults 50 and older (National Consensus Project [NAC], 2009) and the numbers are increasing, yet most people do not expect to undertake full-time caregiving.

The impact of assuming the role of an adult caregiver may be even more intense if the caregiving involves terminally ill parents. According to Grbich et al. (2001) and Janze and Henriksson (2014), the emotional depths experienced by home-based caregivers appear to be more complex than previous findings had suggested. Paradoxically, researchers have also found that the loss of a parent in adult life is rarely pathological. In fact, such a loss may present as an opportunity for growth (Calhoun & Tedeschi, 2013). In a similar vein, researchers (Gillies & Neimeyer, 2006; Neimeyer, 2001) have noted that an active process of post-loss meaning reconstruction may contribute to a positive adaptation to bereavement. Few researchers, however, have qualitatively explored in-depth subjective experiences of adults who have provided

home-based end-of-life care for a parent and the meaning-making process for such

individuals through the bereavement process. Further, although I conducted a

comprehensive review of the literature, some references are dated, indicating the need for

more current research on this topic.

 In this chapter, I include a review of the literature on adult caregiving, provide a

brief historical context of caregiving in the U.S., and discuss the role of the adult

caregiver and critical incidents that impact the caregiving experience. I also discuss the

salient transitions that typically take place during the course of caregiving, and explain

how illness trajectory determines the course of caregiving. Further, I focus specifically

on the research about adult children caregivers (adults who have assumed the role of

caregiver for a parent), home-based end-of-life care, and meaning making in bereavement

(Neimeyer, 2001). Throughout this chapter, I use the phrases family caregiving and

primary caregiving interchangeably as they are closely related terms in the literature.

Caregiving

Caregiving is a term that can have several different meanings. For example, the

Merriam Webster Dictionary (2004) defined caregiving as a situation in which a person

"provides direct care (as for children, elderly people, or the chronically ill)" (p. 107).

However, others define a primary caregiver as the person who takes on the responsibility

of care for the care recipient (Zarit, 2009). The term *caretaker* has also been defined as

"one in charge usually as occupant in place of an absent owner" (Merriam Webster

Dictionary, 2004, p. 107). While definitions may vary, caregiving is a topic of interest in

disciplines such as counseling, psychology, gerontology, and social work among others.

For this study, caregivers were adult children who provided end-of-life care for a terminally ill parent either in their home or their parent's home. In the next section, I provide an overview of caregiver demographics and trends to illustrate how important it will be for counselors to prepare for the silver tsunami (i.e., a swell in the older adult population; Chapman, MacKenzie, & Parker, 2015), which is soon to take place in the United States.

Caregiving Demographics and Trends

The population of older adults has increased and will continue to rise especially as baby boomers cross into older adulthood. According to the World Health Organization (WHO, 2012), the number of individuals over 60 years of age will double from approximately 11% to 22% by the year 2055 to a record increase from 605 million to an estimated 2 billion older adults worldwide. With this rise in population, older adults are at risk for serious illnesses such as cancer and other terminal illnesses, which will require medical support and the training of family caregivers (Chapman et al., 2015). Parallel to this increase in the U.S. aging population is the rise in family caregivers who provide approximately 80% of assistance in later life. Currently, there are approximately 44 million caregivers (19 % of the population) in the United States providing care to adults age 50 and older (NAC, 2009).

While home care is on the rise and may be the preference for most terminally ill individuals (Gomes et al., 2013), family caregivers must be prepared to face many issues. For example, caregiver burden, unmet needs, changes in illness trajectory, and learning additional skills to faciliate home-based care (Waldrop & Meeker, 2011) make it

challening for some families to meet such preferences (Higginson et al., 2013; Stajduar, 2013). Caregiving needs, however, may vary.

Every caregiving experience is different, and the needs of caregivers, therefore, will vary regarding the level and types of care required by the care recipient. The typical adult caregivers in the U.S. are middle-aged women and *sandwich generationers* who not only provide care to parents, but also to their own families (Bedini & Gladwell, 2014; Hammer & Neal, 2008; Penrod et al., 2014; Pope, 2013; Roberto & Jarrott, 2008). Although according to Denby, Brinson, Ross, and Bowmer (2014) there is a rise in male caregiving, more women assume the role of primary caregiver for a parent (NAC, 2015). Currently, 60 % of family caregivers in the U.S. are female, 40% are male, and the average age of caregivers is 49.2 (NAC, 2015). Furthermore, family caregivers will often assume the role of primary caregiver of a loved one (McMillan, 2005; NAC, 2015), and caregivers between the ages of 45-55 report the highest levels of caregiver burden compared to caregivers from other age groups (Gallagher-Thomson, & Coon, 2007; Haley et al., 2002).

Family caregivers are unpaid, and informally provide care for a family member or a loved one (Gallagher-Thomson & Coon, 2007). Family caregivers may include a spouse, partner, adult child, relative, or a friend who assumes the role and responsibility of caring for the older adult family member (Knussen, Tolson, Swan, Stott, & Brogan, 2005; Mehta, 2005). Adult children who assume the role of primary caregiver engage in helping behaviors when an aged parent faces a chronic illness or disability and requires

assistance (Barnet, 2013; Liu & Gallagher-Thomson, 2009; Miller, Shoemaker, Willyard, & Addison, 2008).

Adult caregivers who provide care for elderly parents at the end stage of life are required to make important medical decisions regarding treatment and financial administration, in addition to physical and emotional support (Hudson, Remedios, & Thomas, 2010). Primary caregivers, in particular, are the voice for their loved ones. They work closely with medical professionals to advocate for quality care, provide extensive support, and communicate the needs of their loved ones to ensure they are supported and comforted (Adams, 2013; Dhar, 2012).

In a meta-analysis of 84 articles on differences between caregivers (i.e., spouses and adult children caregivers) and non-caregivers, Pinquart and Sörensen (2003) found the psychological and physical health of caregivers tends to be more compromised than for non-caregivers. For example, caregivers who participated in the studies reviewed by Pinquart and Sörensen (2003) reported being more stressed, depressed, and had lower levels of subjective well-being, physical health, and self-efficacy than non-caregivers. Other studies have also indicated that female caregivers tend to report higher levels of depression, anxiety, and general psychiatric symptomatology and lower levels of life satisfaction than male caregivers (Pinquart & Sörensen, 2006; Yee & Schulz, 2000).

Although people in the United States are living longer lives compared to years past, as older adults may experience health challenges such as chronic illness or physical and cognitive impairments, their quality of life can be compromised (Stephens & Franks, 2009). While it is important to address the needs of an aging population, it is also

imperative that caregiver needs be addressed as they are also at risk for health related

illnesses associated with caregiver strain (Pinquart & Sörensen, 2003; Stephens &

Franks, 2009; Ward-Griffin et al., 2012). Next, I provide a brief historical context and

trends of caregiving in the United States to explain the complex nature of modern day

caregiving and what it is projected to look like in the future.

Historical Context of Caregiving in the United States

Traditionally, family caregivers consisted of a mother, father, children, and other

family members, such as grandparents, aunts, uncles, and cousins (Blum & Sherman,

2010). Providing care for elderly family members was expected and built into the

structure of family life (Miller et al., 2008). Around the 19th century, informal caregivers

were gendered, unpaid, and performed their caregiving duties in the home (Blum &

Sherman, 2010). Women were solely responsible for the care of the family and elders

and did not work outside the home (Feinburg & Levine, 2015). Despite economic shifts

in the U.S., which resulted in more women in the workforce, women continue to bear the

primary caregiving responsibility for the elderly and their families in addition to holding

a job outside of the home (NAC, 2009; Singer, Biegel, & Ethridge, 2010).

While some healthy older adults age well and retire, living healthy lives, it is not

uncommon for parents to move closer to their adult children if a parent should become ill.

Many caregivers who become primary caregivers may live at a distance, and manage and

provide long-distance caregiving by hiring professional caregivers or rely on other family

members and friends to facilitate caregiving (Roff, Martin, Jennings, Parker, & Harmon,

2007). While more families live further apart, including many elderly parents living

alone and independently, family caregiving has become more common, complex, and stressful, requiring more resources and support for caregivers (Miller et al., 2008). Families in need of resources often look to websites of agencies such as the American Association of Retired Persons (AARP) and the National Alliance for Caregivers (NAC) for information about support groups, caregiving services, legal assistance, and other programs to assist caregivers and families with caregiving needs.

MetLife (MET, 2004) estimated that at least five million Americans provide long-distance care, living at least one or more hours away. While some family caregivers may live nearby and have the ability to provide hands-on care, long-distance family caregivers can provide support in a variety of ways. MetLife (2004) reported that 75% of distant caregivers help with instrumental activities of daily living (IADL) through financial support and constant contact. IADL assistance may include hiring help to provide transportation, shopping, financial management, and emotional support (MET, 2004). According to Houser and Gibson (2008), caregivers spend an average of $5,531 annually of their money to supplement the cost for an individual over age 50 in 2007. Caregiving for loved ones with dementia can cost three times more per month, making an even more significant financial sacrifice to provide care (Liu & Gallagher-Thompson, 2009).

The modernization of healthcare is another trend or factor that may impact family caregiving (Feinberg & Levine, 2015). The high costs of healthcare and increase in expensive technologies have ultimately put additional pressures on family caregivers to provide care in the home (Feinberg & Levine, 2015). With the advent of in-home technologies that can assist home-based caregivers (e.g., devices to administer oxygen,

devices to measure glucose, blood pressure, heart rate, temperature, and devices to

manage medications) already stressed family members are required to adapt to and learn

additional skills to use such technologies (Feinberg & Levine, 2015), yet many still feel

ill-prepared and overwhelmed to facilitate home-based care (Aoun et al., 2005).

Moreover, the role of the adult child caregiver is one that is complex as each

circumstance is unique and largely dependent upon the needs of the care recipient.

Role of the Adult Child Caregiver

Primary caregivers play an important role in the caregiving process. They embark

on a journey presented with numerous shifts in roles and tasks, and many are unprepared

and lack the skills necessary to provide care for their loved one (Aoun et al., 2005;

Pearlin, 1992; Roth, Perkins, Wadley, Temple, & Haley, 2009). In fact, authors have

often referred to caregiving as the "unexpected career" (Aneshensel, Pearlin, Mullan,

Zarit, Whitlatch, 1995). While caregiving might not be a "chosen" career, as noted,

many adults assume the role of caregiver at various points in their lives for their parents.

This role can become overwhelming to the point that it can impact other areas of a

caregiver's life, displacing other roles and adversely affecting the health and well-being

of the caregiver (Roth et al., 2009).

Caregiving roles and responsibilities will vary depending upon the needs of the

care recipient and often involve constant adjustments, reorganizing of activities, and

accommodations throughout the process (Pearlin, 1992; Phillips & Reed, 2010). Some

tasks involve a range of activities from providing assistance with activities of daily living

(ADL) such as bathing, feeding, getting in and out of bed and chairs, getting dressed, and

dealing with incontinence, to providing complete physical care. Other assistance may involve instrumental activities of daily living (IADL), which include medical management, housework, shopping, meal preparation, and transportation (Liu & Gallagher-Thomson, 2009; Miller et al., 2008). While caregiving involves support with both ADL's and IADL's, caregivers also provide emotional support, financial support and case management (Liu & Gallagher-Thomson, 2009; Miller et al., 2008).

Tasks associated with caregiving can be physically and emotionally overwhelming as well as financially draining (Blum & Sherman, 2010; Liu & Gallagher-Thomson, 2009; Northfield & Nebauer, 2010; Stephens & Franks, 2009), especially as caregiving activities intensify in response to changes in the physical and cognitive changes in care recipients (Roberto & Jarrott, 2008). For example, some of the physical demands can be excessive, requiring 24 hours of support, especially at the end of life (Stajduhar, 2013). Stressors associated with caregiving can, therefore, impact the overall health and wellbeing of caregivers (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Schulz et al., 2003; Waldrop, 2007).

Caregiver stress is multidimensional, rather than previously viewed as a single unit (Aneshensel et al., 1995). Noting this distinction may help counselors and other mental health professionals understand how to work with caregivers. According to Zarit (2009), there are four levels that fall under the dimensions of caregiving stress: 1) primary stressors, 2) appraisal (subjective meanings and stressfulness of events), 3) secondary stressors, and 4) outcomes. The first level of stressors, or primary stressors, is related to the care recipient's illness trajectory. Primary stressors include helping with

ADLs, managing emotional and behavioral problems as well as with supervision of care

recipients (Zarit, 2009). The second level includes appraisals, which are the caregiver's

subjective experience of stressors, or meanings that caregivers ascribe to these stressors,

which can include role overload, role captivity, and loss of a person and the relationship

(e.g., caregivers of individuals with dementia; Zarit, 2009). At the third level, stressors

are referred to as secondary stressors as these signify the stress and strain that affects

other areas of life (e.g., work-caregiving conflict, family conflict, financial strain, and

loss of self; Zarit, 2009). Lastly, the final dimension consists of the outcomes or the

collective amount of stress overall.

Caregivers with high levels of caregiver stress often experience a range of

negative symptoms such as increased levels of anxiety and depression (Pinquart &

Sörensen, 2006; Redinbaugh et. al., 2003; Stajduhar, 2013), anticipatory grief (Holley &

Mast, 2009; Waldrop, 2007), family discord (Waldrop, 2007), and uncertainty as

impending death of care recipients approaches (Haley et al., 2002; Hebert et al., 2009;

Stajduhar, 2013). Also, some caregivers experience difficulty in adjusting to the loss of

the care recipient (Ling et al., 2013) and a loss of meaning or purpose (Gillies &

Neimeyer, 2006). Authors have pointed out that caregiving can also impact the physical

health of caregivers, causing fatigue, burnout, chronic illness, and an increased risk of

mortality (Pinquart & Sörensen, 2006; Schulz et al., 2003; Waldrop, 2007). Few

researchers, however, have explored the roles that caregivers assume as impending death

of the care recipient approaches.

Phillips and Reed (2009) examined caregiver perspectives of their role as end of life (EOL) caregiver. In their qualitative study, researchers used constant comparative analysis and identified four categories from the data associated with caregivers' constructions of EOL caregiving role: centering life on elder, maintaining a sense of normalcy, minimizing suffering, and gift giving (Phillip & Reed, 2009). Phillip and Reed (2009) identified the EOL caregiver role as having both existential and transcendent qualities. For example, some participants in their study found the caregiving role demanding. Other participants felt that their roles were sacrificial acts of love and satisfying. In fact, these caregivers made their highest priority to affirm their elder and co-create memories by spending time, making trips together, or having parties. Generative caregiving refers to creating memories while caring to create more meaning at the end (Phillip & Reed, 2009). While every caregiving experience is unique, it is important to consider some critical incidents that may also shape the caregiving experience.

Critical Incidents of Parental Caregiving

Changes that caregivers encounter while providing care for a parent who is terminally ill shape their caregiving roles and experiences. Adult caregivers can expect rapid changes in the course of their parents' illness (Blum & Sherman, 2010; Northfield & Nebauer, 2010). They can also anticipate changes in the parent-child relationship (Birditt, Miller, Fingerman, & Lefkowitz, 2009; Lin, Chen, & Li, 2013) and a disruption of balance within the caregiver's life (Holley & Mast, 2009; Waldrop, 2007). These challenges add to the emotional toll of caregiving (Gill & Morgan, 2012).

Parent-child relationship. The relationship between parents and their children is important, unique, and changes over the course of a lifespan (Quadagno, 2011). The bonds between these relationships are significant and long lasting (Birditt et al., 2009). Some researchers, in fact, have suggested the importance of parents and their children maintaining good relationships across the lifespan (Birditt et al., 2009). Lin, Fee, and Wu (2012) noted that older adult parents who maintain close ties with their children tend to be less depressed and lonely than those who have strained relationships with their offspring. However, when a parent's health begins to decline and adult children become more aware of the signs of aging (e.g., physical and cognitive decline) it is most likely that the adult child will step into the role of 'parent' (Barnett, 2013). As these relationships undergo role transitions, the caregiver must negotiate this new role and prepare for the caregiving endeavor, which may add to caregiver stress (Gill & Morgan, 2012). In addition to understanding how relational dynamics impact the caregiving experience, the course of illness, or illness trajectory, will also determine the type of care that is involved (Blum & Sherman, 2010; Northfield & Nebauer, 2010).

Illness trajectory. Blum and Sherman (2010) and Northfield and Nebauer (2010), suggested that illness trajectory determines the caregiving experience. Typical chronic conditions of older adults may include cancer, diabetes, cardiovascular disease, arthritis, hypertension, osteoporosis, and dementia (Stephens & Franks, 2009). Other physical ailments may include injuries due to falls, disabilities, and impairments due to illness and frailty typically referred to as geriatric syndromes (Stephens & Franks, 2009). Functional limitations are common among older adults, often precipitating the need for

both formal and informal care. In addition to the many conditions that determine the

course of care, the context in which one provides care will ultimately impact the

caregiving experience, such as when individuals provide home-based care. Before the

need for caregiving of a parent occurs, adult children and their families have established

their own natural rythym of daily life. Once adult children have assumed the role as

primary caregiver, the balance of their lives is temporarily disrupted, especially if they

provide the care in their home (Holley & Mast, 2009; Waldrop, 2007)

     Struggle for balance. Life changes once the adult child caregiver takes on the

responsibility of caring for a parent. As the adult child caregiver embarks on caregiving

in the home, caregiving becomes a family matter, especially in EOL care. It requires the

support of all family members involved, including those who live in the home (e.g.,

spouses, children, and others who reside in the home; Haley et al., 2002). As the needs of

the parent increases, caregivers and their families must make constant adjustments such

as creating an environment that supports the parent. Examples of other adjustments

include increasing the level of care within the home as needed (i.e., medical assistance

such as visiting nurses), reorganizing activities (e.g., their own acctivities and those for

the terminally ill parent and other family members), and making accommodations

throughout the process (Pearlin, 1992; Phillips & Reed, 2010). Many individuals who

provide care in the home do not expect to undergo these changes and find themselves

learning how to care "on the job" encountering each day with a new adventure. Some

caregivers might even feel as if their job is never ending. As caregiving duties intensify,

caregivers become more distressed and are less inclined to promote their self-care,

compromising the well-being of caregivers (Pinquart & Sörensen, 2006; Schulz et al., 2003; Waldrop, 2007).

In addition to managing their own emotions, primary caregivers must also manage the emotions of their family members and their ailing parents. The emotional attachment (Bowlby, 1980) and relationship that each family member has had with the dying parent will result in the intensity of emotion or grief reaction expressed (Neimeyer et al., 2006), which cannot be understated. Emotions experienced by caregivers are complex ranging from anger, sadness, resentment and despair, and can become cataclysmic for the primary caregiver and their families, resulting in discord, especially as decisions are made regarding a dying parent (Harrington et al., 2012; Hudson et al., 2010; Ward-Griffin et al., 2012). The combination of caregiver distress, role-reversal in the parent-child relationship, and family strife will shape the caregiving experience and result in a journey that is often tumultuous and wrought of imbalance (Nadeau, 1998). The primary caregiver will continue to strive for balance throughout caregiving. It is the eventual death of a parent that brings caregiving to an end and helps restore equilibrium (Grbich et al., 2001; Stroebe & Schut, 1999). Although the may feel that equilibrium is restored, caregivers are left to make sense of their caregiving experiences as well as their loss. This quest for meaning is a normal response in post-loss adjustment (Neimeyer, 2001). The emotional experience of losing a parent, therefore, may continue well into bereavement as the adult child caregiver must now adapt to the world without their parent.

Home-Based EOL Care

In this next section, I focus specifically on home-based EOL caregiving. I also discuss the emotional intensity of anticipatory grief that caregivers experience, important decisions that caregivers must make, particularly end-of-life decisions such as transitioning from curative to palliative care, and the positive aspects of providing home-based EOL care.

End of life (EOL) is a critical time during the caregiving journey (Phillips & Reed, 2010) especially as adult children caregivers witness their parents' rapid decline (McMillan, 2005). We know more about this precious last stage of life due to the ground breaking work of Elisabeth Kübler-Ross. She was a pioneer in death and dying research and paved the way for bereavement counseling with the development of her stages of grief model and end-of-life care with the terminally ill (Kübler-Ross, 1969). Although critics have argued that her stages of grief are linear and that people do not experience grief in a sequential manner, most would agree that Kübler-Ross did not intend for people to interpret her model in such a linear manner (Kübler-Ross & Kessler, 2005). Rather, she developed her stages of grief as a framework for how individuals can experience grief at any time. One can apply her stages of grief model (i.e., denial, anger, bargaining, depression, and acceptance) to caregiver anticipatory grief (Holley & Mast, 2009; Waldrop, 2007), and other types of loss as well (Kübler-Ross, 1969; Kübler-Ross & Kessler, 2005). More importantly and relevant to this research study, Kübler-Ross established a movement towards home-based end-of-life care, that is, for dying

individuals to have a natural death with loved ones, in a home-like setting, similar to how

end-of-life care was provided centuries ago (Kübler-Ross & Kessler, 2005).

End-of-life is considered a family matter where multiple family members tend to

become involved (Haley et al., 2002). Making the decision to utilize hospice and

palliative care services is difficult for most people (Harrington et al., 2012). When a cure

is no longer an option and death is inevitable, the primary goal of treatment shifts from

curative to palliative (Ward-Griffin et al., 2012). Therefore, illness trajectory presses

upon caregivers to make difficult decisions (Harrington et al., 2012).

Adult children caregivers often face a deep sense of loss as a parent's health

declines (Gill & Morgan, 2012). This sense of loss can be an emotional and physically

exhausting time, especially as care demands increase. Additionally, anticipatory grief

tends to escalate as caregivers watch their loved ones lose functioning (Holley & Mast,

2009; Waldrop, 2007).

Anticipatory Grief

Anticipatory grief is a term coined by Lindemann (1944), a psychiatrist well

known for his specialty in grief and bereavement. He asserted that anticipatory grief,

originally diagnosed as a 'syndrome,' is a reaction that occurs under the threat of death

(Lindemann, 1944). EOL caregivers tend to experience high levels of anticipatory grief

while providing care for a loved one (Holley & Mast, 2009; Waldrop, 2007). As

impending death nears, EOL caregivers will continue to experience anticipatory grief and

may naturally prepare by distancing themselves emotionally in preparation for the actual

death (Lindemann, 1944; Nadeau, 1998). Grief can manifest in many ways (e.g.,

relational tension, sadness, depression, and physical symptoms) before a loss and well into bereavement (Holley & Mast, 2009; Kübler-Ross & Kessler, 2005; Waldrop, 2007).

Key findings from studies of caregiver grief (Waldrop, 2007) and caregiver anticipatory grief (Holley & Mast, 2009) suggest that caregivers struggle with many intense emotions such as anxiety, sadness, anger, and hostility due to the impending loss of a loved one. These complex emotional responses are expressions of anticipatory grief which is common for caregivers who care for loved ones during the end-stages of life (Holley & Mast, 2009: Waldrop, 2007). Moreover, Holley and Mast (2009) identified that anticipatory grief is a key component in understanding caregiver burden; especially for those providing care for loved ones with dementia. Anticipatory grief is expressed uniquely in that caregiver burden is higher for caregivers who care for a loved one with cognitive impairments (Holly & Mast, 2009). Caregivers have reported anger due to loss of freedom, loss of their relationship and meaningful communication with their loved one, and loss of emotional closeness as common grief reactions (Holly & Mast, 2009). These findings indicate the importance of understanding varied caregiving experiences and how a care recipient's illness will impact caregiving outcomes.

Bereaved Caregivers

Despite the grief reactions by caregivers expressed during and after caregiving, most bereaved caregivers are resilient and experience an adaptive outcome (i.e., positive outcomes such as personal growth, spiritual growth or change; Stroebe & Strut, 1987) or adjust in bereavement after a major loss (Bonnano, 2004; Center for the Advancement of Health, 2004). Approximately 10-20% of individuals, however, experience complicated

grief with symptoms such as psychological distress, anxiety, and depression (Bonanno, 2004; Waldrop, 2007). Some individuals also suffer from prolonged grief disorder, a more serious condition than major depression and Post Traumatic Stress Disorder, with symptoms presenting as intense periods of grief, which can potentially result in suicidal thoughts following the death of a loved one (Parkes & Prigerson, 2010). Important to note is that depression and prolonged grief disorder should be differentiated. In a study by Kypriotakis, O'Toole, Bowman, and Rose (2015), researchers found that although grief can trigger depression, they are distinctly two different emotional states, and therefore, clinicians must diagnose with caution when working with bereaved caregivers.

EOL Decision-Making

End of life decisions are usually made between adult child caregivers, care recipients, and their families. While such decisions may be difficult and may add additional pressure for primary caregivers (Harrington et al., 2012), the communication between all parties is necessary and can alleviate the pressure on the primary caregiver (Kübler-Ross, 1969; Kübler-Ross & Kessler, 2005). In fact, Kübler-Ross (1969) maintained the importance in keeping communication open between the dying and their families by sharing thoughts, feelings, and needs and working through anticipatory grief together. However, lack of prior communication and the absence of advanced directives to guide adult children caregivers make decisions even more difficult (Kübler-Ross & Kessler, 2005). Additionally, while most caregivers try to accommodate their parents' wishes, this is not always possible, especially when providing care in the home far exceeds the caregiver's capability (Gill & Morgan, 2012). For example, as mentioned

previously, although the preference of many care recipients is to be cared for and die in the home (Higginson et al., 2013), caregivers cannot always meet these preferences, often leaving caregivers feeling guilty for not being able to accommodate their loved ones. Establishing congruence between caregivers and their dying loved ones is the ideal and a goal to aim for, yet can be a challenge for families, nonetheless (Gardner & Kramer, 2009).

Harrington et al. (2012) explored the emotional challenges that 15 Australian carers (authors used the term *carers* instead of caregivers) faced while transferring loved ones to an in-patient palliative care facility. They employed semi-structured interviews and designed their study to elicit the experiences of carers, their emotional, social, physical, and spiritual needs, and the coping mechanisms used by participants. The researchers highlighted the importance of understanding the disease trajectory as this eventually dictates the need for caregivers to transition to palliative care services. Additionally, Harrington et al. (2012) emphasized the importance of addressing caregiver needs. They identified participants as having two overlapping emotional responses as they transferred their loved ones to in-patient palliative care, expressing both feelings of "guilt" and "relief." While participants felt relieved to find support from in-patient palliative care, they also felt guilty for the inability to honor the wishes of their loved ones to die at home. For some individuals, having their loved one in hospice alleviated some of the strain of providing the physical care, some felt comforted by the expert care provided to their loved ones, and most importantly, transitioning to hospice was illustrated as a means of 'letting go.'

Preparing for the end stages of life can be intense. Most caregivers feel unprepared no matter how much effort is put into preparation (Aoun et al., 2005). Family caregivers are the backbone of EOL caregiving, and as they make the difficult decision to transition from curative to palliative care, the emotional toll can be high. Caregivers do find comfort in and have benefited from supportive services such as hospice and palliative care, counseling, respite care, and supportive social networks, especially when end-of-life care takes place in the home (Funk et al., 2010; Hudson, 2004; Northfield & Nebauer, 2010; Strang, Koop, & Peden, 2002; Ventura, Burney, Brooker, Fletcher, Ricciardelli, 2014; Ward-Griffin et al., 2012). Such services can bring relief to families from the burdens and emotional turmoil of providing EOL care.

Palliative Care

At the end stages of life, many families opt for hospice services, often referred to as palliative care, a type of comfort care that takes the place of treatment when cure is no longer an option. These services are typically offered through in-patient facilities or a person's home depending upon the needs of families and their loved ones (Koop & Strang, 2003; Ventura et al., 2014). The World Health Organization (WHO, 2002) defined palliative care as:

> An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment, and treatment of pain and other problems – physical, psychosocial and spiritual (p.3).

Researchers have consistently reported that most individuals prefer to die at home as opposed to living their last days in an institution such as a hospital or in-patient hospice center (Gomes et al., 2013; Higginson & Sen-Gupta, 2000; Higginson et al., 2012, 2013; Payne et al., 2012). According to Higginson et al. (2013), the percentage of Americans dying in hospitals decreased from 54% to 41% between 1980 and 1988, resulting in more home deaths. Higginson et al. (2013) reported a slow and steady increase of home deaths from 18.3% in 2004 to 20.8% in 2010. Higginson et al. (2013) proposed three reasons for the decrease in hospital deaths. First, health care costs are extremely high, and many people just cannot afford the expense of institutional care. Secondly, there has been an international move to reduce hospital stay due to high health care costs, hospital-acquired infection, and patient and family choice to receive care at home. Thirdly, Higginson et al. (2013) contended that offering hospice and palliative care services in the home became more common as a result of the U.S. Hospice Care Benefit Act (introduced in the U.S. in 1982), leading to an increase in home-based care (Higginson et al., 2013).

In a recent study, Gomes et al. (2013) conducted a systematic review to understand the heterogeneity of preferences regarding dying in a medical facility or at home. The researchers reviewed 210 studies, which included over 100,000 participants from 33 countries around the world. Twenty-eight percent of the studies (n=59) presented evidence from the U.S. One hundred and thirty studies presented with participants who expressed a preference for dying at home. Based on their study, Gomes et al. (2013) concluded that most people prefer to die at home and that the path or trajectory of the

illness did not change preferences. Funk et al. (2010) also carried out a systematic review of published qualitative research on home-based family caregiving at the end of life and reached the same conclusion as Gomes et al. (2013). However, many caregivers experience intense negative emotions while providing such care. Funk et al. (2010) proposed that such feelings could be brought on by impending loss, uncertainty, and feeling unprepared for the job. Additionally, Funk et al. (2010) found that caregivers felt anxious, powerless, and vulnerable yet responsible for providing end-of-life care and concluded that both formal and informal supports are necessary for facilitating end-of-life caregiving.

While home-based end-of-life caregiving may be the preference for most families, other factors may make home-based caregiving unachievable for some people (Higginson & Sen-Gupta, 2000; Higginson et al., 2013). Race, for example, has been found to be a significant factor in attitudes toward home-based end-of-life (Higginson & Sen-Gupta, 2000). Additionally, culture and ethnicity can also play a role in the place of end-of-life care and death. For example, according to Coupland, Madden, Jack, Møller, and Davies (2011), Black African, Black Caribbean, and Chinese patients were all significantly more likely than White patients to die in hospitals in the United Kingdom. Additionally, people living in metropolitan areas are more likely to die in hospitals than those living in less populated areas (Houttekier et al., 2010). While inequities and unmet needs continue to exist (Higginson et al., 2013), more research is needed to understand the preferences, perspectives, and experiences of EOL family caregivers from racially and culturally

diverse backgrounds as well as the perceived options that families have given their life

circumstances and public policy supports.

Negative and Positive Aspects of EOL Care

While previous studies have focused on negative aspects associated with

caregiving, within the past ten years, some researchers have looked at both positive and

negative aspects associated with caregiving (Boerner, Schulz, & Horowitz, 2004;

Hudson, 2004; Koop & Strang, 2003). Researchers have made strides in discerning grief

reactions in post-loss adjustment (Boerner et al., 2004). For example, Boerner et al.

(2004), reported that higher levels of post loss depression and grief may be due to loss of

a meaningful role (caregiver) as well as in response to the actual loss of a loved one.

Similarly, Neimeyer (2001; 2006) argued that often bereaved individuals search for

meaning in post-loss adjustment.

In studies regarding positive aspects of caregiving, Hudson (2004) reported that

caregivers could identify positive aspects of their experiences and were able to rely on

meaning-based coping resources in bereavement. For example, in Hudson's (2004) study

caregivers reported that caregiving had strengthened relationships, an example that may

allude to the individual's ability to find meaning in the experience.

In a prominent study often cited in the caregiving literature, Koop and Strang

(2003) examined the bereavement experiences of fifteen caregivers who provided home-

based family caregiving for persons with advanced cancer. In this qualitative study, the

researchers found that caregivers were able to identify both negative and positive aspects

of their experiences. Some of the common themes of positive aspects associated with the

EOL caregiving experience were personal growth, unexpected gifts (e.g., the ability to

preserve a loved one's dignity), and strengthened relationships. Interestingly, males in

Koop and Strang's (2003) study (n=2) reported feeling defeated after losing their loved

one and sensed the death as an awful failure. As Carol Gilligan (1982) once asserted,

males tend to focus on results and achievement where females think more about the

possibilities and relationships before taking action. Gilligan's (1982) assertion points to

the importance of understanding that there may be gender differences in the caregiving

experience and perceived outcomes as well (Yee & Schulz, 2000).

Death and Bereavement

Bereavement, also referred to as grief, defined in its origin as "the state of being

deprived" (Attig, 2001, pp. 36) denies individuals of the living presence of a loved one

(Attig, 2001). Bereavement is the period of grief and mourning, a normal process of

reacting to loss, which may or may not produce physical pain (Parkes & Prigerson,

2010). It results in a period of disorganization and despair, which can involve oscillation

between two orientations, loss orientation and restoration (or change) orientation (Stroebe

& Strut, 1999). Most bereaved individuals come to terms with loss and eventually move

towards acceptance (Parkes & Prigerson, 2010).

As previously mentioned, bereaved caregivers feel catapulted into a search for

meaning after a loss (Neimeyer & Harris, 2011). Bereavement is a period after a loss

when individuals struggle to understand why their loved one has died, also viewed as a

time of "crisis in meaning" (Neimeyer & Anderson, 2002, p. 61). Some bereaved

individuals will struggle with meaninglessness, and some will eventually discover a silver

lining in their experience or their outlook on life (Davis et al., 2000). Adaptation in

bereavement, therefore, is important to consider in the context of post-loss caregiving.

Bereaved Caregivers

While most family members who provide care at the end of life are resilient and

able to adapt and adjust well to bereavement (Schulz et al., 2008), some may be prone to

physical and psychological morbidity (Hudson, Thomas, Trauer, Remedios, & Clarke,

2011; Pinquart & Sorensen, 2003). Many caregivers experience peak levels of stress and

depressive symptoms during caregiving, especially while providing EOL care and one

month after a loved one's death. These levels tend to subside after the death of the care

recipient (Schulz et al., 2003; Schultz et al., 2008). The research, however, indicates that

some caregivers continue to experience chronic depression and poor psychological well-

being during bereavement (Hudson et al., 2011; Schulz et al., 2008). In fact, caregivers

who had poor physical and psychological health while caregiving tend to be at risk for

more depressive symptoms after their loved one's death (Allen, Haley, Small,

Schonwetter, & McMillan, 2013; Ling et al., 2013).

Allen et al. (2013) investigated risk factors that predict psychological distress in

caregivers. Their sample included 188 cancer patient-caregiver dyads. The caregivers

were predominately White (99%) and female (78%; Allen et al., 2013). Allen et al.

(2013) reported that 50% of bereaved caregiver participants (mix of parents, spouses,

partners, and siblings) had clinically significant depressive symptoms one year following

the death of a loved one. In a similar study, Ling et al. (2013) analyzed the trajectory of

the depressive symptoms of primary family caregivers (n=186). They found that

depressive symptoms peaked at one month after the loss of a loved one and decreased to

the threshold for clinical depression at three months and then below this threshold at six

months. While this result may seem perplexing, it makes sense. Grief comes in waves,

and as the reality of the loss sets in, that is an adaption to bereavement, it is not

uncommon for grief to heighten as the reality of the loss is finally accepted (Neimeyer,

1998; 2001). Additionally, depressive symptoms dropped to the lowest levels at 13

months. Similar to results of other studies (Allen et al., 2013; Hudson et al, 2011; Schulz

et al, 2008), caregiver participants in Ling et al.'s (2013) study who reported higher

levels of depressive symptoms and poorer health prior to the death of a loved one and

spousal caregivers tended to exhibit higher levels of depressive symptoms and poorer

health after the loss of a loved one.

Death and Meaning

Loss of a loved one often presents challenges and disrupts one's emotional world

(Nadeau, 1998; Neimeyer, 2001). However, when individuals lose a parent, they must

come to terms with their mortality. After the loss of a parent, adult children will often

reevaluate many aspects of their lives, particularly, their attitudes regarding themselves,

their families and how to move forward in life without their parent (Neimeyer et al.,

2002).

In an attempt to make sense of loss, most individuals will engage in existential

questioning or a search for understanding (Nadeau, 1998; Neimeyer et al., 2002). Family

members may begin to experience self-doubt and question whether there was some way

that they could have alleviated suffering or have prevented the death (Nadeau, 1998) of

their loved one. Some individuals may call upon their religion or spiritual practices for

answers (Bray, 2013). For those who cannot make sense of or find any meaning in loss,

which typically occurs after a traumatic loss, adaptation to bereavement becomes even

more difficult (Currier, Holland, & Neimeyer, 2006). Some individuals will try to

maintain a connection with the deceased somehow, as a means of coping, which is often

referred to in the professional literature as *continuing bonds* (Field, Gao, & Paderna,

2005; Neimeyer, Baldwin, & Gillies, 2006; Stroebe, Schut, & Boerner, 2010). Rituals,

legacy creation, and meaning making are common ways of experiencing continuing

bonds.

Rituals, legacy, and meaning making. A majority of individuals engage in

ritualistic behaviors and legacy creation to continue the bond with the deceased

(Neimeyer & Harris, 2011; Vale-Taylor, 2009). Some of the rituals or activities that

survivors of loved ones may perform include listening to music enjoyed by the deceased,

visiting a grave or revisiting special places enjoyed by the deceased. Other activities may

include enjoying photographs of loved ones, attending a house of worship and having a

mass or lighting a candle in remembrance of the deceased. Examples of therapeutic

activities include grief counseling, letter writing to the deceased, and narrative therapy

(Neimeyer, 1999). While these bereavement strategies are a means of continuing the

bond with a loved one, there is much uncertainty among researchers as to whether

continuing the bond with a loved one is helpful in bereavement adjustment (Bowlby,

1980; Neimeyer et al., 2006).

Continuing bonds. Several authors (e.g., Field et al., 2005; Neimeyer, 2001; Neimeyer et al., 2002; Neimeyer et al., 2006) have referred to the construct of continuing bonds as the need for bereaved individuals to seek new and sustain old bonds with the deceased by preserving memories and through the use of metaphors in an effort towards healthy bereavement adaptation. Originally, Freud (1957) claimed that to permit psychic and behavioral adaptation after a loss one must properly work through bereavement, essentially 'break' the bond or emotionally detach from the deceased (decathexis) with detachment being the central task of mourning (Hagman, 2001; Neimeyer et al., 2006). Years later, contemporary grief theorists became enamored with a model of mourning, in which they argued that 'letting go' or 'saying goodbye to' the deceased was a better approach to bereavement adaption (e.g., Neimeyer, 2001). In the past twenty years, a growing number of scholars have argued that rather than 'letting go' or breaking the bond with the deceased, continuing bonds may help bereaved individuals to reorganize and ease into bereavement with successful adaption (Field et al., 2005).

Researchers continue to examine the construct of continuing bonds to understand the grieving process and bereavement adaption (Stroebe & Schut, 2005). Neimeyer et al. (2006), however, furthered this research by investigating the interaction between continuing bonds, coping, and sense-making, benefit-finding, and identity change, namely meaning reconstruction, in predicting complicated grief symptomology. In their 2006 study, Neimeyer et al. recruited 506 bereaved adults (119 men [23.5%], 387 women [76.5%], $SD = 3.83$, age range: 18-53 years, $M_{age} = 20.52$) from undergraduate psychology courses. Participants completed two instruments, the Inventory of

Complicated Grief (ICG) and the Continuing Bonds Scale (CBS). The researchers also

asked participants questions regarding meaning reconstruction and factors surrounding

the loss experienced and the relationship between the participant and the decedent. Based

on hierarchical regression models Neimeyer et al. (2006), reported that two patterns

emerged. The first pattern indicated a positive relationship between high sense-making

and lowered traumatic distress. The second pattern indicated low sense-making

correlated with higher traumatic distress, especially for participants of younger decedents.

The results from this quantitative study indicate that continuing bonds and meaning

reconstruction were reliable predictors of both traumatic and separation distress

experienced by participants. Interestingly, higher levels of meaning making predicted

more positive grief outcomes, whereas high levels of post-loss attachment to the deceased

were associated with complicated grief symptoms, especially under conditions of low-

sense making (Neimeyer et al., 2006).

Finding meaning in loss. Human beings have a need for meaning. Classically,

Viktor Frankl (1959) argued for the importance of finding meaning and purpose in life.

He believed that people must pursue a quest to find one's meaning in life; that it is

important to live for something. In his teachings of logotherapy (logos derived from the

Greek word *meaning*), Frankl (1959) demonstrated that meaning could be found through

tragedy and translated into triumph. In a similar vein, Yalom (1980) pointed to the

importance of meaning, with a sense of meaninglessness being one of the four ultimate

concerns experienced by individuals. Yalom extended this thought by encouraging

therapists to facilitate meaning-making through the use of existential therapy and the

therapeutic process, guiding clients towards engagement with others (Yalom, 1980, 2002). Other theorists and researchers (e.g., Janoff-Bulman, 1992; Nadeau, 1998; Neimeyer, 2001; Thompson & Janigian, 1998) have also maintained the importance of active engagement and immersing oneself in a purposeful search for meaning in the aftermath of loss.

While many researchers continue their pursuit of understanding meaning making, especially as it relates to the context of stressful life events, Park (2010) differentiated the term meaning-making with constructs such as global and situational meaning and between *meaning making effort* and *meaning made*. Simply put, Park (2010) presented that situational meaning can be construed as the meanings made from experiences, whereas global meaning refers to meaning made in the larger context of life. For my study, it is important to remember that meaning-making or meanings made are subjective and personal.

Attig (1996) maintained that people feel challenged through loss; that recurrent occasions and singular events (e.g., birthdays, anniversaries, and times of need) are both challenging for people. People try to make sense and question the meanings they had for such events before and after experiencing a loss. Individuals must relearn how to be in the world without their loved one. Through this relearning process, they must also relearn about themselves (Attig, 1996; Neimeyer, 2001). In a similar vein, meaning reconstruction plays an important role in the first two years of bereavement (Currier et al., 2008; Gillies & Neimeyer, 2006; Holland et al., 2006; Neimeyer, 2001). Moreover, finding meaning in life has consistently been correlated with positive mental health

outcomes (McLennon, Habermann, & Rice, 2011; Noonan & Tennstedt, 1997). Also,

finding meaning in life has been shown to relate positively to multidimensional life

satisfaction and negatively to psychosocial problems (Brandstaater et al., 2013; Ho,

Cheung, & Cheung, 2010).

Neimeyer (1999) and other constructivists have reported on the effectiveness of

meaning reconstruction in their work with bereaved individuals. Meaning reconstruction

is an active process that begins with a deep engagement with the client's experiential

world (Neimeyer, 2001). Additionally, narrative approaches are effective and typically

used in meaning reconstruction; I further explain the method and techniques utilized in

the following section.

Holland et al. (2006) examined the role of sense-making, benefit finding, and time

loss in predicting complicated grief. The researchers recruited a racially and ethnically

diverse sample of recently bereaved college students (n=1,022; 75% women, 25% men;

56% Caucasian, 38.4% African American, 1.6% Asian American, and approximately 4%

identified as other) from undergraduate introductory psychology courses at a large

southern urban university. Participants completed the Inventory of Complicated Grief

(ICG) and Likert-type scales that measured both sense-making and benefit-finding.

Holland et al. (2006) reported that making sense of and finding benefit in loss are both

associated with decreased complications in grieving. Interestingly, the researchers found

that sense-making was a stronger predictor of grief outcomes in comparison to benefit

finding, yet time since the loss was not correlated with complicated grief (B = -.26, t(966)

= 13.76, p < .001). This study was in part a replication of Davis, Nolen-Hoeksema, and

Larson's (1998) study, in which the researchers suggested that sense-making predicts

adaptation to loss early in bereavement. That is, making sense of loss in the first months

of bereavement was important in bereavement adjustment, however, making sense after

six months or longer did not alleviate distress (Davis et al., 1998). Contrary to Davis et

al.'s (1998) finding, Holland et al. (2006) maintained that time since a loss is not related

to grief complications. Furthermore, as the length of time following a loss was not found

to be associated with sense-making and benefit-finding nor complicated grief, the

researchers concluded that meaning-making could take place at any time during

bereavement adjustment.

        In a recent study, Brandstätter et al. (2014) explored the experiences of individual

meaning in life (MiL) and its relationship to well-being. The researchers recruited 84

primary caregivers (69% female and 31% male; average age 55.5) of palliative care

patients from two palliative care wards and a radio-oncology department in Munich,

Germany. The researchers compared the participants' meaning in life (MiL) scores to

MiL data from a German nationwide representative sample. Results indicate that

bereaved caregivers had substantially impaired framework and fulfillment of MiL, which

implies that coping with the loss of a loved one impacts MiL framework and impairs the

ability for caregivers to experience MiL fulfillment. As a result of this study,

Brandstätter et al. (2014) suggested that specific interventions such as meaning

reconstruction during palliative care and bereavement are important in helping

individuals strengthen and regain a sense of meaning and purpose. These findings are

important for two reasons. First, meaning reconstruction in bereavement as it relates to

caregiving has not been researched. It is therefore important for researchers, especially from the counseling perspective to see the benefits of meaning reconstruction and how it can be used preventatively with bereaved clients. Secondly, research is lacking regarding the association of meaning making in bereavement. Therefore, examining meaning structures or how people ascribe meaning after a loss may help deepen our understanding of the process of meaning-making in bereavement.

While Brandstätter et al.'s (2014) study illuminated the potential benefits of meaning reconstruction with palliative care bereaved caregivers, participants were recruited early in bereavement (range, 4-183 days post-loss). Gillies and Neimeyer (2006), however, have maintained the importance of allowing time for individuals to grieve to find benefit in the loss or as researchers term this process, 'benefit-finding' in the overarching process of meaning reconstruction. In my study, I recruited participants who had lost a parent between approximately one to three years before participating in the study as it allowed for more time for bereaved caregivers to engage in reflexive processing as they told their stories of loss (Neimeyer & Anderson, 2002). While there is no way to determine when an individual has completely grieved a loss, I understood that the quality of the relationship, the circumstances that surrounded the death, and one's life experience(s) can affect the grieving process (Nadeau, 1998) and was prepared to debrief with my participants.

In another recent study, Saito (2014) used ethnographic research methods to describe and interpret the lives of Japanese immigrant women to understand how they integrated their experiences of loss, and how their social and cultural contexts shaped the

reconstruction of meaning after a loss and the meanings that emerged from their loss experiences. Nine Japanese widows aged 56-79 participated in this study. Saito (2014) reported that four major themes emerged from the narratives of these women, all of which fall under the umbrella of finding meaning after a loss. Similar to Attig's (1996) statements regarding bereaved individuals, the first theme from Saito's participants indicated that these widows had to relearn how to live new lives and be in the world without their husbands – and through this process, they also had to relearn who they were (Attig, 1996; Neimeyer, 2001). The second theme identified by Saito (2014) indicated an acceptance of human finitude and solitude and a reminder of participants' mortality. The third theme presents a parallel finding to Neimeyer et al.'s (2006) findings on continuing bonds with the dead. The participants in Saito's (2014) study reported that they engaged in activities such as rituals from their native culture that helped in bereavement adjustment and provided meaning and consolation in their lives as well. The fourth theme involved reengagement in their communities through activities in Japanese American faith communities, which became a source of practical, emotional and spiritual support for these women.

To summarize, results of previously published research indicate that loss is traumatic for most people, especially if the loss is significant such as the loss of a parent, and that the death of a loved one is challenging for the bereaved. While some individuals respond to loss resourcefully, others experience complicated grief; research has shown that 20% of bereaved individuals experience extended crisis in meaning after the loss of a loved one (Bonanno et al., 2002, 2004). Furthermore, individuals who cannot make

sense or find meaning in loss may lose interest in the world around them (Neimeyer &

Anderson, 2002). Meaning reconstruction theory offers a different perspective. Research

has shown support for meaning reconstruction as a major constructivist contribution,

especially regarding work with individuals who experience complicated grief (Neimeyer,

2006).

Methods and techniques for meaning reconstruction. Constructivist

counselors who incorporate meaning reconstruction in grief work believe that human

beings are inveterate meaning makers who come to therapy with stories or narratives

(Neimeyer, 1999; 2001). They recognize that through this process of telling and retelling

the story of loss, healing can take place (Neimeyer, 1998, 1999), though this must begin

with the establishment of a trusting relationship between the counselor and the client.

The constructivist counselor is actively engaged and prepared to listen to the

client's story of loss. Narrative work used in meaning reconstruction often involves

strategies that engage clients both cognitively and affectively (Neimeyer, 1999). There

are a variety of methods and techniques counselors use in narrative work. For example, a

counselor working with a client who experienced sudden or traumatic loss and who has

difficulty discussing her story might have the client write about the trauma in a session.

The counselor may have several sessions involving writing exercises. Even the mere act

of writing about a traumatic experience has been shown to be therapeutic, to improve

subjective and somatic functioning, and can dramatically increase one's sense of well-

being (Pennebaker, 1993).

Constructivist counselors believe that people continually *reauthor* their life stories through reflexivity, interpretation, and reinterpretation of what happens in their lives (Gillies & Neimeyer, 2006). Through meaning reconstruction and narrative approaches, counselors provide a safe and therapeutic space to allow clients the ability to talk about their stories of loss. Counselors are merely facilitators in the process. Together, counselors and clients co-create new meaning structures as clients tell their stories (Neimeyer, 1999). The goal of narrative work in meaning reconstruction is to "use some form of writing to promote reflection on and integration of loss" (Neimeyer, 1999, p. 71). The goal of therapy is to facilitate the meaning making process by helping clients re-story or rewrite a new narrative, one that reflects on their old narrative and then incorporates their new reality that assimilates loss into a 'master narrative' (Neimeyer, 2001).

Chapter Summary

Research has demonstrated the impact of end-of-life caregiving on caregivers. Home-based care is the choice for many chronically ill parents. However, many adult children are unprepared and lack the skills necessary to provide care in the home. Research has also indicated that the graying of America is well underway, which will result in an increase in family caregivers. Historically, women were typically the caregiver of the home and have continued to assume this role as a parent ages. Today, as home-care increases, other family members partake in caregiving duties and therefore, home-based care has become a family matter. The role of the primary caregiver, however, remains to be a tremendous responsibility and a journey that can be challenging. Providing EOL care is a challenge in and of itself. In addition to the many

tasks of providing EOL care to a dying parent, the adult child caregiver must manage the

emotional upheaval that occurs within families. As death approaches, stress levels

increase impacting an entire family system. After a death and in loss and bereavement,

individuals search for existential answers. Finding meaning or the process of meaning-

making in bereavement is a necessity and can help the bereaved make sense of loss.

Meaning reconstruction, which is the therapeutic process of meaning-making, has been

shown help bereaved individuals make meaning after a loss. The voices of adult children

who have provided home-based end-of-life care can further illuminate the issues and

complexities faced by middle-aged caregivers. Through my research, I intended to

expand upon what professional counselor have known about end-of-life caregiving and

offer perspectives from the unique experiences of participants in this study to inform

counseling practices.

CHAPTER THREE

Methodology

Because of the lack of research on end-of-life care, particularly home-based end of life care and meaning reconstruction, the goal of this study was to illuminate the issues and complexities of providing end-of-life care for a parent and how meaning, if any, can be made of the experience and/or after a loss.

Research Questions

The following research questions guided this study:

1. What was the experience of adult children who assumed the role as primary caregiver during in home-based end-of-life caregiving of their parent?

2. How do adult children caregivers attribute meaning after post intensive caregiving of a parent?

In this chapter, I explain in the methodology I used, including information about my research design, demographics, sampling procedures, methods of data collection and analyses, and efforts to maximize trustworthiness

Research Paradigm

Qualitative research is based on the ontological belief that reality is subjective, that it cannot be measured objectively as with quantitative research (Creswell, 2007, 2009). In fact, qualitative research is similar to counseling in that both researcher and counselor are interested in the lived experiences of an individual. Further, in qualitative research, the researcher investigates with the belief that there is a co-construction of meaning and multiple truths or answers to questions (Merriam, 2009). Qualitative

researchers, therefore, are interested in an individuals' perception and how they make

sense of and interpret their experiences (Merriam, 2009).

The goal of this qualitative study was to provide a deeper understanding of the

unique perspectives of participants, both individually (through individual interviews) and

collectively (through a focus group) as a means to identify the commonalities that existed

across these perspectives. Therefore, a qualitative inquiry was best suited for this study.

In addition to my research questions aligning well with qualitative inquiry, my belief

system is congruent with social constructivism and the epistemological perspective that

truth exists through multiple perspectives, that is, reality is socially constructed and

influenced by cultural, historical and political forces (Hays & Singh, 2012; Merriam,

2009). Through prolonged engagement with my data and consultation with my

participants, I identified relevant themes that best answered my research questions. Next,

I present a description of participants and describe sampling procedures.

<div align="center">**Procedures**</div>

Participants and Sampling

Participants in this study were recruited and selected using purposive sampling

methods, an approach that focuses on a group of participants that are partners in helping

the researcher discover, understand, and gain insight into the phenomenon under study

(Hays & Singh, 2012; Merriam, 2009). I used convenience sampling to locate

participants based first on those who met my research criteria and next on those who

were most available. Furthermore, I employed a snowball technique (Merriam, 2009) as

a means to build upon the momentum of locating enough participants to meet my desired

sample and was successful in locating enough participants for this study. Although a

desired sample size of 10-12 tends to be a suggested range as a starting point (Merriam,

2009), qualitative methodologists suggest that sample size should be consistent with a

minimum number that is best guided by the study's purpose (Miles & Huberman, 1994).

Keeping this in mind, I was flexible and aimed for a sample size of 10-12 participants.

After interviewing ten participants, I was able to identify enough categories and patterns

that helped to answer my research questions. Additionally, by my ninth and then tenth

interview, I was not gaining any additional information or insight, which was an

indication that I had reached data saturation (Merriam, 2009).

 To address my research questions I first contacted directors of regional hospice

and homecare facilities and churches (See Appendix A-Recruitment Email) for assistance

in the recruitment of participants in the Northeast United States. The purpose in choosing

regional hospice facilities and churches was to help locate individuals who may have

utilized hospice services or clergy who have provided counseling or other services during

the time they provided EOL care for their parent. Also, with the assistance of directors

and clergy, I was able to distribute flyers to locate additional participants.

Sampling Procedures

I contacted potential participants by phone to discuss the purpose of the study,

procedures in terms what participating in this study would involve, and their rights as

volunteers. I then made arrangements for individual interviews, which took place in

private settings, arranged with each participant. After completing the first interview, I

asked participants to refer other individuals to me who might be interested in

participating in the study, hence, snow ball sampling (Merriam, 2009). I invited each

person who agreed to participate in my study to meet with me for two interviews. After

completing two rounds of interviews, I invitied all participants to attend a focus group.

Given the significance of loss of a parent and understanding the challenges that

bereaved individuals might experience, I was mindful in establishing a criterion that

participants had been primary caregivers of their parents and provided home-based end-

of-life care approximately one to three years ago. While grief theorists agree that

individuals uniquely experience greiving (e.g., Neimeyer, 1998, 1999; Stroebe & Schut;

1999; Worden, 2009), most would concur that full resolution of mourning takes place

between one to two years, especially in the loss of a close relationship (Worden, 2009).

Through the use of mulitple interviews, my participants had the opportunity to

examine retrospectively with me their experiences as caregivers. This exploration helped

them process their experiences and for some participants allowed them to make meaning

of those experiences. Lastly, I thought it was important to see beyond my own personal

and professional goals for my study. I also wanted my participants to benefit from this

study. For this reason, I provided $25 gift cards for every individual who participated in

two rounds of interviewing. I provided an additional gift card to volunteers who

participated in the focus group, as compensation for their additional time and energy.

Demographics

I interviewed ten (10) adults of varying ages (32-64; M=48), nine females and one

male. The participants resided in different urban and suburban locations in the northeast

United States. All participants identified as married and white and described their

religious or spiritual beliefs as Roman Catholic, Protestant, Quaker, and one participant

identifying as not having any religious affiliation but describing herself as a spiritual

person. Each participant assumed the role as primary caregiver and provided home-based

end-of-life care for a parent. Please see Table 1, Description of Participants, in chapter

four for additional information on the sample.

Data Collection

I chose a research design that consisted of two rounds of interviewing and one

focus group to help crystalize my findings (Merriam, 2009) and best answer my research

questions.   Upon written consent, I conducted two rounds of in-person, individual

interviews with each primary caregiver in the location of his or her choosing. While in-

depth interviewing does not pose any serious threat or life threatening harm, I was aware

of the potential of risk. There is, for example, a measure of intimacy involved during the

interview process (Seidman, 2013) as I was asking personal questions that involved grief

and loss and asked participants to reflect and share their special moments that surrounded

the death of their parent. I realized that there could potentially be some discomfort or

emotional distress during the interview process. Participants were aware of these risks

and understood their right to stop at any time during the interview or withdraw if need be

without any penalty (Seidman, 2013). My informed consent forms clearly stated the

potential risks associated with this study (see Appendix B). Also, I outlined the

guarantee of confidentiality and the benefits for participating in this study as well

(Creswell, 2009).

Generally speaking, qualitative researchers conduct interviews that are usually between 60-90 minutes long (Merriam, 2009; Seidman, 2013). The key with any qualitative study is to obtain rich data, which begins with asking good questions (Merriam, 2009). I interviewed each participant for the suggested 60-90 minutes, using a semi-structured interview format with open-ended questions designed specifically for individual interviews and the focus group (see Appendix C). The use of open-ended questions enabled participants to reflect on and select the manner in which they chose to respond (Krueger, 1998). I digitally audio recorded all interviews using two recorders to ensure that I had a back-up in the event one recorder was to fail.

Seidman (2013) maintained the importance of "asking participants to reconstruct rather than ask individuals to remember as reconstruction is based both partially on memory and what the participant now senses is important about the past event" (p. 90). After beginning each interview with general introductions, I asked the interviewees to reconstruct their stories. I found that each participant was eager to share her or his experience and had something important to tell. I also noticed participants' emotional responses as they shared their stories. It appeared to me that all participants had experienced difficult caregiving journeys. This reflexive process of having participants share their story allowed for deep reflection of the entire experience. Each participant was engaged and immersed, as was I, in their story from beginning to end and beyond. After each interview, I recorded notes in my reflective dissertation journal regarding any thoughts and impressions that arose for me during the interview.

I offered participants the opportunity to review transcripts of their first interview as a form of member checking. Some participants preferred to discuss the themes in person during the second interview without receiving a copy of the transcript in advance. Whether or not participants chose to review the full transcripts before our second individual meeting, I discussed key themes with them in person during the second interview. This discussion offered the opportunity to verify the accuracy of my interpretations while also providing an opportunity for participants to share any new information or additional insights (Merriam, 2009).

Upon completion of the second round of interviews, I invited all participants to participate in a focus group. The purpose of the focus group was to clarify research findings from the two rounds of interviews, further explore themes that I identified as emerging across the interviews, and to ascertain further perspectives and experiences from participants (Merriam, 2009). I also used the focus group as an additional strategy of building trustworthiness through the means of member checking and gaining additional information from participants (Hays & Singh, 2012; Merriam, 2009). The focus group further provided an opportunity for the validation of participant experiences (Merriam, 2009), which I found was beneficial to participants as evidenced by the positive feedback I received from all focus group participants.

Four female participants, all of whom participated in the individual interviews, volunteered to attend a focus group. Before the onset of the focus group, I created a focus group interview guide (Appendix D). I began the focus group by reiterating the purpose of the group and my role as a facilitator, after which participants and I

established ground rules. I created and used a semi-structured interview guide to initiate

a dialogue among participants. In the interest of maximizing time for discussion during

the focus group, I created a thematic sheet (see Appendix E), which contained the themes

that I had identified at that point from across the individual interviews. Participants had

the opportunity to read and expand upon any of the themes that resonated with their

experiences and to offer new themes based on their experiences. The advantage of this

format was that it encouraged the interaction among participants and allowed participants

to add additional information while listening to similar experiences they might not have

otherwise been willing to share during the individual interviews (Krueger, 1998).

A possible disadvantage to the focus group format is that participants may have

perceived pressure to conform to and agree with others (Krueger, 1998). Another

potential drawback to the use of a focus group is that the possibility that individuals may

not have felt comfortable in sharing with others (Krueger, 1998). In keeping these

potential issues in mind, I carefully planned ahead by having my focus group meet in a

location that was convenient for all who wanted to participate. I also created a safe and

trusting environment where participants felt comfortable sharing their stories, and I

monitored the comfort level of participants. I also provided light refreshments during the

interview.

Aforementioned, due to the delicate nature of this study, I was mindful of the fact

that participants might still be grieving the loss of their parents. Although a sufficient

amount of time had passed since the two rounds of interviewing, I was aware that our

conversation encompassed the illness and death of their parents. To this point, I

understood well my roles as both researcher in this study and as a licensed professional counselor and was prepared to debrief the interview with participants. For example, I checked in with each participant after the individual and focus group interviews to see how he or she was feeling. I wanted to be sure that they felt heard and that both they and I understood their experiences. Seidman (2013) maintained the importance for researchers to support participants during the interview process by being aware of non-verbal and verbal behaviors, as they are good indicators as to whether or not they feel supported and understood during the interview. Further, I believe that as a licensed professional counselor I have the skills to notice and appropriate handle emotional responses. While these skill sets came in handy, I was still mindful of my role of researcher, that is, the main instrument of data collection (Merriam, 2009), and ensured that participants felt supported throughout the interviews. I also reminded participants to take liberty in stopping the interviews at any time if they needed a break. Lastly, I was prepared to share the names of support groups and counseling resources available if needed.

Data Analysis

I began analyzing my data from the very first interview, as suggested by Merriam (2009). I transcribed each interview verbatim and journaled my impressions in my dissertation reflexive journal as a means of recording the impressions, feelings, and reactions I had after the interview, any hunches I had, and noted anything I wanted to follow up with in the next interview (Merriam, 2009). I organized and managed data carefully throughout the process. I kept two binders, which contained all of my

transcribed interviews, one for the first round of interviews and the other for the second

round of interviews and stored them in a locked cabinet. I further describe in detail this

process in two stages.

First Stage

In the first stage, I conducted two rounds of interviewing with participants. I

employed a rigorous coding process to identify themes, which began with open-coding of

each transcript. Open-coding is a process that helped me identify bits of information or

anything that struck me as potentially relevant to my study (Merriam, 2009). For

example, I made notations in the margins of my transcripts, which may have included

some of the words of my participants or short segments that seemed relevant in

addressing my research questions. After recording these initial codes on every transcript,

I began to identify and make a note of any patterns that were relevant. I organized all

emerging patterns on a separate sheet and color-coded all tentative themes. Through

constant comparative analysis, I was able to systematically compare sections of text and

flesh out initial patterns that no longer held value (Merriam, 2009). I also referred to the

narratives I had written after each interview to compare the emerging themes I previously

identified while coding and began building tentative themes and sub-themes (Merriam,

2009). Although tedious and time consuming, I realized the importance of this process.

Once I identified tentative themes, I found myself renaming themes and recorded my

ideas and process as these themes developed. Additionally, to ensure that my tentative

themes and sub-themes made sense, I talked through my process and developing themes

with my methodologist and two peer debriefers, both of who have doctoral degrees and

experience in qualitative research. I employed intercoder agreement checks (Miles & Huberman, 1994) with one peer debriefer to provide for consistency as I coded transcripts and worked with my other peer debriefer through the iterative process of renaming themes. Throughout this process, I continually reflected back to my research questions to ensure that I was answering them and to see if new ones emerged. The first stage of data analysis helped me uncover preliminary findings. I recorded thoughts and questions on which I wanted to follow up in other interviews. I then compared what I had originally found from the first set of interviews and confirmed findings during the second stage of analysis (Merriam, 2009).

Second Stage

During the second stage of data analysis, I collapsed my raw data and began to refine and rename themes that I identified from across the interviews (Merriam, 2009). During this part of analysis, I conducted a focus group, which offered the opportunity for me to hear my participants once again in a different setting and to observe non-verbal behaviors as they shared their stories with other participants. The focus group also helped check my findings and the accuracy of how I had identified emerging themes from the individual interviews, hence, became a form of member checking, and an additional strategy aimed at achieving trustworthiness (Merriam, 2009). I followed the same protocol when analyzing the data from the focus group. That is, I transcribed this group interview verbatim, conducted two rounds of coding, wrote a narrative for this focus group interview, and compared and clarified participant responses from individual interviews. Additionally, I reviewed my overall findings through constant comparative

methods and, once again, identified tentative themes and sub-themes from across the

interviews and the focus group. As I identified themes, I renamed them until they each

accurately reflected the data (Merriam, 2009).

Trustworthiness

Trustworthiness is a qualitative term, often considered synonymous with validity

and reliability in quantitative methods, which encompasses the truth, value, rigor,

credibility, authenticity (Lincoln & Guba, 1985), and confirmability (Lincoln & Guba,

1985; Merriam, 2009) of a study. To maximize trustworthiness of my study, I kept an

audit trail, which provided physical evidence of how I collected data, how I identified

categories and themes, and how I made decisions (Hays & Singh, 2012; Merriam, 2009).

Items in my audit trail consisted of a timeline of my research activities, demographic

sheets, interview guides, field notes, narratives of each participant, and reflexive journals.

I also kept research notebooks (four to be exact) that I used to record my thoughts,

impressions, and ideas during the recursive process of data analysis, notes on

consultations with my dissertation chair and methodologist, and thoughts after speaking

with my peer debriefers.

My results culminated in rich, thick descriptions that contextualized my study,

also a strategy used to achieve transferability (Merriam, 2009). In this document, I

included information about the research setting, participants, and the process of data

collection and analysis in detail so that readers can find ways to potentially apply these

findings to comparable settings (Merriam, 2009). In the next chapter, I include

representative quotes and important statements from participants as a way to help readers

understand how I identified themes (Merriam, 2009). Next, I discuss how I located

myself as a researcher and further explain some of my experiences that I believe added

meaning to my study.

Positionality

As the researcher of this study, I was aware of how my professional and personal

experiences, assumptions, and beliefs may have potentially impacted the outcome of this

study. I was also mindful that participants might perceive power differentials and how

that might influence the co-construction and sharing of knowledge and the ideas that

emerge between researchers and participants (Hays & Singh, 2012). Moreover, I took

my role as researcher and as the primary instrument of data collection seriously.

Therefore, I carefully reflected and recorded in my reflexive journal any personal and

professional biases throughout this research process that would potentially influence in

any way the outcomes of this study.

My years as an educator, counselor, and learner have led to my interests in end-

of-life issues. Early in my career I became inspired by the work of Elisabeth Kübler Ross

and years later volunteered for hospice. I was fascinated with the family dynamics that

surround end-of-life care for a loved one. In addition to having the privilege of working

with many families as a volunteer, I also experienced the role as the primary caregiver of

my father and observed other family members providing care for loved ones.   However,

as fate would have it while working on my dissertation and in the middle of data

collection, my mother received a terminal diagnosis of lung cancer and a poor

prognosis—that she had only months to live. There I was, finding myself once again in

the role of the primary caregiver, this time for my mother. I would continue in that role

and provide home-based end-of-life care for her in my home until her death on August

28, 2015. It is also of note that while my family and I endured a tremendous loss, my

experience left me with an empathic understanding for caregivers who have a very

difficult and tumultuous time while providing care for a dying parent. After my

experiences, I could humbly relate to my participants, yet, was aware of the potential for

how my experiences might influence my interpretation of data. In addition to reflecting

on caregiving for my mother in my dissertation reflective journal, I processed my

experiences with my dissertation chair and methodologist. I consciously put aside my

feelings and biases and honored and respected my participants' personal journeys as

caregivers. I believe that my skills as a professional counselor contributed well in this

regard.

Chapter Summary

Ten primary caregivers participated in this qualitative interview study to give

voice to caregivers who provided home-based end-of-life care for terminally ill parents.

Four of these participants also volunteered to participate in a focus group, which I used as

an additional strategy (e.g., member checking) and a means for obtaining additional

information. I transcribed and analyzed all interviews in two stages, which helped me

identify and determine patterns and themes across the data. I also maintained an audit

trail to maximize trustworthiness and crystalize the findings of this study. I present the

analysis of data and findings of the study in the following chapter.

CHAPTER FOUR

Findings

The goal of my study was to explore the experiences of and meaning made, if any, of adult children who had provided home-based end of life care for a terminally ill parent. In this chapter, I present the findings from my study, which included two rounds of individual interviews and one focus group. I begin by presenting a description of the participants and the focus group. I then provide an overarching summary explaining how I analyzed data and identified themes and sub-themes from individual interviews and the focus group.

Description of Individual Participants and Focus Group

I conducted individual interviews with 10 participants; eight Caucasian females, one Caucasian male, and one Caucasian female who identified as Italian-American. The ages of participants ranged from 32-64 years with a mean age of 48. All participants in both individual interviews and the focus group provided home-based end-of-life care for a parent between one and three years before participating in the study. See Table 1 for a description of the participants, including their age, gender, race/ethnicity, marital/partner status, geographical proximity to parents at the time of caregiving, and religious/spiritual beliefs or practices.

Table 1

Individual Interview Demographics

Parti-cipant	Age	Gender	Race/ Ethnicity	Marital/ Partner Status	Geographical Proximity at time of caregiving	Religious/ Spiritual Beliefs or practices	Children
P_1	57	Female	Caucasian	Married	3 hour drive to parent	Quaker	2 Teens
P_2	43	Male	Caucasian	Married	Lived next door	Roman Catholic	1 Toddler
P_3	60	Female	Caucasian	Married	Lived in participants home	Protestant	2 Young Adult Children
P_4	42	Female	Caucasian	Married	10 minute drive to parent	Roman Catholic	3 Young Teen-agers
P_5	32	Female	Caucasian	Married	8 mile drive to parent	None	1 Toddler
P_6	64	Female	Caucasian Italian-American	Married	In participant's home	Roman Catholic	4 Grown Children
P_7	55	Female	Caucasian	Married	10 minute drive to parent	Roman Catholic	4 Young Adult Children
P_8	60	Female	Caucasian	Married	1 block away to parent	Roman Catholic	3 Young Adult Children
P_9	55	Female	Caucasian	Single	Lived in parent's home	Roman Catholic	None
P_{10}	63	Female	Caucasian	Married	Lived in participant's home	Roman Catholic	3 Young Adult Children

Four participants, all of whom engaged in the individual interviews, volunteered

to attend a focus group, which took place after the completion of the second round of

individual interviews. The ages of focus group participants ranged from 55-63 years with

a mean age of 59. Participants for this study chose their pseudonyms, however, to ensure

anonymity I use numerical notations when referring to participant quotes and individual

participant statements.

I identified the following three major overarching themes and eight sub-themes of

this study: Unchartered Territory (sub-themes: An Uncertain Role, Caregiver Distress,

and Struggle for Balance), Transitions of Uncertainty (sub-themes: Unbearable Endings,

and Support Essentials), and Multiplicity of Meaning (sub-themes: Caregiver Regret,

Comforting Signs, and Unexpected Gifts). It is of note that these overarching themes are

representative of a process in that each major theme builds upon the next. This process

also best illustrates a story of how participants experienced caregiving journey. That

journey began with the onset of caregiving when participants first committed to caring

for their parents (e.g., unchartered territory). Their stories continued through how they

experienced the final days and hours until the death of their parent, a critical point of the

caregiving trajectory and one filled with uncertainty about the ending of their parents'

lives (e.g., transitions of uncertainty). Their stories ended with how participants made

meaning of their experiences (e.g., multiplicity of meaning). See Figure 1 for a visual

representation of identified themes and sub-themes of the study. After Figure 1, I include

a detailed narrative presentation of my findings related to each overarching theme and

sub-theme.

Figure 1. Emergent Themes
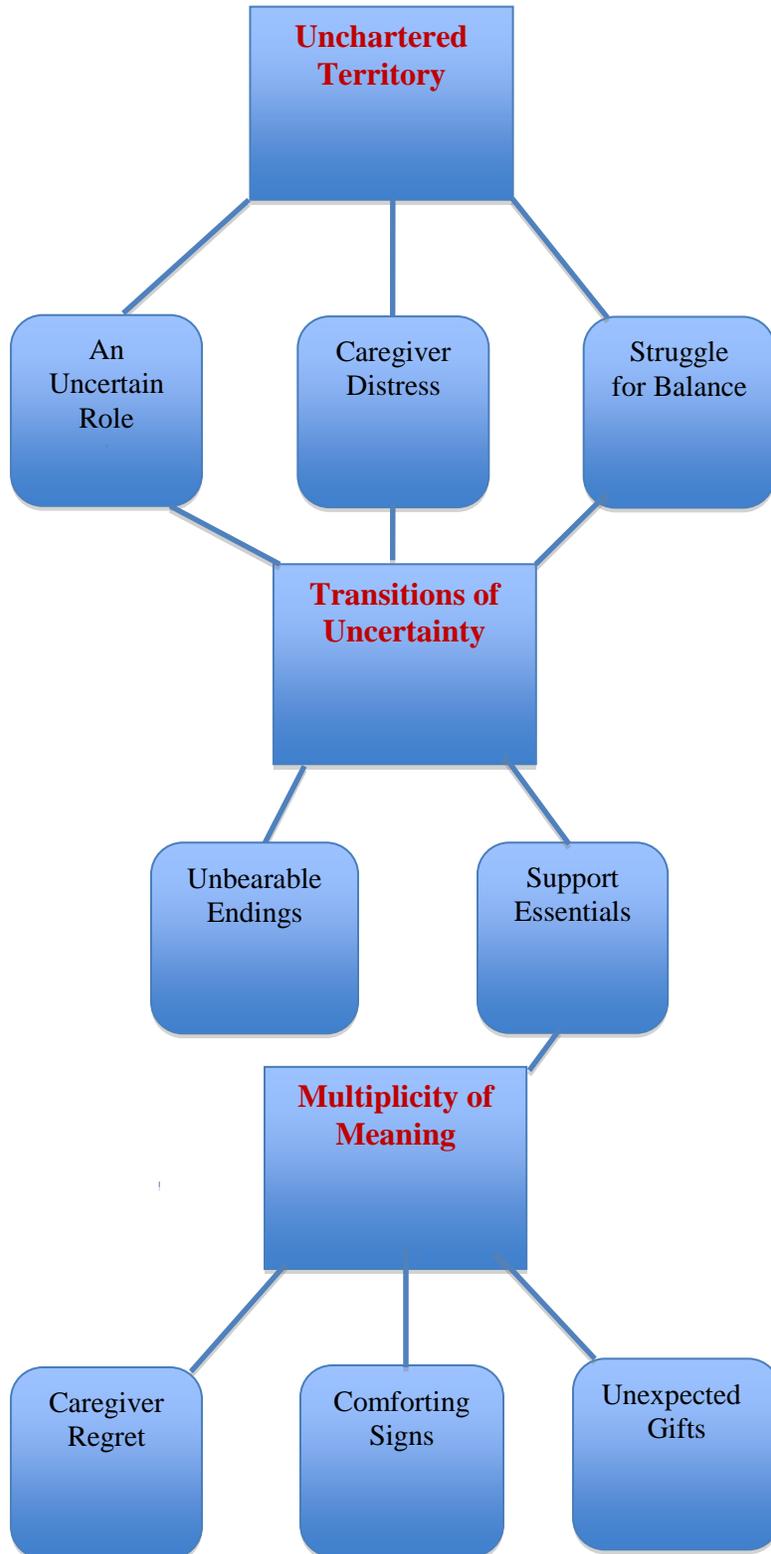
Unchartered Territory

Unchartered Territory is the first major overarching theme I identified as it encompassed the initial experiences of participants as they first assumed the role as caregiver. Although each story was unique, there were commonalities of distress, uncertainty, unanticipated struggles, and despair during the end-stages of caregiving. In general, participants reported that they were unprepared for their caretaking roles, always racing behind, and trying to maintain balance. These finding are supported by other researchers (Aoun et al., 2005; Gomes et al., 2012, 2013; Pinquart & Sörensen, 2006; Redinbaugh et al., 2003; Stajduhar, 2013) who have found that caregiving is challenging and stressful for the caregiver and that most are unskilled and unprepared to provide care for a loved one.

Some of the distress that participants experienced was due to sibling and family relational tension within the family. In fact, most participants reported tension between siblings or an extended family member during their EOL caregiving experiences. As a result, I had initially included *family strife* as a sub-theme of Unchartered Territory. However, after analyzing all data through constant comparative methods to reexamine the interrelationships of sub-themes and conferring with my methodologist and dissertation chair, I concluded that the additional stressors produced from family strife contributed to the imbalance felt by participants, which I further explain under the sub-theme *Struggle for Balance* later in this chapter.

As participants set out on their caregiving journey, an unexpected endeavor for most participants, it was a job that was unfamiliar and one that did not come with

directions. Skills had to be learned quickly, and tasks became overwhelming and even

more complex as illness took hold of their parents. I identified Unchartered Territory as

my first over-arching theme, based on the thoughts, feelings, and perceptions of

participants captured from each individual's narrative, across the individual interviews,

and collectively from the focus group interview. This theme represents the start of

providing home-based end-of-life care for a terminally ill parent and the difficulties that

participants experienced as they navigated through to the very end of their parent's life.

The phrase Unchartered Territory seemed to represent well the overall picture presented

by participants of what it was like for them to take on the new job and role as primary

caregiver for care for a terminally ill parent. This new role was daunting, uncertain, and

lacked stable ground, resulting in a journey that was completely unknown, however,

paradoxically, a labor of love, according to participants. As difficult a journey as it was

for participants, it appeared that each participant was genuinely concerned for their

parent's care, dignity and comfort until the very end.

Parents' illness trajectory had a general path, yet that trajectory remained

unpredictable. In other words, there was no clear way for participants to predict how

their parent would fare along the way. Participants reported feeling unprepared due to

the unpredictable nature of their parent's illness. Although some participants reported

receiving instructions on how to provide care in the home, according to participants, there

always seemed to be unexpected events along the ways, which made caregiving difficult.

For example, some participants reported unexpectedly having to make frequent trips to

the emergency room. Other participants reported many incidents of accidental injuries

(e.g., falls) or spikes in a fever that resulted in frequent trips to the hospital. Most participants described their caregiving experiences likened to a roller coaster ride with many twists and turns, resulting in much uncertainty and high levels of anxiety.

As primary caregiver participants continued on the path of caring for their terminally ill parent, the natural balance of their family was also temporarily catapulted into disequilibrium. Immediately family members had to adapt to the new situation, and once again, there was no way for the participants to predict how their siblings or extended family members would respond to the decisions that the primary caregivers had to make along the way.

Unchartered Territory Subtheme One: An Uncertain Role

I identified An *Uncertain Role* as the first sub-theme of Unchartered Territory as it illustrates how participants felt about their new roles as primary caregivers of their parents. As a researcher, I wanted to understand what it was like for participants to first assume this new role, including what their thoughts and feelings were regarding the onset of their caregiving journey. Participants spoke about their reactions to first learning about their parent's illness. All expressed shock and sadness, but more importantly, they felt catapulted into their new role. It seemed as though participants felt caught off guard, and some participants resented the temporary disruptions in their lives. I could sense the discomfort in some participants as they reported feeling somewhat resentful about taking on their new role as caregiver for their parent. In fact, most participants reported feeling guilty for admitting how stressful and difficult caregiving was. Some participants

referred to caregiving as "taking ownership" of their new role, and some described their experience as endeavoring on "completely unknown territory."

Upon taking full responsibility of their terminal parents, participants spoke about the preparation that was involved in providing home-based care. According to participants, there were many different tasks involved in caring for a parent. Much depended on the type of illness from which the parent suffered. The first order of business for participants, therefore, was to gather as much information on their parent's illness. Participants reported having to re-organize their lives, prepare their families, restructure their homes or their parents' homes, and emotionally and physically prepare themselves for their caregiving journeys.

Most participants reported feeling uncertain and distressed about their new role as primary caregiver. One participant, for example, had anticipated that in the future, she would bear the responsibility of caring for her parents. She did not, however, expect to care for two parents simultaneously, and within a short period. This example illustrates how the onset of a loved one's illness can immediately impact the life of a caregiver and their family at any given point.

All participants reported high levels of stress, and that their roles were complicated and overwhelming. For example, some participants spoke about having to learn how to administer medicines and use medical equipment to assist their parents. In addition to attending and managing their parent's care, they also coordinated doctors' appointments and visitations from extended family and friends. For example, one participant spoke about the stressors of having to prepare his mother for guests and

resented unscheduled visits. The amount of time that was involved in caring for their

parent became all- consuming for participants.

Only one participant in this study reported having some previous medical

knowledge and previous caregiving experience. Most participants, however, reported

that they had to learn "on the job" and navigate the difficult waters of illness trajectory

and medical systems. While participants had received direction from health care

professionals, there was no clear way to predict the course of their parents' illness, which

made caregiving more uncertain. The following section of this chapter contains

statements made by participants that illustrate the perspectives and feelings regarding the

initial experiences of caring for a terminally ill parent.

Participant 1 found herself left with the job of having to care for her terminally ill

father. She and her brother had made no previous agreements regarding who would

provide care for her father. Rather, there was an unspoken assumption that she would

assume the role and responsibility of caring for her terminally ill father, especially being

she was the only daughter. This unspoken assumption may be in part due to cultural

norms here in the U.S. that women, although most are now in the paid work force, are

still expected, thus assume the duty and responsibility of caring for aging parents

(McMillan, 2005). Further, it was clear that this participant also felt obligated to care for

her ailing father being that she had more flexibility in her schedule.

Participant 1 began her new role as a long-distance caregiver until her father's

care needs increased. Within months Participant 1 stayed by her father's side until his

death. Participant 1 shared: "I was the one who had the most availability. I have a half-

sister who really wasn't emotionally or physically able to and my brother he wasn't able

to either. Someone had to take the reins." After this response, I probed a bit more to

understand what it was like to assume the role and responsibility of caring for her

terminally ill father and Participant 1 stated:

> It was very daunting and completely unknown territory. And all along we thought
>
> it was going to be six months. It was like a descending and never reaching a
>
> stable place. Every time we thought we had everything in place, he got to a more
>
> needy place. It was just a whirlwind of six weeks. (P_1)

In her statement above, Participant 1 used the words *daunting*, *completely unknown*

territory, *descending,* and *whirlwind*, words that described succinctly the experience of

first assuming the role as primary caregiver. There is no climbing or improvement with

end-of-life caregiving. Rather, the experience of providing EOL care is a rapid descent

that involves some ups and mostly downs, until death brings their job to a screeching

halt.

In this next statement, Participant 3 detailed some of the caregiving duties she

assumed while providing care for her mother and how she felt about these:

> I had to learn to give her shots in her stomach. I still, till to this day, can't believe
>
> I did it because it was so scary for me to do. I would start the day where I would
>
> have to get her out of bed, get her washed, lug the oxygen in here. Almost every
>
> week for about six weeks in a row she would constantly get pneumonia, and she'd
>
> have to be rushed by ambulance to the emergency. And we'd be sitting in the

emergency room for hours. So she had a lot of hospital stays the last six months

of her life. It was always something.

Participants 3 also spoke about her initial experience of becoming the primary caregiver

for her mother. Although she was the youngest of three daughters, she had the closest

relationship with her mother and was more financially able to care for her mother. It

seemed that participants experienced many complexities in their roles and as their

parent's health declined, their experiences became more intense. All participants

described their experiences as constantly running, and having no time for themselves or

their families, which made it more impactful. For example, some participants described

how they would run back and forth to doctor appointments, and made frequent trips to the

emergency room as their parent's health declined. One participant reported having to

quit her full time job to fulfill her caregiving responsibilities for two parents. Some

participants reported working full time in addition to having their caregiving roles. These

findings are compatible with findings by other researchers who have suggested that mid-

life caregivers experience the highest levels of caregiver burden (McMillan, 2005; NAC,

2009).

The majority of participants cared for their parent in their parent's home, which

required the primary caregiver to make frequent trips to the parent's home in addition to

coordinating doctor's visits, and managing and providing hands-on care. Providing care

in a parent's home is difficult and can be particularly challenging if siblings still reside in

the home with the parent, as reported by some participants. Participant 4 added:

I was the one who made all the appropriate measures and steps in getting someone

in the home. I have to say that I thought it would be less work than I thought it

would be. Things got more complicated because of other family members. It was

a struggle. It was very harried, confusing, and constant.

Participant 4 reported that caring for her father became more involved than she had

originally thought. In fact, most participants were surprised by the amount of work that

was involved and felt caught off guard by the challenges they encountered while caring

for their parent.

Participant 10 had forecasted that she would at some point be caring for her aging

parents, although did not anticipate that she would have the sole responsibility of caring

for both parents, especially being that her brother lived closer to her. In her statement,

Participant 10 described briefly the difficulties of organizing and preparing for caretaking

and then expressing her disappointment for her brother's lack of support. Her example

succinctly depicts a caregiving role that although carefully coordinated, her role became

more uncertain as she found herself caring for her parents alone, a job that became

distressing, and resulted in having to juggle many responsibilities which resulted in a

temporary life of imbalance. Participant 10 explained:

I was able to secure an aid to come in with Mom. I'm still working full-time and

was able to work three days a week from home and then go into the office two

days a week. I'm juggling all this, and in the meantime, my brother's working

full-time, but he's not really there supporting me. My husband was really the one

who was stepping up and helping, but it was fully on me. (P_{10})

In addition to the expectations that women typically assume the care of the aging parents, there are times when caregivers are simply left with the responsibility of caring for an aging or terminal parent due to the fact that there was no one else who could fulfill this role.

Participant 2 had a unique caregiving experience to share. First, he was the only male in this study and was able to offer a different perspective, that being an experience of an adult male caregiver of a terminally ill mother. Participant 2 described his initial experience of assuming the role as primary caregiver for his mother as difficult and stressful. He expressed frustration and resentment for his father's inability to assist him with caregiving responsibilities and described the impact caregiving had on him and his pregnant wife. Participant 2 stated, "My father had a hard time handling it so I became the person who would deal with her cancer." Participant 2 used the word "deal," which indicated some resignation to his new role as a caregiver being he was the only person able to care for his mother. Additionally, it was a job that became increasingly difficult, especially as his mother's illness took hold. Participant 2 also expressed frustrations with additional responsibilities he did not anticipate such as being the coordinator of visitations and needing to attend to nursing duties, adding additional pressure to his role. He reported feeling stressed and always on edge. His statements also illustrate the complexity of this uncertain role and the resentment that some participants felt for having the sole responsibility of primary caregiver. Participant 2 explained:

> We had to monitor her temperature and stuff, and if that goes over a hundred
>
> point three, we would have to go the hospital, and we could spend, you know,

eighteen hours there or longer. And later on she had blood-clotting issues, and I

used to give her injections of heparin twice a day on a daily basis. So that

changed also, and also it changed as her. I mean I guess it's hard to say that

there's a constant like, time because unfortunately as she got sicker, the time

commitment grew. There were just things that – that come up that you really

can't control and, trying to manage those things (sighs).

Providing care in a home setting presented participants with many challenges. While

most participants were accepting and willing to take on their new roles, their initial

thoughts and impressions regarding caregiving were very different from their actual

experiences. All participants were surprised by the difficulties of providing care for a

terminally ill parent. Moreover, they did not anticipate the high levels of distress and

disruption they experienced and which would eventually impact their lives. *Caregiver*

Distress, my next sub-theme, illustrates how EOL caregiving took its toll on the

caregiver, affecting participants to varying degrees.

Unchartered Territory Subtheme Two: Caregiver Distress

End-of-life caregiving impacts the overall well-being of the adult child primary

caregiver. Participants reported high levels of anxiety, depression, anger, grief, and

sadness. Participants also reported physical ailments such as rashes, backaches, and

physical exhaustion. In addition to the physical and emotional impact of EOL

caregiving, participants reported high levels of stress due to the continuous monitoring of

their parent in the home, and they reported constantly feeling on edge and having little or

no time for themselves.

Although participants understood that their job was temporary, they reported

feeling as if caregiving was never ending. One participant commented, "Once you take

this role – it's yours." (P₁) It seemed that owning the role as primary caregiver meant that

there was no turning back. As a result, participants had to prioritize their lives and put

their energies and focus on their parents' care. All participants reported feeling

overwhelmed and consumed with caregiving responsibilities. Participant 1's statement

illustrates how physically impactful caring for a terminal parent can be.

> I really got myself quite sick and was not able to take care of myself during that
>
> time. I had some physical ailments that had to do with stress. I remember the
>
> bizarre skin rashes. It was just a lot of tension and stress.

While participants tried to manage their parent's care, they were also trying to engage in

joyful experiences within their own lives, yet found it difficult. The bittersweet tension

between positive life experiences and the realities of life such as watching a parent

nearing death bear down on the adult child caregiver. The suffering that adult children

endure while they provide care for their parent often goes unnoticed. As participants

tried to maintain composure and stay strong for their families, it seems that suffering in

silence took its toll.

Another participant (P₃) shared her experience as she provided care for both

parents over the course of ten years, including one year where she cared for both parents.

Her example illustrates the distress of EOL caregiving and the heightened levels of

anticipatory grief that caregivers experience as they watch a loved one decline.

Participant 3 explained:

It was both mental and physical and emotional - the emotions were horrific. I was

depressed because I couldn't handle all of it. It was pretty difficult. I had a lot of

different feelings such as sadness, guilt, and anger and never felt like I was doing

enough even though I was doing a lot. (P3)

Participant 10 found her experience emotionally difficult, especially as she

prepared for two of her grown children's engagement parties while caring for both of her

ailing parents. She stated, "I was swinging the pendulum of being elated for them and

being sad knowing that, you know, my mother and father were nearing their time. So it

was an emotional rollercoaster. A very big emotional rollercoaster." (P10). Participant 5

reported bouts of insomnia after caring for her father during his last days. She found it

extremely sad to see her father suffer at the end of his life and after his death and found

herself haunted by the images of his suffering. She shared, "I have nightmares every

night. I have to take medication to sleep at night because I can't sleep." (P5). The stress

continued well into bereavement.

Participant 6 provided nine years of home-based EOL care, having the most

experience of all participants in this study. She not only provided home-based EOL care

for both of her parents, but she also provided care for her in-laws and most recently, her

mother-in-law who was dying of Alzheimer's disease. Regardless of experience, the job

of primary caregiver is stressful and difficult, and a role that is uncertain. Participant 6

described her most recent experience with her mother-in-law:

My husband was too uptight and overwhelmed. It was very difficult; the whole

ordeal was difficult. It was like everything was dumped on me, and I felt I just

can't do this anymore. The stress level was high.

It was evident that each participant in this study suffered alongside their parent,

experiencing multiple stressors, high levels of anxiety and stress, and anticipatory grief as

they watched their parents decline from illness. The suffering that adult children

participants endured went unnoticed, until physical and emotional symptoms ensued.

Unchartered Territory Subtheme Three: Struggle for Balance

While navigating through unchartered territory, all participants encountered the

struggle of maintaining a balanced life. Whether caregivers had pre-school age children,

school-aged children, children in college, older children, or no children at all, all

participants reported that maintaining a balanced life while providing EOL care for their

parent was impossible. Responsibilities of work, family, and caring for their terminally

ill parent became all too consuming for participants. The stressors incurred from the

increased levels of responsibility continued to have a negative impact on the lives of

participants.

Providing home-based EOL care impacts the entire family household.

Participants made efforts to restore homeostasis in their busy lives. However, in spite of

their well-intended efforts, some participants admitted having experienced relational

tensions within their immediate families. For example, most participants reported that

caregiving caused additional strain on their marriages. Although participants felt

supported by their spouses at times, caregiving seemed to cause marital strain, producing more stress and imbalance, affecting their families.

Aforementioned, participants did not attend to their self-care in spite of their high levels of distress, which also contributed to a sense of imbalance in their lives. Participants described their lives as chaotic, never feeling that they were able to catch up. According to participants, it was nearly impossible to keep all family members happy and accomplish all daily tasks. Responsibilities simply added up; stress levels continued to build, and participants felt depleted. Participant 7, who had four children, three out of college and one away at college, noted the difficulties of managing caregiving responsibilities and family. She stated, "I was also dealing with some health issues with my husband so, it was difficult in that way, to try to balance both." Other participants with pre-school and school-aged children found it extremely difficult to manage the care of a dying parent as illustrated in the following two statements made by Participant 4 and Participant 5. Participant 4 stated:

> It was a constant stressor! I mean, my husband would come home, I was so
>
> exhausted from taking care of my father, the kids, and dinner wasn't done. I was
>
> rattled and always running, and the house was always just so chaotic. (P4)

Similarly, Participant 5 shared:

> I had my daughter, so it was kind of hard for me – and she was young at the time -
>
> just turned one. So it was hard for me to go back and forth with her and it
>
> affected my marriage too. I didn't know how to balance my time. It was very
>
> difficult for me. (P5)

Participant 1 shared her experience, which had originally started out as long-distance caregiving as she traveled back and forth through several states in the northeast until her father's illness took a turn for the worst. This participant had to leave her family to provide care for her father during the last three weeks of his life. Participant 1 shared her struggles regarding seeking life balance:

> I was working and had two children at home. I would drive down to stay with him and take him whenever he had an appointment and then back up home. Then it came to be 24-hour care... It was insanity. I gave up taking care of myself because there were so many other things that needed to be done and I did not want to give up. My younger son was only a junior in high school.

In addition to discussing with me the challenges of maintaining a balance between caregiving and attending to family, Participant 3 expressed a range of emotions as she reflected back on her experience as a primary caregiver for both parents simultaneously. Participant 3 explained:

> It became all-consuming. It's physically and mentally exhausting. By the end of the day, I was wiped out and had little to give to my family. I'd go through a lot of different feelings like guilt like I wasn't doing enough or I'd get upset and get angry. So, I had a lot of different feelings, felt like it was and questioned 'Why do I have to do all of it?' And then felt guilty about feeling that way. To maintain my life with my husband and in doing the things we needed to do together, I had to find help to stay with my mother and make sure – you know, it was a lot of responsibility that I had to do before I could go out.

Note the words "consuming" and "guilt" in the statement above by Participant 3. All participants assumed the role of caregiver with the intention of meeting the needs of their immediate families while proving care for their parent. When caregivers could not fulfill and satisfy the needs of all, guilt and defeat set in. In fact, some participants reported feeling guilty for not being able to accomplish all tasks they set out for and satisfying the needs of all family members. This self-imposed pressure added additional stress and therefore, resulted in more emotional turmoil. Hence, the suffering continued.

In addition to the challenges of balancing family and caring for a parent, participants also had to contend with difficult and often opinionated family members, such as siblings, who opposed the decisions made by the primary caregiver. In fact, most of my participants felt judged by certain family members during the time that they cared for their parent. The combination, therefore, of having to balance immediate family and caregiving, and the enduring suffering experienced by the caregiver and parent seemed to impact other relationships between caregiver and other family members. The rise of relational tensions with extended family members occurred for eight of the ten participants, which also impacted the balance of life.

The intensity of home-based EOL caregiving can be so taxing and burdensome it can leave primary caregivers feeling stressed, anxious, angry and physically and emotionally exhausted, and resenting certain family members. Emotions tended to run high for all family members who were involved in caring for their terminally ill parent, especially for the primary caregiver. The majority of participants in this study reported having experienced family or sibling relational tension, which resulted in higher levels of

stress for the participant. Some participants, for example, reported feeling angry with

their ill parent or surviving parent for being left with the entire responsibility of

caretaking. Others reported feeling angry and resentful for receiving very little or no

support at all in providing care, while other participants reported having disagreements

with extended family members or feeling frustrated with friends for constantly wanting to

visit. Moreover, participants felt unappreciated and judged by those who disagreed with

their decisions regarding treatment. It seemed that the lack of support received and the

adversity experienced by participants were additional stressors, which contributed to

feelings of anger, resentment and higher levels of caregiver burden and exhaustion. This

next example illustrates the emotional intensity and relational tensions between primary

caregiver and siblings. Participant 4 explained:

> The siblings that resided in my father's home became such roadblocks. It was a
>
> constant fight with them to respect the fact that this was his home. My siblings
>
> were a constant burden to me. It started to open my eyes to just see how disturbed
>
> they were. I focused on my job – caring for him was something I felt was so
>
> critical to his health. The relationship with siblings became toxic and continues to
>
> be. I have no relationship with them with the exception of my one brother.

Other participants expressed their frustration with family members regarding

outspoken remarks and criticisms for the decisions that the caregivers made. As I further

probed into their stories regarding relational tension, all participants maintained the

importance of centering on their parent, that is, each believed that it was more important

to follow the wishes of their parent, regardless of what other family members said. For

example, Participant 5 expressed her disappointment with her aunts for criticizing her

decision to transition to palliative care, a decision that can be agonizing for families. She

stated, "They felt that we should have kept him in the hospital and on treatment. They

were not happy with our decision to call hospice, but we were following my father's

wishes" (P$_5$). Participant 5 did not have to contend with other siblings. However, she

experienced adverse reactions from extended family members who opposed the decisions

she made regarding her father's care.

Almost all participants expressed anger, resentment, and frustration due to

relational tensions. According to Holley and Mast (2009), it is common for levels of

emotional intensity and anticipatory grief to escalate in families who are about to lose a

loved one. Evidently, participants accepted the reality of their parent's fate and therefore,

prepared for their parent's last days. However, it seemed that extended family members

and siblings were not as prepared. In addition to the adversity participants experienced,

they struggled with their emotions which carried through well into bereavement.

During the focus group, I discussed with participants the emerging themes and

sub-themes I identified across the two rounds of individual interviews. Participants

immediately expressed an interest in talking about the emotional toll of caregiving and

zeroed in on the feelings of guilt and resentment during the time they provided EOL care

of their parent, which launched an interesting conversation. Participant 8 spoke about the

resentment she had with her family, which she had not discussed with me during our two

individual interviews. Her disclosure is also an example of how the focus group became

catalytic and beneficial for participants due to the element of universality (Yalom, 1980).

Participant 8 initiated:

> Let's start with guilt and resentment. I do have some resentment about my
> family a little bit…the children could have, you know, they were two young
> adults and one still in high school. They could have stopped and visited her more.

Participant 10 also shared:

> My brother lives nearby, but I was the one who worked a full-time job, came
> home, and took over and did what had to be done with mom and dad. When dad
> got sick it was, my father was my mother's caregiver. But then my father got
> stricken with bladder cancer and the roles reversed so now we had to take care of
> dad, and it was my husband and myself, and my brother was never on. Let's just
> say that, never on and I don't ever recall, during this whole time or up until this
> day ever hearing 'Thank you, you really did a good job with mom and dad.' And I
> love my brother dearly, but there is that little like - all you had to do was say
> thank you.

In addition to groups being catalytic in nature, the findings that I obtained from the focus group also helped to crystalize some of the initial themes I had identified during the individual interviews, which also added to the trustworthiness of my study. Participants shared their feeling of frustration, burden, guilt and resentment during their caregiving experience. These findings align with those of other research studies indicating that caregivers can experience family discord, which can result in negative feelings towards other family members (Holley & Mast, 2009; Waldrop, 2007).

Participants in this study willingly took on their caregiving role, determined to provide the care necessary to comfort their parent and help them through the last phase of their life. This role was full of uncertainty and distress, resulting in high levels of caregiver burden that impacted the natural rhythm and balance of life. Moreover, both their efforts and the suffering that participants endured went unnoticed. Most participants reported having to deal with negative comments and criticism made by other family members, which resulted in family strife, relational tensions, and participants feeling some resentment after their experience. Participants also contended with heightened levels of emotional turmoil, tensions within their nuclear families, yet managed to stay afloat until the very end. However, the overall impact of caregiving took its toll emotionally and physically. Participants had little or no time to promote their own self-care, which impacted their overall well-being and reported feeling depleted by the time they reached the end-stages of their parents' lives, especially during final days of their caregiving experience.

Transitions of Uncertainty

I identified *Transitions of Uncertainty* as the second overarching theme from across the interviews through the commonalities of responses expressed by all participants as they shared their perspectives on what it was like to provide care during the last days for a dying parent. It seemed that as participants witnessed their parent's rapid decline of health, the level of intensity increased. This period of caregiving tended to be full of emotional upheaval, sadness, and despair. Navigating the final hours of caregiving can be intense and traumatic, leaving caregivers fatigued and emotionally

exhausted and with lasting impressions. Already feeling depleted, caregivers are even

more vulnerable to stress during this critical point in the caregiving trajectory. The final

hours of caregiving also seemed to be a turning point where support became paramount.

To this end, there was a host of responses made by participants, for some, very

emotional, and for some very sad yet relieved that their parents no longer suffered.

Moreover, the job of caring for their parent had finally come to an end, which also, once

again, resulted in mixed emotions. I identified two sub-themes under Transitions of

Uncertainty, *Unbearable Endings* and *Support Essentials*. The first sub-theme illustrates

the ongoing distress of providing care to a dying parent and the second sub-theme

highlights the important of having supports in place.

Most participants were willing to share with me the final moments of their

caregiving experience except for one participant, who reported having experienced a

traumatic ending and preferred not to discuss this with me during my first interview with

her. It seemed, however, that most participants felt the need to describe in detail the

moment-to-moment experience of caring for their parents until the very end.

Participants also emphasized the importance of having support, especially during

the final days of caregiving. The statements made in this next section illustrate the

continual suffering that participants endured. Although their caregiving duties had

ended, it appeared that participants still felt the emotional pain of this part of the

experience, indicative of the tears that streamed as they described the events that lead to

their parent's death.

Transitions of Uncertainty Subtheme One: Unbearable Endings

The hours before a parent dies can be incredibly difficult and intense for adult children caregivers and can have lasting effects well into bereavement. Participants reported once again, increased tension between siblings and other family members as they made difficult EOL decisions. In addition to dealing with the stress of the role of caregiver, participants also continued experiencing high levels of anticipatory grief and dealt with the emotional turmoil as family members each grieved the impending loss of their parent. Once medical professionals inform the family that their parent has only days or hours to live, families tend to experience emotional upheaval. Hearing the words "palliative care" or "hospice" can cause a stir for families. All participants reported feeling ready and accepted that it was time to transition their parent from curative care to palliative care. However, this was not the case for other family members.

Whether it was with a spouse, a sibling, an aunt, or an uncle, participants continued encountering difficult emotional reactions from family members. Despite the opposition they encountered, participants emphasized again that circling around their parents was of the upmost importance. That is, they made their decisions based on their parent's needs and wishes, rather than the needs of other family or extended family members. In fact, in the individual interviews and focus group, all participants concurred that honoring and implementing their parent's wishes was most important. Concerning increased tension that occurs between family members when an impending loss is eminent, it is possible for certain family members to be in denial and are not ready to "let go." Denial likely played a powerful role in the heated debates between participants and

their family members, all which evidentially contributed to caregiver distress. It was also clear that participants experienced grief uniquely (i.e., individuals may have been at different stages of grief at different times) and that grief impacted family dynamics during the end stages of life (Kübler-Ross & Kessler, 2005).

In some cases, the final days and hours were very traumatic and therefore, the impact seemed to last well into bereavement. In thinking about my first interview with Participant 5, I recalled the anger and sadness she expressed and how difficult her experience was while providing EOL care for her terminally ill father. In addition to her caregiving experience, Participant 5 also provided emotional support to her grieving mother. She became emotional as she told her story and after the interview was over, she hugged and thanked me. The following quote illustrates the trauma that some caregivers experience during the final hours before and after the death of a parent and the necessity of processing this traumatic experience.

> My mom and I just sat there – she was sitting upstairs on the bed just looking at
> him, and I ended up there, sat on the bed, and we just hugged and then we went
> downstairs, and we said we need to call the hospice nurse. It was weird because
> you don't know what to say. I think that was probably the hardest thing. Because
> those are the vision that I see that I don't want to remember about that (crying). I
> don't wanna be in the house. I have nightmares every night. I have to take
> medication to sleep at night because I can't sleep. As soon as I lay down, the first
> thing that pops into my head is my dad laying in the hospital bed in his bedroom.
> And I relive those ten days every night. (P$_5$)

Participant 1's experience, which I had touched upon earlier, was similar to that of

Participant 5 in that she too experienced a traumatic ending while caring for her dying

father. Fortunately, we were able to circle back and talk more about her experience in

detail during the second interview. Perhaps the time that passed since the first interview

along with the support from counseling helped her further process her experience.

These following statemtents are indicative of how primary caregivers endure

emotional strain even during the final days of caregiving and how caring for a dying

parent can indeed be traumatic and impactful for the adult child caregiver, especially in

the context of home-based caregiving.

> I was the only one there. It was scary. I woke up. I was sleeping in the same
>
> room with him because he had this machine with oxygen and he was given
>
> morphine, and I hadn't slept really for many days because I was up with him all
>
> the time. He would shoot straight up right in bed and try to get out and walk
>
> places, and he would throw his arm-his leg over the railings. I had to constantly
>
> monitor him - it was just me. (P$_1$)

Participant 2 described for me the final hours of his caregiving experience. Although he

did not report feeling distressed during the last hours of providing care for his mother, the

emotions he expressed while sharing this part of his experience appeared otherwise.

Participant 2 noted, "It was almost like a deathwatch, not to be morbid, but that's kind of

what you did. We were all there; she didn't die alone. And you just try to implement

people's wishes." The statements made by Participants 1, 2, and 5, although varied in

intensity, demonstrate clearly the emotional experience of providing EOL care to a dying parent.

The death of a parent can be tragic and sad. Participants described the final moments of their caregiving experiences as distressing, sad, and exhausting and that they felt helpless. Also, four of ten participants reported that their distress continued even after their caretaking experiences due to the lingering effects of the image of their parent suffering. Participants felt helpless in being unable to alleviate their parent's suffering, which continued to haunt them for some time. This finding aligns with results of Koop and Strang's (2003) study in which they found that caregivers suffer from visions of a loved one's suffering. In their study, participants described their last moments as a death scene, which is similar to Participant 2's description as a "death watch." As a result of these findings, it was evident that support systems were critical during caregiving and bereavement.

Transitions of Uncertainty Subtheme Two: Support Essentials

Professional support such as hospice services has become widely used in the home as a result of the U.S. hospice care benefit, which was introduced in 1982 (Higginson et al., 2013). Participants reported finding comfort in supports such as hospice services, counseling, clergy, friends, and family. Participants also reported that they had not sought support early in their caregiving experience, and reflected on how doing so may have helped to reduce their stress levels. It is of note that few participants sought counseling after their experience and participants did not mention the use of formal psychoeducational or support groups.

All participants reported using hospice services to facilitate palliative care. This next statement illustrates the effectiveness of hospice services and how beneficial this service became for participants in this study.

> I called hospice, and there was the man who came - was so perfectly wonderful about it, I'm sure knew exactly what was going on…the rattle. He knew exactly where he was and what was going on and he just… he eased the process along for both of us. Thank God he was there. Just lovely. Three in the morning till five in the morning. I just never forget that was just an angel of mercy to come and be with me during that time and new exactly what to do. I don't know what it would have been like if he weren't there. (P1)

Another participant commented on her experience with hospice, "There would have significant suffering without it." (P8). Other participants found counseling to be a supportive aspect of their experience, as illustrated by the following exchange between myself (K) and Participant 3 as we discussed the topic of self-care during the focus group:

> K: Did you ever practice self-care?
>
> P3:   The only self-care was when I went to a psychologist for help – to talk about my feelings.
>
> K: Did you find that helpful?
>
> P3:   I did, I definitely found that helpful. I don't think I would have went, gotten through it, and the guilt feelings and the emotions and for

somebody to tell you that - to kind of let you know it's okay to feel that

way.

In a similar vein, Participant 7 commented on the appreciation she had for the

support of her friends. Her example illustrates how friends can be supportive in helping

alleviate some of the stress of caregiving.

It's always been a family joke; I said you know, 'If I really needed psychological

help, I'd save hundreds of thousands of dollars for just calling my friends.' My

friends are very important to me, my girlfriends, and as every single one of them

has heard me say time and time again, 'I love you guys.' (P7)

During the focus group, participants identified with each other the stressors of

caring for a terminally ill parent. They were also able to validate for each other the

feelings that accompanied those stressors (e.g., anger, resentment, and guilt) and

emphasized the importance of having a support system while providing home-based EOL

care. In this next statement, Participant 9 expressed her gratitude for the support she

received from her family and recognized how the collaboration of support from all family

members actually strengthened family ties and helped reunite her brother, from whom

she had been estranged, to the rest of the family. Her example illustrates the positive

aspects (e.g., silver-lining) of providing EOL care. Participant 9 shared with the focus

group:

So, they would all come after work and want to see and spend time and talk, and

so it was really, we were really lucky that we had that support system, and we still

have it. We were raised together, but it did bring my brother, the only brother out

of the family of three sisters back to the family a little bit more and then also his

children.

Similarly, Participant 10 spoke about the support she received from her husband in light

of the lack of support from her brother. After her caregiving role had ended, this

participant was left feeling resentful towards her brother, which resulted in a strained

relationship between them. However, through the support provided to her by her

husband, her marriage had strengthened after caregiving. Participant 10 shared:

> He was by my side when I needed this physical support as well as emotional
>
> support – to the point that he was by my side when I delivered my eulogy for my
>
> mother and my father. It was not my brother that stood there - it was my husband.
>
> (P_{10})

Participants responded positively to the support received from friends, family and hospice

services. In fact, participants found supports essential and suggested that caregivers

should have support systems in place at the onset of caregiving. Further, support systems

that are in place early may help alleviate some of the stress and burdens of caregiving.

As of note, not all caregivers have access to support systems and resources, which can be

problematic, as I discuss in chapter five.

Multiplicity of Meaning

The third major theme I identified, *Multiplicity of Meaning* was comprised of the

various responses around meaning making made by participants, resulting in both

positive and negative aspects of the caregiving experience. It was evident that

participants experienced meaning subjectively and in a variety of ways. It also appeared

that participants were at different points in their meaning making process. I was able to ascertain this by their responses during the first round of interviews and second round of interviews, which took place approximately six months apart.

The phrase Multiplicity of Meaning has particular significance for two reasons. First, it addresses my last research question, "How do adult children caregivers attribute meaning after post-intensive caregiving of a parent?" Second, this last theme along with its sub-themes well represented the various meanings and degrees of meaning-making made by participants, which relates to my theoretical framework, meaning reconstruction theory of bereavement (Neimeyer, 2001). I identified *Caregiver Regret* as the first sub-theme, which denoted participant regret and rumination over some of the decisions they made during the course of their caregiving journey. This finding directly related meaning reconstruction in the context of sense-making, the process, according to Neimeyer (2001) when bereaved individuals seek to make sense of loss in post-loss adjustment.

Participants reported meaning in numerous ways, which resulted in my use of the term *multiplicity*. Some participants reported finding meaning in signs and symbols, and other participants described their caregiving experiences as an unexpected gift or reward. Meaning-making after experiencing a loss was clearly subjective and personal, and during the interviews, it was evident that participants were still processing their experiences.

During the second round of interviewing, I also noticed that some participants struggled with the semi-structured questions I posed around meaning-making. As a result, I adjusted the questions to clarify for participants. It is likely that participants

were still processing their experiences and making sense of their loss, another example of

sense-making, according to meaning reconstruction theory (Neimeyer, 2001). These

findings were significant, again highlighting the importance of meaning-making in

bereavement.

Most participants discussed meaning-making regarding attaching meaning to

signs, symbols, or happenings. Some participants made meaning by identifying

something postive or finding "benefit" after their experience. Further, some participants

viewed their caregiving experience as an unexpected gift or reward, again, relating to

meaning reconstruction in the context of benefit-finding (Neimeyer, 2001).

It was also clear that meanings varied, and did not always result in a positive

aspect, as evidenced in this first sub-theme, Caregiver Regret, which highlighted the

ongoing internal struggles of participants as they looked back on their caregiving

experience. For some, the emotional suffering of providing home-based EOL care for a

dying parent continued well into bereavement, illustrated by participants' statements in

the next section. All participants shared with me their regrets and guilt and questioned

their process as they looked back on their roles as caregivers. Participants also

questioned their actions regarding treatment protocols and wondered if they could have

done something differently. Clearly, adult children caregivers in this study continued to

berate themselves over their caregiving process.

Multiplicity of Meaning Subtheme One: Caregiver Regret

All participants reported feeling guilty after their caregiving experience and

mostly after the loss of their parent. Whether participants regretted not spending enough

quality time with their parent or questioned their caregiving approach or some decision

that they made, participants commonly expressed regret as they reviewed their caregiving

experiences. Participant 6 spoke about her multiple experiences as the primary caregiver

for both her parents and in-laws as well. She took on these roles mainly because of her

nursing experience. Despite her years of experience with home-based care, she still

regretted some of her decisions while caring for her mother-in-law. She goes on to say,

in her last sentence in the following statement, that rumination is normal (she cared for

three other family members) and that she was resigned to acceptance. Participant 6

shared some reflections, making sense of her experience.

> You have to go through everything you did and say 'Oh, I didn't do that right' or
>
> 'I shouldn't have done that' or 'we should have taken the chance on that trial.'
>
> You relive in your head and say, 'did I do that right?' Like with my mother-in-
>
> law – should I have left her that morning? Should I have done that? Uhm, you
>
> question, it's normal, and you doubt it until you've really come to terms with
>
> that's how it was supposed to be. (P$_6$)

Participant 6 also shared with me her experience with caring for her father, which was

over 30 years ago. Her statement is indicative of the guilt adult children primary

caregivers may continue to feel long after their experience of caring for a parent.

> I felt that I did not do what I could have done. We made bad decisions because
>
> you have to make so many decisions. Are they right, are they wrong…I don't
>
> know. Do you give them meds? Do you not give them meds? And my father

would say, 'you decide whatever you want to do, whatever you think.' So I felt

that guilt after and I look back- I felt that for a long time. (P$_6$)

Two other participants spoke about the questions they had regarding treatment

protocols. Participant 4 wondered whether using a peg tube, which is a feeding tube that

is inserted into the patient's stomach, prolonged her father's suffering.

You look at all the work that went in, and then we say, 'Who's... no one's

benefiting! He just wants to die! He's not happy!' We would build him back up,

and he would then fall again. It became torturous for him. It felt like… what were

we trying to prove? Are we intervening too much? It became a little hopeless for

him. Maybe he would have been better off if he had just lived a shorter period of

time because he struggled so much. (P$_4$)

After my interview with Participant 4, I reflected on her question, "Are we intervening

too much?" and found this statement profound. In my experience, I have seen caregivers

provide care and go to great lengths to "save" their parent, that death was not an option at

that point. This next statement is another example of the second-guessing that caregivers

do after a loss. Participant 5 wondered whether she should have had her father participate

in one more clinical trial, commenting, "There were trials. I wish I had tried one with my

dad. We were talked out of it by the doctor. I wish we just would have tried one." For

these caregivers, perhaps they are not ready to let go.

Most participants also regretted not spending enough quality time with their

parents. They admitted being so caught up in their caregiving duties and the "busyness"

of caring for their families, that they did not consider the importance of spending quality

time, as evidenced by Participant 5's statement, "I absolutely wished I would have spent more time with my dad, especially in those last couple of days when hospice was there. I had a hard time. I was there every day but had a hard time." (P5). In addition to regretting the amount of time spent with her mother, Participant 3 also expressed the frustration and regret of losing her patience at times. This finding parallels other research (Holly & Mast, 2009; Koop & Strang, 2003) that after caregiving, caregivers may feel guilty after loss, wondering whether or not something could have been done differently. Participant 3 explained:

> Could I have done it different? Should I, could I have had more patience? Could I have spent more time? I don't know. It's just like…you just wish you could have done it even better. I lost my patience once in a while. It's hard. It's really hard when you're going through it. I could have spent more time with them. It wasn't the best quality time but spending time and having family together. I did have those special times with her but wished I had a little more patience at the end. I was shot from dealing with both parents. (P3)

Similarly, in addition to comments made during individual interviews, during the focus group Participants 10 and 8 shared their feelings regarding time spent with their parents during the following exchange:

> P10: That was my guilt, I mean, I pretty much know…
>
> P8: I'm sure you did do enough.

P10: Uhm, but it was still like did I do enough? I mean, for both of them and then

that's the only thing for once in a while I'll think, could I have spent a little bit

more time. That sort of thing.

P8: I'm thinking more of not the last year of when illness was, I mean for me, I

was thinking about she moved here fifteen years before she died, although the

other years -that's where I might feel guilty.

In the above exchange, Participant 8 reflected beyond EOL caregiving, noting how she

regretted not spending more time while her mother was well.

Participant 1 was able to make sense of her complex feelings regarding the

relationship she had with her father and her caregiving experience. As she explained:

I've taken the experience both of having him as a father and then being this

caregiver, which I'm sure has informed the way I've gone forward in my life, but

I'm not really clear on all that yet. The thing about being a caregiver and all the

complicated emotions is sitting with those, just being with those painful emotions

- difficult emotions. It's okay to have those complicated feelings and the pain and

the feeling of 'I didn't do enough' or I' wish I could've done more.' That timing, if

I've done this before, there might have been a little more relief.' All of those

things... it's okay to have those feelings but not to pin our identity on them. (P_1)

The first sentence in Participant 1's statement is an example of meaning-making in the

context of identity reconstruction, that is, when bereaved individuals reflect on questions

such as "who am I now?" or "who is my family now?" Such reflections signify a shift in

establishing a new identity, or a new way of being in the world without the deceased

(Neimeyer, 2001). Some participants reported feeling a void after their parent's death. It is likely that the void felt by participants was due to the loss of the caregiving role as it is not uncommon for caregivers to feel lost or experience a void after a loss (Waldrop, 2009). Moreover, this example demonstrates participants' attempts to process a new identity, hence, the process of identity reconstruction (part of meaning reconstruction) in post-loss adjustment.

My next sub-theme, *Comforting Signs*, illustrates participant meaning-making in the context of benefit-finding, part of the process of meaning reconstruction. It also indicates that participants were engaged in continuing bonds, where individuals may identify with rituals or signs to continue the bond with the deceased in a spiritual sense (Field et al., 2005; Neimeyer et al., 2006; Stroebe et al., 2010).

Multiplicity of Meaning Subtheme Two: Comforting Signs

I had a unique experience during my first interview with Participant 4, an occurrence that did not present during any other time of data collection, however, is relevant enough to mention as it relates well to this sub-theme. As I started my digital recorders, both of which were fully charged, one of my recorders shut down. I stopped the interview to examine the recorders. I knew for certain I had fully charged both, something I regularly did before interviewing. To my amazement, Participant 4 was certain the recorder not working was her deceased sister and commented, "I know why… it's my sister; she's around here. She always does these things." She proceeded to find me a replacement battery. After replacing the battery, we resumed our discussion without any interruption. Still perplexed by this experience, when I got home I installed

the original battery back in to recheck its power level – the battery appeared fully

charged. Perhaps this was an extraordinary experience (Parker, 2005), and something

that we cannot explain scientifically. However, according to Participant 4, she felt

comforted by this occurrence. I simply validated her experience, and we continued with

the interview. I believe it could have had negatively impacted the interview had I not

validated her experience and gave the impression that it was pure nonsense.

　　　For other participants, symbolic representations such as black butterflies

appearing had personal significance. Participant 5 described the comfort in seeing black

butterflies, explaining that black butterflies are the symbol for pancreatic cancer, the

illness that her father battled until his death. She believed, however, that black

butterflies, when she saw them, were also an indication of her father's presence in spirit.

Participant 5 stated:

　　　　　The signs are crazy. The signs are absolutely crazy, and I love them. I absolutely

　　　　　love them. So that – that's what makes me happy. Yeah. But the signs are crazy.

　　　　　The signs – you can't – you cannot make it up. I didn't believe it until that stuff

　　　　　started happening. I definitely did not believe it at first. But there's signs all over

　　　　　the place. The black butterflies. My mom and I see black butterflies all of the

　　　　　time. (P$_5$)

　　　During the focus group, three of the participants also shared their experiences

with signs that brought a sense of comfort and peace. Some participants spoke about

seeing visuals that reminded them of their deceased parent; others indicated that they had

encountered smells and sounds that reminded them of their parents. For example,

Participant 10 spoke about the unexplained smell of her mother's perfume that permeated

throughout the house. She shared, "I'll get a smell of Shalimar perfume, which was my

mother's favorite perfume and my father bought her a tiny bottle of, you know, the pure

perfume of Shalimar and every once in a while I'll get, 'Okay, where are you?' That type

of thing." Similarly, Participant 9 shared a "happening" with the group and spoke about

the significance of it:

> And there's a little toy like… a musical toy box and it was a dancing bear, and
>
> everybody was into bears. If you pull the draw out just a tad, the music box will
>
> go on and the bear will dance. And there are times in her, now it's a guest room,
>
> the bear will, the music box will go on, and the bear will dance. No, you can't
>
> make that up, and we'll all come running, and we're like, 'Who's there?' (P9)

Participant 7 also spoke about the significance of seeing a rainbow and what that

represented for her:

> I saw double rainbows on the way home from D. C. the other day and I thought
>
> of her (her mother). So, you know, it's sometimes visual for me… I see symbols,
>
> and it gives me joy actually. So, you miss the person but I feel the symbols
>
> around me are signs, clues. (P7)

> Participants were able to find meaning after loss through attaching significance to

various signs, happenings, or occurrences that indicated a spiritual presence. This finding

also suggests that participants engaged in continuing bonds, that they were trying to

maintain a connection with the deceased somehow, as a means of coping (Field et al.,

2005; Neimeyer et al., 2006; Stroebe et al., 2010). Further, it is likely that participants

were able to construct meaning based on their spiritual beliefs, which brought comfort and meaning to their life.

Multiplicity of Meaning Subtheme Three: Unexpected Gifts

While findings suggest that the experience of providing care for a terminally ill parent was negatively impactful, participants also reported that the time they spent as a caregiver of their parent was a time that was also special and one that should be cherished. I sensed that participants were able to step back and view their experience as part of the cycle of life, that is, parents give birth and life to their children and children, as they become adults provide love and care at the end of their parent's life.

I identified *Unexpected Gifts* as the third subtheme of Multiplicity of Meaning based on thematic statements made by participants that seemed to contradict some of what they reported during the first round of interviewing. During the first round of interviews, I uncovered the tale of EOL caregiving that consisted of many twists and turns and major upsets as each participant set out on their caregiving journey. Although it seemed that participants were cautious initially not to label their caregiving experience as burdensome, it was clear that each participant had experienced high levels of stress, which impacted them physically and emotionally, leaving participants feeling depleted. Additionally, their lives had been thrown into turmoil as each participant struggled to maintain balance while operating in their own families. Moreover, participants were competing against opposing forces such as siblings and extended family members who consistently opposed some of the decisions the participants had made, which contributed to the intensity of the caregiving experience.

The second round of caregiving offered the opportunity to confirm themes I had

heard across first round of interviewing and to ask questions around meaning-making. I

offered participants the opportunity to add what they may have forgotten to share during

the first interview and to add anything else they wanted. Participants seemed more

relaxed during the second interviews and appeared lighter regarding their energy levels.

It is possible that they felt more relaxed with me during the second time around. They

shared how relieved they were that their caregiving duties had ended. One participant

admitted that although she missed her mother, she did not miss caregiving. Participants

also reported that life was much easier now that their caregiving duties had ended and

enjoyed having their freedom again. All participants reported that the experience felt like

an eternity, and when their duties ended they all reported feeling relieved. Moreover,

participants felt as if their lives had resumed back to normal and that they were able to

breathe again. Paradoxically, participants also reflected on their experience as being

unique and special.

Several participants reported that caregiving was special. Others reported that

caregiving had been an unexpected gift or reward. For example, Participant 1 stated,

"There is a beauty in this cycle," and Participant 3 noted that caregiving "Can be a

rewarding experience." As I thought about the difficulties that participants endured, the

sacrifices that they made, and how their experiences compromised their well-being, I was

struck by their paradoxical statements. I sensed that time might have played a role in

participants identifying benefits in their experience. Nevertheless, it appeared that this

tale of caregiving was a mixed blessing, which gave meaning and purpose to their experiences as caregivers.

Participant 1 described that it was a "tremendous gift" to care for her father during his very last days. "It's definitely a gift to be a caregiver… to have that opportunity in life with another human being. It was a huge reasonability and equally a gift to be able to be there." (P_1). During the second interview with Participant 1, which was approximately six months after her first interview, she once again reflected on the specialness of caregiving.

It's a preciousness in being part of this part of life – of this process of life…being able to be in this, in these moments…to – to witness and to be really empathically engaged and involved in this process was something that was very moving and it made my heart full. (P_1)

During the focus group, the majority of participants shared examples of what they felt were special moments. "I don't think I'd trade it for the world." (P_{10}). "Caregiving is a special time even though it's a stressful time. It's still a gift because I have so many fun memories and I had more time than my siblings because I was there in the house with them for that whole year." (P_9). Participant 10 elaborated,

The whole ordeal was really special. It was a very precious time to me. It was not easy but still as I look back on it I wouldn't have traded places with anyone while I was going through it - with both mom and dad. (P_{10})

While EOL caregiving was daunting for all participants, a majority of these participants were able to reflect on their experiences positively, with deeper meaning, as a time to cherish, noting that they could never capture sharing the last days with their parents

again. The following exchange between two participants during the focus group is an example of how they saw caregiving as a gift:

P 9:   I agree. I think caregiving is a special time even though it's a stressful time.

P10:   I really think cherishing, even though this is difficult.

K: M-hmm.

P10:   And but there, you know, at some point this is going to end, this caregiving. But I think when you're in it, as hard as it may be, cherish those moments 'cause you're at the end, this is all you have. These are the moments that are gonna, that you're gonna hold in your heart for as, as long as you're alive. I just think… and as difficult as the situation is, cherish that situation. Because you love that parent so much. I mean, I had a very, very close relationship with my parents and it's, the whole ordeal was really special because I, I…

P9:   You participated, you did it.

P10:   Yeah, I did. I did it. You know, I did. It was really, I wouldn't trade places with anybody.

During the above exchange, it was evident that group members were able to help each other make sense of their experiences, another example of how participants were still processing their experiences and yet another demonstration of the importance of sense-making in post-loss adjustment. It was clear that participants were still were processing

their experiences and discovering new meaning while talking with me and with each

other.

After processing some of their pain and suffering, it appeared that participants

were also able to identify benefits from their experience. For example, some participants

reported an improvement in communication skills (e.g., with family members or a

spouse), others reported strengthened relationships, a stronger sense of self-efficacy and

personal growth, and learning about new aspects of their deceased parent. As an

example, Participant 5 noted, "I learned how to communicate with my mom like there

was a purpose. I learned to talk to my mom more about the things that concerned me

regarding her."

Participant 1 spoke about the difficulties she had with her father over the years.

However, after learning about her father's impact on his former students, she saw him in

a different light. She expressed appreciation for her father's positive impact and how he

inspired her son to pursue doctoral study. After deep reflection, she recognized the

positive impact her father had on many, which resulted in a newfound appreciation for

her father. Participant 1 shared with me some new thoughts about her father.

> He [son] was also inspired by him, and his charisma, and by his personality and
>
> I've been kind of in my own journey thinking more about the other side of him.
>
> So it was nice to see that there is a little bit of a balancing. It was definitely a
>
> renewed appreciation for the lives that he touched - including my own son. The
>
> ways that he touched people, and he did it; he had a wonderful fun, loving,

inspiring, he told terrific stories about the antics that he would do in his classes,

and I'm imagining I would have loved it if I were a student of his. (P$_1$)

During the focus group, participants shared with each other some of the aspects of their

parents about which they had not originally thought. It seemed that by talking with

outsiders and amongst themselves in the focus group that participants were able to

develop new insights. Participant 9 shared with the group her thoughts regarding her

father:

> You really realized how many people cared and what an impact that person made
>
> on people's lives. He was a football coach and all that stuff…like all those guys
>
> that were my age now were stopping in at the house to visit him. And, you know,
>
> he was just a different person. He just made such an impact on people's lives.
>
> (P$_9$)

These findings suggest that in addition to a search for meaning, participants were

identifying benefits after their experience, a process that seemed to unfold over time and

after careful reflections. Participants continued to develop new insights that lead to

newfound appreciation which also became meaningful. These findings are congruent

with reports by other researchers indicating that caregivers have experienced benefits

after informal family caregiving (Hogstel, Curry, & Walker, 2005), and in previous

literature (e.g., Holland et al., 2006; Neimeyer, 2001) that suggests the importance of

benefit-finding in meaning reconstruction.

It was evident that providing home-based EOL caregiving was a mixed blessing.

Participants in this study expressed hardship as they navigated through unchartered

territory of providing care for their terminally ill parent. They struggled emotionally and physically, suffering alongside their dying parents. They had to deal with difficult family members who were critical of their decisions and the emotional upheaval of both siblings and extended family members. As participants transitioned through the final hours of caring for their parent, a critical time in the caregiving trajectory, endings became unbearable, which resulted in emotional distress that carried into bereavement. Participants also continued to question their approaches and decisions and shared regret after their experience. Regardless of the negative experience of providing EOL care for a dying parent, participants were able to find meaning in their experiences. Participants were able to derive meaning from signs, symbols, and happenings. Moreover, they viewed their caregiving experiences as an unexpected reward and time that was precious and part of the cycle of life.

Discussion

The aim of this study was to examine and give voice to the experiences of adult children who had provided home-based end-of-life care for a parent. Analysis of two rounds of ten individual interviews and a focus group revealed that providing home-based EOL care for a terminal ill parent was wrought with many challenges, stressors, and greatly impacted the physical and emotional well-being of participants. Additionally, caring for a dying parent during the very last hours of a parent's life was distressing and traumatic, leaving many participants with lasting images of their parent's suffering and sorrow. Providing home-based EOL care for a parent was difficult and impactful, and as a result, participants in this study suffered in many ways during and after their

experience. Support became paramount and was found to help alleviate some of the stress and strain of caregiving. Moreover, most participants reported that support was an imperative and suggested that caregivers should always seek support and never attempt to provide care without it.

In light of the distressing aspects of providing care for their parent, participants were able to find meaning and benefit after a loss. Participants applied meaning in various ways. Some participants were able to develop new insight after their caregiving experience. Examples of such insights included the development of a newfound appreciation for a parent, a new connection with a family member, or a strengthened relationship. Others reported learning to communicate more effectively with family members. These findings suggest that participants in this study were able to find benefit or a silver lining after their loss. Participants also found meaning through comforting signs (e.g., objects, smells, happenings) and validation that their loved ones were around in spirit. Some participants also reported that providing home-based EOL care for their parent was a gift or unexpected reward. Moreover, it appeared that most participants relied upon their spiritual beliefs as a source of comfort while they provided care for their parent and in bereavement as well.

In response to questions around meaning-making, some participants struggled and needed clarification of my interview questions. It is possible that participants found it difficult to comprehend their losses and adapt in bereavement. Overall, it appeared that those participants who struggled in making meaning of their experiences also struggled emotionally after their caregiving experiences and in mourning. This result was striking

and related directly to the importance of meaning-making in bereavement and meaning

reconstruction theory of bereavement, as my theoretical lens of the study, which I further

explain in chapter five.

CHAPTER FIVE

Introduction

This study was designed to explore the experiences and meaning making of adult children who have provided home-based end-of-life caregiving for a terminally ill parent. Upon completion of this qualitative inquiry, consisting of two rounds of individual interviews and one focus group, it was evident that all participants in this study had unique and very personal EOL caregiving experiences. Although participants described caregiving as distressing and negatively impactful on their well-being and inadvertently affecting their families, many participants reported that EOL caregiving was also a gift in many ways. Moreover, I identified end-of life caregiving as a process that unfolded over time, represented by three major overarching themes to illustrate important points of the caregiving trajectory and a timeline of events through which caregivers endeavored. My findings also emphasize the importance of meaning reconstruction for caregivers, which could be used preventively and therapeutically at different points in the journey of caregivers to help facilitate a positive adaptation to both the caregiving and bereavement experiences.

Elizabeth Kübler Ross (2005) challenged the medical model by maintaining the importance of respecting the dying process and dignity of persons who are terminally ill. While it was unlikely that participants were intentionally focusing on the dying process, being more focused on their parents, it was clear that participants took on their roles as primary caregiver in an effort to help their parents live out the rest of their lives in the comfort of the home with dignity and respect, abiding by their parents' wishes to achieve

a home death. However, providing EOL care for a dying parent in the context of the

home can be one of the most challenging times in an adult child's life.

Caring for a dying parent can have profound implications, and many families are

unprepared to embark on such realities. In this chapter, I discuss the findings of this

study and relate my findings to professional research literature. I also include limitations

of the study and recommendations for counseling practice and future research.

Discussion

In response to questions about the experiences of providing home-based EOL care

for a terminally ill parent, participants provided stories that explained what led to their

roles as caregivers, how they felt about their roles, and details of the very end of their

caregiving experiences. Most participants were middle-aged adults caring for their own

families and did not anticipate the job as a primary caregiver. This finding aligns with

prior research, which has indicated that caregiving in mid-life is an unanticipated event;

most middle-aged adults are typically busy caring for their immediate families and do not

have their sights on caring for an ill parent (Aneshensel et al., 1995; Housner & Gibson,

2008; Pearlin, 1992; Phillips & Reed, 2010; Roberto & Jarrott, 2008). All participants in

my study reported on the length of their caretaking, the caregiving duties that were

involved, and the responsibilities they assumed, describing their roles and experiences,

which varied. Despite the struggles and distress associated with their caregiving

experiences, participants were able to identify meaning after their loss, which reflects the

importance meaning-making in post-loss adjustment (Neimeyer, 2001). In subsequent

sections of this chapter, I discuss my interpretations of the following overarching themes

of the study: Unchartered Territory, Transitions of Uncertainty, and Multiplicity of

Meaning.

Unchartered Territory

        Participants described the onset of their caregiving journey as if they were

navigating through unchartered territory, clearly indicating that although one can

"prepare" for caregiving, the caregiving journey is unpredictable, a role that is uncertain,

and a process that unfolds over time. These findings are supported by those of previous

researchers (e.g., Aoun et al., 2005; Funk et al., 2010) who reported that caregivers often

lack in preparedness and the skills necessary to endure the difficult stages of caregiving.

Additionally, participants reported high levels of distress and difficulty in maintaining

balance within their lives, congruent with previous studies in which caregivers noted

negative effects of caregiving on their physical and emotional well-being (Funk et al.,

2010; Pinquart & Sörensen, 2006; Schulz et al., 2003; Waldrop, 2007).

        Consistent with findings presented by McMillan (2005) and NAC (2009),

balancing home and caregiving was challenging for all participants in my study. In fact,

during the focus group, participants broached the issue of women still bearing the burden

of paid work and caregiving responsibilities. It is of note that although the age range of

the participants varied, most participants in my study were mid-life women who cared for

their immediate families and an ailing parent. The composition of participants represents

a microcosm of the current state of caregiving in the U.S. Roberto and Jarrott (2008) note

that we can consider caregiving to be a developmental task for middle-aged adults.

Already feeling depleted from their roles, participants reported feeling worn out from the conflict between themselves and their siblings. While I did not consider family strife as a sub-theme, I do find it important to discuss. Participants endured a great amount of pressure from family members, which they did not anticipate when they assumed the role of primary caregiver. Participants seemed hurt and disappointed by their siblings and extended family members. They worked very hard to meet their parents' caregiving needs, yet experienced a lot of opposition while trying to do the best they could. It seemed that participants were more accepting of their parent's illness and that compared to their siblings, they were more emotionally prepared for their parent's death. Moreover, it appeared that family members might have been in denial and were not prepared to lose their parent, which I discuss further in this next theme.

Participants were distressed from the adversity experienced as they made decisions along the way. Based on my interviews, I suggest that at this point in the caregiving process families might benefit from psychoeducation to ameliorate some of the tension experienced between family members. Participants felt that other family members could have benefited had they been educated on their parent's illness or received help from a family mediator to provide unbiased information that could have lessened the emotional upheaval during the course of caregiving. At the onset of illness, families became overwhelmed by the news of their parent's illness and may become unable to process the amount of information that is presented. Moreover, as the caregiving process unfolds and primary caregivers and their families experience the final

approach of the caregiving journey, this critical point in the caregiving trajectory can be rather traumatic, leaving caregivers feeling depleted and traumatized.

Transitions of Uncertainty

Participants reported feeling extremely anxious, helpless, vulnerable, and devastated as they witnessed the final hours of their parent's life, especially as they made the difficult decision to bring in hospice. Family relational tensions continued to increase as not all family members were in agreement with caregiving approaches, especially when it came time to transition their parent to palliative care. Deciding to end treatment and utilize hospice services can be difficult for most families. Aforementioned, it is likely that denial or the emotional bond between an offspring and a parent (Carver, Hayslip, Gilley & Watts, 2014) may play a large role in the readiness to make such decisions. Nonetheless, it seemed that participants in this study were able to pace their grief during the duration of their caregiving experience (Kübler-Ross & Kessler, 2005). Further, it is possible that participants' direct contact and prolonged exposure to their dying parent may have also helped pace their grief. Accepting their impending loss did not mean that participants felt alright that their parent was dying, rather, that they came to terms with their new reality—their parent was dying (Kübler-Ross & Kessler, 2005).

Participants reported that palliative care brought comfort to their families and their parents, which aligns with previous research on caregiving and the benefits of hospice services (e.g., Koop & Strang, 2003) and the rise in the utilization of hospice services in the home (Gomes et al., 2013; Higginson & Sen-Gupta, 2000; Higginson et al., 2013). Participants also utilized other supports such as clergy, counseling services,

and family support (e.g., spouses and adult children and friends). Participants found that

support helped alleviate stress and brought them comfort during the final stages of illness.

Further, participants emphasized the importance of having supports in place at the onset

of caregiving, which they had not done for themselves yet realized later how critical it

was for facilitating EOL home care.

Multiplicity of Meaning

In response to questions related to meaning-making, participants identified

meaning in a variety of ways, hence, the term of my last overarching theme, Multiplicity

of Meaning. As an organizing framework, meaning reconstruction theory highlights

meaning-making in the context of three processes (sense-making, benefit-finding, and

identity reconstruction; (Neimeyer, 2001). Most participants engaged in meaning-

making through all three contexts of meaning reconstruction.

Through the process of sense-making, all participants reported having some form

of regret and guilt after their caregiving experience. Participants expressed feelings of

guilt or regret regarding not spending enough time with their parent, for the decisions

they made, or wondering whether or not a different care approach would have resulted in

a different outcome. Other researchers have similarly reported that caregivers often feel a

sense of guilt during and after a loss, especially when transferring a loved one to

palliative care (Harrington et al., 2012) and that caregivers will ruminate over their

choices (Holley & Mast, 2009; Waldrop, 2007). I also noticed that participants with

stronger religious affiliations reported less regret than other participants. Other

researchers (e.g., Higgins & Prigerson, 2013) who have examined caregiver perceptions

of EOL care also found an association between caregiver regret, fear (e.g., exposure to

suffering), and negative religious coping (Higgins & Prigerson, 2013). Further,

participants who reported traumatic endings to their caregiving experiences expressed

more regret, indicating that they still engaged in sense-making (as part of meaning

reconstruction) or attempting to make sense of their experience (Holland et al., 2006;

Neimeyer, 1998; 2001).

As previously mentioned, although most participants had or were in the process of

finding meaning in their caregiving experience and the loss of their parent, some

participants had difficulty with my meaning-based questions. After clarification, a few

participants continued to experience difficulty in ascribing meaning to their experiences.

I had suspected that those participants had not fully processed their experiences. In fact,

participants also reported feeling a void and felt displaced after their caregiving job had

ended. It appeared that participants had a difficult time adapting to life without their

parent and for some, they had difficulty adjusting to no longer being in the role of

caregiver. It is important for counselors to be aware that depression and prolonged grief

can also be attributed to the loss of a meaningful role (Boerner et al., 2004; Lin et al.,

2013). It is of note that those participants who seemed to struggle regarding the loss of

their caregiver role had close relationships with their parents. From an attachment

perspective, it is likely that the permanent physical separation after a parent's death may

have triggered intense emotional despair (Bowlby, 1973, 1980; Parkes & Prigerson,

2010). Moreover, Nadeau (1998) and Neimeyer and Anderson (2002) contended that

death often catapults the bereaved into an existential crisis. As a result, bereaved

individuals are left on a quest to understand and conceptualize their loss through an active

pursuit of meaning (Neimeyer & Anderson, 2002).

Comforting signs. Participants spoke about meaning symbolically, that is, they

found meaning after a loss in symbols, happenings, and scents, believing that such signs

represented their parents' presence in a spiritual form. In essence, participants felt

comforted by these signs and found them "meaningful." One may construe that this

spiritual connection is a means of continuing the bond with their parent. These findings

parallel those of other researchers (e.g., Field et al., 2005; Hudson, 2004; Neimeyer et al.,

2006; Stroebe et al., 2010) suggesting that some individuals will attempt to maintain a

connection with the deceased through meaning-based coping resources. More

importantly, it appeared that participants considered these signs to be gifts that helped

them transcend themselves to a new way of being in their world without their parent.

However, despite the fact that some participants found comfort in these signs and a

means of continuing bonds, it was evident that some participants still struggled with their

loss (e.g., Participant 10 was able to identify with comforting signs yet still expeienced a

void after a loss). Neimeyer et al. (2006) indicated that individuals who maintain

ongoing bonds with the deceased more closely, yet are unable to integrate the loss or still

have difficulty in conceptualizing the loss (through the processes of sense-making and

benefit-finding), are at risk for complicated grief. My findings reflect Neimeyer's (2001,

2006) contention that meaning-making is a predictor of bereavement outcome (Neimeyer,

2001; Neimeyer et al., 2006).

Although finding benefit in caregiving has been a topic seldom discussed (in the professional literature (Feinburg, 2004), current research has indicated that some caregivers do find benefit after their caregiving experiences (Holley & Mast, 2009; Hogstel et al., 2005; Waldrop, 2007). As participants responded to my questions around meaning, most were able to identify positive aspects of their caregiving experiences, the process of benefit-finding, which occurs in meaning reconstruction (Neimeyer, 2001). For example, Participant 1 stated, "There is beauty in this cycle of life – this was a tremendous gift to me" and further stated after the completion of the second interview, that talking about her experiences had opened the door to further exploration. This participant had initially experienced a traumatic EOL caregiving experience, yet despite feeling traumatized while caring for her dying father, her reflective statements were remarkable. In fact, after our second meeting, she reported that participating in this study and talking about her experiences had led her to more inquiry on meaning. Similarly, focus group participants echoed the same sentiments and concurred that although providing EOL care was extremely difficult, it was a privilege to spend time with their parent to the very end, a special time to be cherished.

My findings are compatible with those of Koop and Strang (2003) who reported that in addition to experiencing the negatively impactful aspects of caregiving, bereaved caregivers can identify positive aspects (or benefits) of their experiences such as a sense of fulfillment, a stronger sense of self-efficacy, and strengthened relationships. Moreover, these findings are reflective of Neimeyer's (2001, 2006) construct of benefit finding. That is, in a search for the incomprehensible loss, there is a necessity for

bereaved caregivers to identify benefits (or positive aspects) of their experiences to reach a more positive adaptive outcome of their grief (Neimeyer, 2001; Neimeyer et al., 2006).

It appeared that participants had a transcendental desire to be present and be part of something larger (Parker, 2005) such as sharing together, adult child and parent, the final phase of life. Despite the difficult journeys experienced, participants' involvement in their parents' care offered many a deeper connection to something larger, an unexpected gift to treasure for a lifetime.

During the second round of interviews, I asked participants to share what it was like to talk with me about their caregiving experiences. All participants reported that talking about their experience was helpful. In fact, it seemed that the experience of being interviewed in essence helped participants further process their experiences as stated in by Participant 1:

> It raised my level of curiosity a lot. I hadn't gone there, so it was an opportunity to dive into things that I would not, on my own, probably have done, and I think there's a benefit, a definite benefit from it. I feel more able to address that whole period reflectively on my own. And like I said, the time I need on my own that I now have in my life to do that reflection is it will probably come up, and it has come up, at least the relationship with my father has come up in those reflections. So it like opened a door, um, that I could walk in now and the door with remain open and I will continue to walk in it. (P$_1$)

I believe that my participants opened up more in the second interview and then in the focus group, in part because I am an experienced professional counselor. I was able

to use basic counseling skills to establish rapport and trust, which allowed participants to speak freely about their experiences. Although it is helpful to use basic counseling skills in the interview process, counselors who conduct research may find themselves slipping into the role of counselor, especially when hearing participant stories that move us. Although counseling skills are useful tools to use in qualitative interviewing, it is important for counselors to remain clear in their roles and function as researchers to maintain objectivity while interviewing participants.

My findings present a distinctive picture of grief and loss in caregiving; one that differs from Kübler Ross's (1969) stages and aligns more with Neimeyer's (2001) meaning reconstruction theory of bereavement. It is important for counselors to be able to conceptualize grief and anticipatory grief as part of the grieving process in caregiving and to recognize how they can help address caregiver grief at different points in the caregiving trajectory through meaning reconstruction. This study has illuminated the importance of utilizing post-modern grief theories such as meaning reconstruction to facilitate meaning making in caregiving and bereavement.

Implications for Practice

Maximizing Meaning in Bereavement

Findings from this study suggest the importance of meaning making in bereavement. There seemed to be a relationship between participants who struggled with meaning-making (e.g., low level of meaning-making) and participants with adaptive outcomes in bereavement, that those who were able to find meaning through the processes (e.g., sense-making, benefit-finding, identity reconstruction) of meaning

reconstruction. These findings suggest that caregivers who struggle with meaning-making in bereavement may be at risk for complicated grief. Of note is that participants who struggled with meaning-making and sought counseling from a licensed psychologist or clergy continued to struggle after a loss. Although participants reported that counseling provided some relief and that they were able to attribute meaning to occurrences (e.g., comforting signs), they exhibited symptoms of complicated grief (e.g., numbness/detachment from others, meaninglessness without the deceased, and feeling bleak about the future). Such symptoms signify that they had not fully integrated their loss.

From the perspective of meaning reconstruction theory (Neimeyer et al., 2006), one would anticipate that low levels of meaning making, or the inability to make sense of or find personal benefits after a loss, correlate with greater levels of complicated grief. These findings support the importance of counselors effectively being able to help clients in the meaning making process. Additionally, supports such as hospice services typically serve dying individuals through palliative care methods and support families by providing information on what to expect during the time a loved one received palliative care. Such services may also offer bereavement groups, which can also be beneficial for families. However, these services are based on traditional theories such as Kübler-Ross's (1969) stages of grief. It is important, therefore, that hospice and other mental health professionals be well versed in post-modern grief theories such as meaning reconstruction to address grief and loss issues with an orientation to wellness and prevention.

Findings from this study suggest that mourning and meaning are processes that are closely intertwined, a contention supported by Neimeyer et al. (2006). Participants were able to identify meaning in various ways, either through attributing meaning to an occurrence or extraordinary experience (Parker, 2005), through olfactory experiences such as odors, auditory experiences, or symbolic events such as the appearance of butterflies or the activation or deactivation of electrical appliances. These findings suggest that meaning can be attributed either globally (i.e., based on beliefs or subjective sense of meaning or purpose) or situationally (an attribution to an event after a potentially stressful situation (i.e., the death of a parent; Park, 2010). Further, comforting signs contributed to participants' perception of continuing bonds with their deceased parents, reinforcing the belief that their parents will stay connected spiritually. These findings have implications for how counselors approach grief work with bereaved individuals.

Counselors must find ways to tap into the belief systems of their clients, including developing an understanding of their client's spiritual and religious beliefs, and their subjective sense of meaning or purpose (Association for Spiritual, Ethical, and Religious Values in Counseling [ASERVIC], 2009; Park, 2010). It was clear that participants' responses were supported by their religious and spiritual beliefs to some extent. These influences were important to understand. Upon making these connections, I introduced the sub-theme of comforting signs to the focus group, and in this context, participants continued to elaborate in this forum, which helped crystalize these findings. Had I not been open to participants' statements on their encounters of these meaningful signs, I would have missed this important finding. The same may be true in the counseling

process. Important to note is that engaging in the process of qualitative research itself

seemed to be catalytic for my participants. Through the individual interviews and focus

group, I provided space for participants to talk freely and tell their stories. In doing so,

they were able to identify meaning in various and new ways and to see their experiences

in a different light.

　　　Counselors need to maximize meaning making in their work with bereaved

individuals by incorporating post-modern grief theories such as meaning-reconstruction.

There are many ways in which counselors can facilitate meaning-making both

preventatively (e.g., during the caregiving process) and after a loss. For example,

counselors can use strength-based therapeutic approaches and narrative strategies to

facilitate the meaning-making process. Through the process of sense-making, benefit-

finding, and identity-reconstruction, in which meaning reconstruction occurs (Neimeyer,

2001; Neimeyer & Harris, 2011), counselors can empower caregivers by validating their

efforts and hard work and by helping clients identify and normalize the complex feelings

that caregiving engenders. For example, participants reported stress-related symptoms

that impacted overall well-being. Despite the difficulties encountered, they survived and

were somehow able to cultivate inner strength during their caregiving struggle.

Counselors can help caregivers identify, appreciate, and harness their inner strengths as

part of the process of benefit-finding to further meaning reconstruction. Through the

process of benefit-finding, counselors can also help bereaved caregivers co-construct and

identify other positive aspects they gained during the caregiving struggle, many of which

they may have otherwise overlooked. Participants in this study spoke about how they

changed in positive ways as a result of their caregiving experiences. Some participants developed more confidence and better communication skills, others were able to resolve some of their conflicts with family members, some found ways to assert themselves moving forward, and many spoke of how they grew to appreciate small things in life. Through the process of identity-reconstruction, counselors can help bereaved clients tap into these new insights by reaffirming and helping them reconstruct a new self-narrative.

Counselor Advocacy

Findings from this study indicate that participants benefited from counseling. However, although participants all noted that the importance of seeking support as early in the caregiving process as possible, only a few participants sought counseling during or after caregiving. It is important that caregivers have information about and access to counseling resources. Perhaps counselors could advocate for caregivers by bringing awareness to their communities about the benefits of counseling and how it can be used preventatively to help support them through the caregiving process. Participants also indicated that faith-based supports, such as talking with clergy, were comforting and provided hope and a new sense of connection. Counselors and communities of faith can mutually assist and support bereaved individuals by providing information and resources for caregivers as well as offering support groups (ASERVIC, 2009). Counselors can also inform caregivers of the benefits of prevention and wellness during caregiving. Only when caregivers are aware of the availability of counseling services will they recognize that perhaps such services might be advantageous (Feinberg & Levine, 2015; Forbat, McManus, & Haraldsdottir, 2012).

Interventions

Participants in this study emphasized the importance of future caregivers having varying supports in place at the onset of the caregiving journey. Preventative measures such as the use of psychoeducation groups could be implemented at the onset of the caregiving journey as caregivers at this point of the process are not ready to make sense of their experiences. However, as caregivers encounter the final stages of their caregiving experiences, they might be supported with interventions such as individual therapy, meaning-based group counseling (MacKinnon, et al., 2014), and support groups that are designed to address the needs of caregivers where caregiving can be most intense. Participants indicated that the focus group provided a means to share experiences and validate feelings. Participants clearly learned from each other and benefited from a group setting; they were able to identify with other members and help each other identify new meaning and purpose in their caregiving and grief experiences.

Findings also indicate a need for counselors to intervene with caregivers at family and relational levels. Participants reported that they experienced an escalation of relational tensions between siblings and extended family members, which caused additional caregiver strain. In fact, participants stated that it would have been beneficial had they elicited the support of counselors and other professionals for themselves as well as to help educate family members on illness and mediate between family members to alleviate some of the tension experienced while caring for their parent. Interventions at a family and relational level before a loss and early in the caretaking process have the potential to decrease conflict and alleviate complicated grief (Forbat et al., 2013).

Counselor Preparation

Prevention begins at the institutional level with counselor education programs preparing counselors-in-training to work more effectively with bereaved caregivers.

Preparing future counselors to work with caregivers begins with recognizing the importance of grief and loss education. The Council for Accreditation of Counseling Related Educational Programs (CACREP, 2009) does not include grief and loss courses in the curricular standards (Doughty Horn, Crews, & Harrawood, 2013). Because of this, while many CACREP-accredited counselor education programs provide courses in grief and loss, they typically do so as electives (Doughty Horn et al., 2013). Additionally, the professional literature has indicated that practitioner attitudes toward grief and loss issues suggest a need for additional training in this area (Doughty Horn et al., 2013). It is therefore important that counselor educators expose students to grief and loss issues and interventions through existing coursework such as in counseling across the lifespan to teach students about caregiving as a developmental issue in commonly experienced around mid-life development.

Counselor educators can facilate discussions on issues related to grief and loss, specifically in relation to the process of EOL caregiving. It is important for students to understand that although caregivers have unique experiences, the journey of EOL caregiving can negatively impact caregivers and that caregivers have different emotional and psychological needs at different points during the caregiving journey. Anticipatory grief, for example, is a ubiquitous reaction of caregivers in response to an impending loss of a loved one. However, it becomes intensified especially during the latter part of the

caregiving journey, particularly during the end-stages of caregiving. Moreover,

counselor educators can teach post-modern grief theories such as meaning reconstruction

to educate students of the benefits of meaning-making during difficult life experiences

such as home-based end-of-life caregiving and in bereavment as well.

Limitations

I believe the findings from this study will benefit professional counselors and

other mental health practitioners from various fields alike. There are, however,

limitations, four of which are important to note. The first limitation is researcher

perspective. I previously discussed the recent experience I had while embarking on this

research study. While conducting my first round of interviews, my mother suddenly

became ill and I became her primary caregiver in my home. As a caregiver, I had also

experienced some of the distress, emotions, and family strife, similar to my participants.

However, I made efforts to maintain integrity in my data collection and analysis. For

example, while endeavoring through my caregiving experience, I kept a reflective memo

journal to record my thoughts, impressions, and reactions to discern researcher bias and

also processed these with my dissertation chair.

The second limitation concerns participant bias during the focus group interview.

It is possible that participants may have offered what they perceived to be more socially

desired responses than they did during individual interviews. To counter this, I made

every effort to honor the uniqueness of every experience and clarified statements if I

observed indications that participants somehow felt pressured to offer what they might

deem to be socially desirable statements.

A third limitation concerns diversity. While I was able to reach data saturation, my sample was limited and lacked a balance of males and females and individuals from different races, ethnicities, and socioeconomic levels. The way in which we care for our elderly and conceptualize grief, and its resolution is primarily drawn from Western sociocultural norms (MacKinnon et al., 2014). It is possible, therefore, that the inclusion of participants from diverse backgrounds could have offered a cross-cultural lens of home-based caregiving and additional insight into how various ethnic groups attend to the care of their elderly, their religious and spiritual beliefs and meaning of death and dying, and the potential variations of grief expression.

A fourth limitation is that all participants utilized hospice services. It is possible that families, especially those from economically disadvantaged populations may not have such resources to facilitate end-of-life care. Moreover, hospice services may not be covered under certain insurance policies. It would be important for future research to explore the experiences of caregivers who have cared for loved ones with limited resources to understand how caregivers cope in such situations and how to help those who are less fortunate in these circumstances.

Suggestions for Future Research

It is my hope that the findings of this study will illuminate the importance of addressing the needs of caregivers. This study is one of the few studies, if not the first, from the counseling profession to examine the experiences and meaning making of adult children who had provided home-based EOL care for a terminally ill parent. It is my hope that more counselors examine home-based caregiving and explore caregiver needs

from a preventative lens. One recommendation is for counselor educators to encourage

doctoral students who are interested in counseling mid-life and older adults to explore the

topic of family caregiving and interventions to mitigate caregiver burden.

Study participants were primarily from a middle social class and were able to

access a variety of services and all used hospice services. Future researchers may focus

more specifically on the needs of caregivers from economically disadvantaged families to

identify resources in assisting families who struggle, including those who families who

do not have access to or choose not to use hospice services. Additionally, qualitative

studies that investigate the effectiveness of narrative work and meaning reconstruction in

bereavement may offer strategies that can enhance the meaning making process of

caregivers and, theoretically, adaptive bereavement. Further, researchers could employ

cross-case analysis to understand the evolution of meaning in caregiving from earlier,

middle, and post-loss adjustment.

My participants experienced the loss of their parents one to three years before my

study. Although my findings indicate that bereaved caregiver are able to make sense of

and find meaning after loss, the meanings discerned by my participants tended to be

situationally based (e.g., meaning about their relationship with a parent). In future

research, I hope to interview bereaved caregivers who experienced loss beyond three

years (further along in bereavement) to see whether or not their meaning making has

expanded; if they make meaning of their EOL caregiving experiences at a more global

level (e.g., meaning about what is important to them or recognizing strengths they have).

Overall, researchers need to help individuals identify ways to enhance the "gift" of

caregiving and minimize the sacrifices and suffering so that the quality of the caregiving experience is enhanced.

As the population of our country continues to age and diversify, further studies such as examining cultural differences in EOL family caregiving and EOL spousal caregiving may help identify specific needs that target interventions that are culturally appropriate and demonstrate humility. Further studies are needed to lessen the burden of home-based care and enhance the quality of care for families during the final phase of life.

Conclusion

The findings of this study suggest that providing home-based EOL caregiving for a terminally ill parent impacts the physical and emotional well being of adult children. Despite describing their experiences as burdensome, full of uncertainity, and stress, most participants in this study reported that EOL caregiving was special. They noted that there was value and meaning in caring for their dying parents and provided many examples that illustrate the overall impact of EOL caregiving and the importance of meaning-making in the bereavement process. Moreover, these findings indicate that caregiving is a process that unfolds over time, with individuals having different needs at different points of the caregiving trajectory. Counselors can use meaning making strategies preventatively and then therapeutically during certain points of the caregiving process, incorporating such interventions more as the intensity of caregiving esccalates, especially during the end-stages of caregiving.

As previously mentioned, counselors are well positioned to provide support for caregivers at all points along the caregiving and bereavement processes, yet there is a dearth of research about effective practices from the counseling perspective. The problem, however, lies in the historical context of helping professions. Medical professionals have long recognized social workers as a support in EOL care. In fact, much of the professional literature on EOL research has come out of nursing and social work practice and from palliative care medical journals. From a wellness perspective, counseling professionals can offer support that is holistic and preventive in nature. As the graying of America continues, it is critical that the counseling profession is prepared to help support families who will potentially face the challenges of providing EOL home-based care for a terminally ill loved one.

Although there is limited generalizability due to the qualitative nature of this research, this study provided insight into the experiences and meaning-making of adult children caregivers who provided home-based care for a terminally ill parent and offers suggested applications for counselors and counselor educators to consider. Because of their experiences and generosity in sharing them with me, participants' voices were heard, offering practice implications for professional counselors and greater insight into the meaning structures of bereaved caregivers and the benefits of meaning reconstruction in bereavement. Also, participants' narratives suggest the need for counselor educators to provide relevant learning experiences for counseling students related to effective ways to conceptualize and treat issues of loss, bereavement, prolonged grief, and meaning-

making. As counselors, we need to further our understanding of grief work and the

benefits of post-modern theories to effectively address the needs of bereaved caregivers.

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Appendix A: Recruitment E-mail to Program Directors

Kim Tassinari
Doctoral Candidate
Montclair State University
tassinarik1@mail.montclair.edu
Phone (203) 313-4313

Email to Program Directors

Dear Program Director:

I am a doctoral candidate in the Counselor Education program at Montclair State University. I am writing to ask for your assistance in my dissertation research project. While I am not asking you to participate in my study, I would like your help in in the recruitment of participants. My goal is to interview 10-12 individuals. All that is required of you is to disseminate my recruitment flyer, which contains the criteria for my study, what participants will do in the study, and my contact information.

In this qualitative dissertation research project, I will be exploring how adults experienced home-based end-of-life caregiving of their parent. I am also looking at how they may have ascribed meaning after the loss of a parent. The objective of this study is to illuminate the importance of home-based end-of-life caregiving, how it impacts the lives of caregivers who provide such care, and the support that is needed to facilitate the caregiving process. Additionally, few studies have examined home-based end-of-life caregiving in relation to meaning reconstruction, or the process of making-meaning after loss. It is my hope that the results of my study will contribute to closing the current gaps in the professional caregiving literature. With your help in assisting me to locate volunteers for my study, I will be able to achieve my goal for this study.

If you would like additional information about my study or have any questions or concerns about this dissertation research project, please feel free to contact me or my dissertation chairperson, Dr. Harriet L. Glosoff (glosoffh@mail.montclair.edu; 973-655-3482). This dissertation research study has been approved by the Montclair State University Institutional Review Board for The Department of Counseling and Educational Leadership, and by my dissertation committee.

Thank you for consideration.

Kim Tassinari

Doctoral Candidate
Montclair State University
tassinarik1@mail.montclair.edu
Phone (203) 313-4313

APPENDIX B: Informed Consent Agreement

Informed Consent Agreement

Please read below with care. You can ask questions at any time, now or later. You can also talk with other people before you sign this form.

Study's Title: End-of-Life Caregiving and Meaning Reconstruction: Experiences of Adult Children Providing Home-Based End-of-Life Care for a Parent

Why is this study being done? The purpose of this study is to explore the experiences of adults who have provided home-based end-of-life care for a parent during the parent's end of life. I am also interested how caregivers experienced their role as primary caregivers and if and how they made meaning of the loss of their parent.

What you will do in the study? You are being asked to voluntarily participate in two in-person interviews. During the first interview I will ask participants questions about their role as caregiver. During the second interview, I will ask questions about how they may have made meaning about the death of their parent. The second interview also offers participants the opportunity to expand on information from the first interview or share additional insights. People who participate in the individual interviews and wish to continue the discussion may choose to participate in a focus group. During the focus group, I talk with participants about themes that I heard after the two rounds of interviewing and ask them to talk more about those themes.

The discussions that take place during the interviews will be digitally recorded and then transcribed. Recording interviews helps make sure that I accurately represent the statements and views presented by each participant rather than rely on from memory. The recordings will not be used for any other purpose other than writing up a written transcript for you and me to review for the accuracy of what has been said during the interview. Prior to meeting for the second interview I will either email or mail the transcript to you for you to review for accuracy. Before sending you the transcript, I will ask to pick a pseudonym or fake name for your transcript. Please note I am the only person who will have access to the audiotape before they are analyzed.

For participants who choose to participate in the focus group, I am the only person who will have access to the audiotape of the focus group and the names of the participants in the focus group. Each participant will have the option of receiving a transcript to review the accuracy of what has been said during the focus group. I will replace each participant's name with a chosen pseudonym or initial for this transcript as well.

Time required: This study will require a total of about 2-3 hours of your time. For participants who choose to participate in the focus group in addition to the individual interviews, this will require a total of 3-4 hours of your time.

Risks: While in-depth interviewing does not pose any serious threat or harm, I am aware that this is not risk free. I will be asking you to talk about your experiences of taking care of your parent and about the loss your parent, which may cause some discomfort or trigger negative emotions. While my role for this study is researcher, as a licensed professional counselor, I am confident in my ability to talk with you after the interview if you had any discomfort during the interviewing. If you choose to participate in the focus group after the individual interviewing, this can also trigger discomfort or negative emotions. Once again, I am confident in my ability to talk with you after the focus group. Some people who participate in focus groups may be concerned about how others may perceive their responses and about confidentiality. I will, however, ensure that I personally will maintain confidentiality and will promote confidentiality among members in the focus group, which would be discussed prior to the focus group discussion. If at any time during the individual interviews or the focus group discussion you become uncomfortable or would like to discuss feelings that come up for you, please let me know and I will be happy to talk with you and to provide you with resources of support groups and counseling services if needed.

Benefits: There are no direct benefits to participating in this study. The results of this study, however, may help us understand how taking care of a parent in one's home at that parent's life impacts primary caregivers and how some individuals cope and adjust to the loss of their parent. The information from this study will also help professional counselors provide support to individuals who are or were home-based caregivers for parents during the end of their parents' lives.

Compensation: To compensate you for your time during the two individual interviews I will offer all participants a $25 gift card. For participants who choose to participate in the focus group, in addition to the two rounds of interviewing, each will receive an additional $15 gift card.

Confidentiality: All information that you provide will kept confidential. The audiotapes will be kept in a locked file in my home, and I am the only person who will have access to the tapes. Tapes will be destroyed one year after the study is completed. Additionally, transcripts will not have your name on them. They will only contain either the pseudonym you provide or your initials, whatever you choose. One "peer reviewer," who is also a doctoral student in my program will have access to the transcript but only after your identifying information is removed. Peer reviewers and members of my dissertation committee may access the transcripts to help me make sure that my interpretation of the information provided and how I label themes that emerge are accurate—based on what participants rather than my opinions.

Do you have to be in the study? You do not have to be in this study. You are a volunteer! It is okay if you choose to stop or withdraw and decide not to participate.

There are absolutely no penalties for stopping, and you will still receive a gift card for any participation.

Do you have any questions about this study?
Contact:
Kim Tassinari
The Department of Counseling and Educational Leadership
Montclair State University
1 Normal Avenue
Montclair, NJ 07043
Telephone: (203) 313-4313, Email address: tassinarik1@mail.montclair.edu

Dr. Harriet L. Glosoff, Doctoral Program Director, Professor
The Department of Counseling and Educational Leadership
Montclair State University
1 Normal Avenue
Montclair, NJ 07043
University Hall 3156
Telephone: (973) 655-3482, Email: glosoffh@mail.montclair.edu

Do you have any questions about your rights as a research participant, contact:
Dr. Katrina Bulkley, Chair, Institutional Review Board for The Department of
Counseling and Educational Leadership
Montclair State University
1 Normal Avenue
Montclair, NJ 07043
Telephone: (973) 655-5189 or Email: reviewboard@mail.montclair.edu

As part of this study, it is okay to audiotape me during each interview:

Please initial: _____ Yes   _____ No

One copy of this consent form is for you to keep.

Statement of Consent
I have read this form and decided that I will participate in the project described above. Its general purposes, the particulars of involvement, and possible risks and inconveniences have been explained to my satisfaction. I understand that I can withdraw at any time. My signature also indicates that I am 18 years of age or older and have received a copy of this consent form.

_____   _____   _____
Print your name here   Sign your name here   Date

_____ _____ _____
Name of Principal Investigator   Signature   Date

_____ _____ _____
Name of Faculty Sponsor   Signature   Date

Appendix C: Semi-structured Interview Guide

Introduction to the Interviews: Participants will engage in two individual interviews.

During the first interview, I will begin by expressing my interest in their experiences as

the primary caregiver of their parent and will ask participants to describe these

experiences from the onset of caregiving through the end of their parent's life. I will

begin with broad, open-ended questions and allow participants to share what they see as

important aspects of the caregiving experience, including their role as caregiver, the

support they received while providing care, if any, and the negative and positive impacts

on family relationships and their experience. Specific questions will be emergent based

on what individuals present as being significant to them in terms of their caregiving

experiences. Following are examples of questions and prompts that I anticipate using

during the first interview.

Questions Pertaining to Role as Primary Caregiver:

1. Please tell me how you came to be the primary caregiver for your parent? Tell me
   what this was like for you.

   Prompt: If not organically part of participants' responses to the above, I will ask
   them to tell me how much time they spent on caregiving each week and to
   describe some of the activities in which they were involved.

2. Please tell me about family relationships. What were they like before and during
   the time you provided home-based care for your parent?

Prompt: If not addressed, I will follow-up with questions such as (a) Who supported you during the time you provided home-based end-of-life care for your parent (e.g., siblings, friends)? (b) What were your family relationships like during the course of caregiving and how did they impact or influence caregiving? (c) What effects did caregiving have on your immediate family? Did this change during the course of caregiving?

3. Tell me about some of the challenges you encountered--what were some of your greatest concerns while providing home-based end-of-life care?

Prompt: If not addressed, I will follow up with more specific questions about any conflicts between participants and their parents regarding preferences related to end-of-life care.

4. How has end-of-life caregiving affected your life (e.g., physical, emotional, spiritual well-being)? Has this impact changed over time? Please explain.

The next set of questions pertain to meaning after loss: These questions will asked during the second round of interviewing. The second round of interviewing will offer participants the opportunity to expand on the themes that were heard across the first round of interviews. Additionally, this second round will be used for member checking where participants can provide verification of what has been said, check for accuracy, and provide any additional information that had not been addressed in the first interview. Following are examples of questions that I will ask if the information was not shared during the first interview.

5. What meaning, if any, does this experience of providing end-of-life care for your parent have for you? Follow-up questions or instructions may include: What strengths have you gained from this experience? Was there anything positive you take with you from this experience (e.g., a silver lining)? Describe for me some of the supportive aspects of providing care for a parent during end of life.

6. What impact has this experience had on you as you see the world now?

7. In thinking about the whole care-giving process, how did you and your family process this experience? If you talked with your family members, were there any lessons learned or truths realized or meaning made from your experience?

8. As we have talked about your experiences today, has anything new come up for you?

9. Thank you for sharing your story with me. Is there anything else you would you like to share with me?

Focus Group Protocol

During the focus group, as researcher/ facilitator, I will encourage participants to share with each other their experiences and points of view. The focus group is about sharing themes that were heard across the individual interviews and for participants to share their reactions and provide any new information they would like. Questions will be emergent based on individual interviews and findings. The group is designed to be discussion oriented and generative. I anticipate that I might ask questions such as the following:

1. I am interested in your collective experiences. Is there anything else you'd like to add that wasn't mentioned during the first interview? Please share any meaning that was made from you experience.

2. Could you expand upon any themes that were heard or provide any additional insight you'd like to share?

3. What advice can you offer to future primary caregivers and/or counselors who work with caregivers?

Appendix D: Demographic Information

Thank you for your participation in my study. I am interested in gathering some general information about the volunteers and would appreciate you completing this form. Confidentiality is very important to me. Therefore, I want to assure you that your responses and any identifying information will not be shared with anyone.

The section below is comprised of some demographic questions. Please fill in your information and place a check mark next to each response. If you do not wish to provide any specific information, please skip over. Please note that there are two spaces for your name: "Name" and "Pseudonym." The pseudonym will replace your real name (if you choose to remain anonymous) to maintain anonymity in the focus group transcription. If "pseudonym" is left blank, I will assign a pseudonym for you.

Name: _____ Pseudonym _____

Age: _____   Sex: _____Male   _____ Female

Race/Ethnicity. Please share how you identify in terms of your race and/or ethnicity:

Marital/Partner Status during caregiving:

Geographical proximity at time of caregiving:

Please describe religious or spiritual beliefs or practices to which you subscribe: