

4-25-2014

Caregiving for a Loved One with Dementia at the End of Life: An Emergent Theory of the Basic Social Psychological Process of Rediscovering

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Caregiving for a Loved One with Dementia at the End of Life:
An Emergent Theory of the Basic Social Psychological Process of Rediscovering

Laura Foran Lewis, PhD

University of Connecticut, 2014

Prevalence of dementia is rising across the world, and with it, more and more individuals confront the challenges of caregiving for a loved one with dementia. Caregivers experience burden, depression, and decreased quality of life, which increase as the care recipient approaches the end of life. A classic Glaserian grounded theory methodology was used to discover the basic problem that caregivers of individuals with dementia face at the end of life and how they attempt to resolve that problem. Using the principle of “all is data,” in-person interviews, online interviews, book and blog memoirs of caregivers, and participant observation were theoretically sampled. Substantive and theoretical coding of emergent categories and memo-writing revealed a basic social psychological problem of role entrapment. Caregivers attempt to resolve this problem through a five-stage basic social psychological process of rediscovering. The stages in this process include: 1) missing the past; 2) sacrificing self; 3) yearning for escape; 4) reclaiming identity; and 5) finding joy. By understanding this process, nurses can support caregivers through this journey by validating their feelings in their current stage, preparing them for future stages, and encouraging caregivers in their natural coping strategies as identified in this process. This study provides a substantive theory that may serve as a framework for future studies on caregiving for individuals with dementia at the end of life.

Caregiving for a Loved One with Dementia at the End of Life:
An Emergent Theory of the Basic Social Psychological Process of Rediscovering

Laura Foran Lewis

B.S.N., University of Connecticut, 2010

M.S.N., University of Connecticut, 2013

A Dissertation

Submitted in Partial Fulfillment of the
Requirements for the Degree of Doctor of Philosophy

at the

University of Connecticut

2014

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2014

APPROVAL PAGE

Doctor of Philosophy Dissertation

Caregiving for a Loved One with Dementia at the End of Life:

An Emergent Theory of the Basic Social Psychological Process of Rediscovering

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Dedication

To Jeffrey Lewis, my unwavering supporter and best friend in good times and in bad, in sickness and in health, til death do us part.

Acknowledgements

I would first like to thank my family for their constant support and encouragement. Jeffrey, thank you for always helping me find the light at the end of some very long tunnels! For everything you are to me, I would not be who I am without you. My parents and my brothers, for believing in me and cheering me on from Sally's Adventures through my dissertation, for your "good morning" emails and lunch dates in the car, for teaching me to "do the loving thing" and for "forgiving me everything," thank you. My other parents, Laura and Bill, for being there for me through it all, for showing me the true love and dedication of family, for understanding the missed visits and parties along the way, and for celebrating each milestone with me, I am forever grateful. For a compound of love and support that showed me how to be caregivers to our Gramma and to each other, thank you.

I would like to thank Cheryl Beck, my dissertation committee chair, mentor, and friend over these last 4 years. You have kept me motivated and inspired. For your remarkable ability to push me forward with gentle patience and understanding, I thank you. Tom Long and Colleen Delaney, my associate advisors, I am so grateful for your constant editing, support, and advice. Thank you for sharing your wisdom with me.

Thank you to my undergraduate and graduate professors at the University of Connecticut who helped me find my niche in research, convinced me to pursue this degree, and helped me to achieve it. And to my colleagues in the doctoral program, thank you for your constant feedback, for venting with me and studying with me, for pushing me forward and for teaching me the entire way. You make me proud to join your ranks!

To my work family on Oncology-6, thank you for the “deep love” we share, for the tears and for the laughter that has kept me going. Thank you to my dear friend Emily Woods for your love, faith, and support through thick and thin.

Thank you to Barney Glaser, Jillian Rhine, Carolyn Glaser, Judith Holton, and the Grounded Theory Institute fellows for your guidance in learning and understanding the grounded theory method.

To Michael Smith and the Alzheimer’s Resource Center, thank you so much for reaching out to me and supporting me in my research endeavors, and for all you do to help individuals with dementia and their caregivers. To Irena Delahunty, for your welcoming spirit, your warm heart, and your faithful wisdom, thank you.

And, most importantly, to all those who shared their stories with me, I will be forever indebted to you for making this research possible. Thank you for your honesty, your sincerity, and your willingness to open your souls.

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CHAPTER 1: INTRODUCTION

Significance

In the United States today, 5.2 million people have been diagnosed with Alzheimer's disease, which is the leading cause of dementia (Alzheimer's Association, 2013). An estimated 35.6 million people have dementia worldwide and prevalence is growing exponentially, expected to reach 115.4 million by the year 2050 (Prince & Jackson, 2009). Costs to society for this population in the United States are projected at \$203 billion this year alone, and by the year 2050 will be as high as \$1.2 trillion (Alzheimer's Association, 2013). Of this amount, an estimated \$34 billion will be paid out of the pockets of persons with dementia and their caregivers this year.

More than 15 million Americans are caring for a loved one with dementia providing a total of over 17.5 billion hours of unpaid care that would be the equivalent of \$216 billion of healthcare costs (Alzheimer's Association, 2013). Caregivers are burdened, strained, and distressed (Sanders, Ott, Kelber, & Noonan, 2008). These caregivers have weaker immune systems and higher mortality rates than their cohorts who are not caregiving and accrued an additional \$8.7 billion in healthcare costs towards their own health in 2011 (Alzheimer's Association, 2012; Prince & Jackson, 2009). Emotional and physical demands of caregiving are increased at the end of life and are further exaggerated by grief. Nearly three quarters of family caregivers reported that they felt relieved when their loved ones with dementia died (Alzheimer's Association, 2013). Caregivers are frequently left with minimal support throughout the progression of the dementia, particularly at the end of life (Godwin & Waters, 2009; McCarty & Volicer, 2009).

Healthy People 2020 identifies "Dementias, Including Alzheimer's Disease" and "Health Related Quality of Life" as nationwide priorities in healthcare at this time (2013). By exploring

the ways in which caregivers navigate the healthcare system and resolve the challenges they face at the end of life, this study aims to address objective OA-9, which is to “reduce the proportion of unpaid caregivers of older adults who report an unmet need for caregiver support services.” Since caregiver burden is associated with increased institutionalization of those with dementia (Waldemar et al., 2007), this study also aims to indirectly contribute towards objective DIA-2, to “reduce the proportion of preventable hospitalizations in persons with diagnosed Alzheimer’s disease and other dementias.”

Statement of the Problem

Caregivers of persons with dementia live in a state of constant change and disruption of everyday life (Prorok, Horgan, & Seitz, 2013). These individuals consistently show high incidence and severity of burden, depression, and physical health deficits throughout the years of caregiving (Papastavrou, Charalambous, Tsangari, & Karayiannis, 2012). Caregiver burden is known to increase as dementia becomes more severe (Kim, Chang, Rose, & Kim, 2012; Liu et al., 2012; Turro-Garriga et al., 2013), and for caregivers of loved ones with any disease process, the end of life is known to be a time of increased grief and burden. Yet, despite continued evidence that this population requires increased support compared to other diseases, caregivers have limited access to end of life support programs such as hospice care (Miller, Lima, & Mitchell, 2010).

Many qualitative studies have explored the overall experience of caregiving for persons with dementia and quantitative studies explore interventions to improve the caregiving experience. Few interventions show consistent results, and service use remains low even for those interventions that are successful despite reports of high unmet need among caregivers (Phillipson, Magee, & Jones, 2013). There is a lack of qualitative research on the experience of caregiving at the end of life in dementia. Since most caregivers have limited access to end of life

support or do not seek formal support to meet their needs, it is critical to understand how they process the challenges they face.

Purpose

The purpose of this study was to explore the general topic of caregiving for a loved one with dementia at the end of life. A classic Glaserian grounded theory methodology was used to inductively unveil a theory that is grounded in data (Glaser, 1978, 1998, 2001, 2003, 2005, 2011; Glaser & Strauss, 1967/2010). The goal of the study was to discover a substantive theory that identifies the main problem that caregivers for loved ones with dementia face at the end of life and the basic social process by which they resolve this problem.

Research Design

Classic Glaserian grounded theory was selected as an appropriate methodology given the purpose of this research study. Grounded theory is a method developed by Glaser and Strauss (1967/2010) in which a theory is developed from data. Theory is allowed to emerge through a constant comparison of evidence. Grounded theory is transcending, as it goes beyond description of data to conceptualize ideas that are substantive. Everything is data, including field work, qualitative or quantitative findings, other relevant literature, and other relevant theories. The wider the spread of data, the more rich and conceptual and accurate the theory will become. This section will provide a brief overview of the method of classic grounded theory as delineated by Glaser and Strauss and continued by Glaser (1978; 1998, 2001, 2003, 2005, 2011). An in-depth description of this method is provided in Chapter 3.

In grounded theory, the goal is to create a theory that describes the phenomenon or process of interest as it actually is, not as it ought to be. To do this, researchers must be theoretically sensitive, letting go of all preconceptions and being open to abstraction of ideas rather than focusing on description. This method utilizes theoretical sampling of the population

of interest, in which the researcher selects participants and interview questions based on needs of the emerging theory.

Data are concurrently analyzed as they are collected using constant comparative analysis. Open coding allows the researcher to explore data and search for the primary concern of the population of interest and the core category, or the main process that participants use to overcome this problem. The core category should become apparent to the researcher through continued data collection and analysis. Once it has emerged, the researcher begins to use selective coding to explore the properties of the core variable.

Throughout this process, the researcher writes memos, or stream of consciousness writings, to explore the abstract concepts emerging from the data. Theoretical sorting of memos and theoretical coding are used to discover how substantive codes relate to one another. As the researcher continues with these steps, a theory emerges. The theory guides the researcher as it emerges until theoretical saturation is reached.

Assumptions

This study inherently relies on assumptions regarding both method and content. This section will describe the assumptions made throughout this study.

1. I assumed that a process could be best understood by looking at it through the viewpoint of the person who has experienced that process. A sample of data was collected from individuals who have undergone the personal experience of being a caregiver to a loved one with dementia at the end of life.
2. I also assumed that participants would be able to adequately recall the past experience of that process and that they would be able to accurately convey their experiences to me through our interactions.

3. In choosing grounded theory, I assumed that this method would be a successful means of understanding the process that caregivers undergo. Specifically, I chose to use classic Glaserian grounded theory, which implies that I believed that an abstract exploration of concepts would provide a richer theory than a full description of the individual experience. I also assumed that by closely following this methodology, I would be able to objectively discover a theory that is true to the experience of the population of interest, rather than one that is co-constructed by participants and me.
4. I believed that exploring this population of interest would lead to a theory with *grab*, or one that captures the attention of the reader, and *fit*, or one that closely relates to the concepts it represents. This assumes that caregivers of persons with dementia have concerns and that they attempt to resolve those concerns.
5. I assumed that caregivers face unique challenges at the end of life and that it is worthwhile to explore this period in isolation of the overall caregiving experience. While I focused on the end of life period, I also relied on participants to provide the context of the end of life experience within the overall caregiving experience.
6. Finally, I assumed that participants would be honest and open to sharing their experiences.

Definition of Terms

Classic Glaserian grounded theory. Classic Glaserian grounded theory refers to the method of grounded theory originally introduced by Barney Glaser and Anselm Strauss (1967/2010), continued in the tradition of Glaser (1978, 1998, 2001, 2003, 2011). This type of grounded theory must be distinguished from variations of the grounded theory method developed by Strauss and Corbin (2008) and Kathy Charmaz (2006). Glaser coins Strauss and Corbin's

method “full conceptual description” (Glaser, 1992). He argues that this method does not allow for true emergence, but instead forces preconceived ideas into theory and focuses on description rather than abstraction. Charmaz developed “constructivist grounded theory,” which Glaser argues is rooted in a pre-conceived framework that inappropriately relies on co-construction of ideas between researcher and participant rather than relying on objectification of data through constant comparison and triangulation (Glaser, 2002).

Formal caregiver. A formal caregiver refers to any person who is involved in the tasks of providing care to an individual who is ill because they have been trained in providing care and are hired to do so. Examples of formal caregivers include home health aides, nursing home staff, or individuals who are hired to visit or live with the person who is ill. For the purposes of this study, family members or friends who receive payment for providing care are not considered formal caregivers.

Informal caregiver. An informal caregiver refers to a family member or friend who is involved in the tasks of providing care to an individual who is ill. Caregiving tasks are not limited to providing physical care, but may also include such tasks as organizing finances, providing assistance with legal issues, or coordinating formal care.

Primary caregiver. A primary caregiver refers to an informal caregiver who has identified himself or herself as the coordinator of care for the ill individual. This person may or may not provide physical care, and may or may not live with the ill individual.

Experiential Context

In grounded theory methodology, the researcher aims to be objective, free of bias and preconception (Glaser, 2002). The researcher should accept the meaning that the participant has placed on the data rather than attempting to interpret the message. I have attempted to follow these principles and strive for objectivity. However, since the researcher serves as the instrument

in qualitative research, it is still important for me to acknowledge my background as the experiential context of this study.

As the student investigator, I have had both personal and professional experiences that have prepared me to conduct this study. I have had personal experience with family members with dementia, including caring for those family members in a family context at the end of life. I have also conducted a phenomenological study on caregivers' experiences seeking formal end of life care for loved ones with dementia (Lewis, 2014). I have worked as an oncology nurse for the past 3 years and have had many professional experiences with end of life care of patients and their families, including care of patients with dementia and those without dementia. I have completed a graduate course series in qualitative methodology and a series in quantitative methodology. I attended a workshop seminar on grounded theory methodology conducted by Barney Glaser through the Grounded Theory Institute, and I have worked closely with the principal investigator, Cheryl Beck, who is experienced in using grounded theory methodology.

Organization of the Remainder of the Study

Chapter 1 provides an introduction the research problem and its significance, an overview of the method, assumptions, and strengths and limitations of this study. Chapter 2 provides a review of the literature on caregiving for persons with dementia and highlights gaps in the literature that support the need for this study. Chapter 3 discusses grounded theory methodology and its application in this study. Chapter 4 reports findings from this study and introduces the emergent theory. Chapter 5 provides a discussion of findings, nursing implications, and recommendations for future research.

CHAPTER 2: LITERATURE REVIEW

Evolution of the Study

Due to the use of a grounded theory methodology, an extensive literature review was deferred until data collection and data analysis were nearly completed. Glaser prescribes that the researcher should not turn to the literature until she is ready to generate theory to avoid contaminating data with preconceived concepts and ideas. He writes, “When the theory seems sufficiently grounded and developed, *then* we review the literature in the field and relate the theory to it through integration of ideas” (Glaser, 1978, p. 31). According to Glaser, “the likely results of a pre-research literature review are inimical to generating grounded theory” (Glaser, 1998, p. 67). Premature literature review may lead the researcher to introduce ideas into the theory that do not “fit,” and may distract the researcher from recognizing the core variable, or the main concept that emerges from the data that will be the basis of the theory.

As advised, a formal literature review was postponed until the core variable had been discovered and explored. Searches were conducted on CINAHL, PubMed, PsychInfo, and ProQuest databases. The following search terms were used: (1) “dementia” OR “Alzheimer’s disease”; AND (2) “end of life” OR “death and dying”; OR (3) “caregivers” OR “family”; OR (4) “hospice care” OR “palliative.” With the exception of searches on ProQuest database, searches were limited to peer-reviewed articles. Searches were also limited to English language only and publication year between 2004 and 2014.

Many quantitative and qualitative studies exist on the topic of caregiving for persons with dementia. Quantitative studies focus on measuring and predicting burden, depression, anxiety, quality of life, grief, perceived physical health and perceived mental health of caregivers. There are also many quantitative studies testing the effectiveness of interventions on the incidence and severity of these symptoms among caregivers (Bakker, Duivenvoorden, Olde Rikkert, Beekman,

& Ribbe, 2011; Bass et al., 2013; Chien et al., 2011; Huang et al., 2013; Kim, Zarit, Femia, & Savla, 2012; Livingston et al., 2013). Qualitative studies focus on the experience of caregiving (Clissett, Porock, Harwood, & Gladman, 2013; Gillies, 2012; Hibberd, Keady, Reed, & Lemmer, 2009; Lin, Macmillan, & Brown, 2012; Prorok et al., 2013; Sanders & Power, 2009). Many of these focus on specific aspects of care or on a subpopulation of caregivers. Few qualitative studies have been conducted on the experience of caregiving for persons with dementia at the end of life, and none of those have used grounded theory methodology. There are also many qualitative studies on caregivers of persons with dementia who claim to use grounded theory, but few of those use classic grounded theory methodology. The current study fills a unique niche in that it rigorously explores how caregivers attempt to resolve the challenges of being a caregiver at the end of life.

This chapter will summarize the current state of the literature on caregiving for persons with dementia at the end of life. In the first section, I will describe dementia as a terminal illness. Next, I will discuss the impact of caregiving for an individual with dementia. This will include an overview of the experience of caregiving, then the emotional and physical impact of caregiving for a loved one with dementia. I will review interventions to improve care, followed by a discussion of hospice access for individuals with dementia. Finally, I will review grounded theory studies that have been conducted on caregiving for individuals with dementia.

Dementia at the End of Life

Dementia is not a specific disease, but is rather a collection of symptoms causing a decline in cognition or behavior with many etiologies. Most common types of dementia include Alzheimer's disease, vascular dementia, dementia with Lewy bodies, and frontotemporal lobe dementia (Prince & Jackson, 2009). Together, these are often referred to as Alzheimer's disease or related dementia (ADRD). In general, there is no way to prevent dementia, and there is no

cure. Treatment is usually limited to palliation and management of symptoms, as reversal of symptoms is not possible (Bowen, 2012; National Institute of Health, 2010). Cause of death in advanced dementia tends to be related either to starvation or infection (Mitchell et al., 2009). Persons with dementia lose appetite, ability to swallow, and often the will to eat. They also lose the ability to compensate, which can cause death from a mild pneumonia or urinary tract infection.

Dementia *is* a terminal illness. Life expectancy is shorter in dementia populations than in control non-dementia populations regardless of other factors (Arrighi, Neumann, Liberburg, & Townsend, 2010; Larson et al., 2004; Meerman, van de Lisdonk, Koopmans, Zielhuis, & Olde Rikkert, 2008; Rait et al., 2010). Comorbidities, depression, and loss of social support have been shown to further shorten life expectancy in individuals with dementia (Covinsky & Yaffe, 2004). Alzheimer's disease is currently the 6th leading cause of death in the United States (Alzheimer's Association, 2013).

Despite this evidence, providers continue to deny the terminality of dementia in practice. This leads to underuse of end of life services and advanced care planning in this population, which will be discussed in a later section of this chapter. Denial of terminality is further complicated by the difference in terminology between dying *with* dementia and dying *from* dementia. Since providers often inaccurately attribute death to an acute cause, such as pneumonia, instead of to the underlying dementia, there are even more deaths associated with dementia than realized on public record (Ives, Samuel, Psaty, & Kuller, 2009). In most cases, prognosis from the time of onset of symptoms is variable and difficult to predict, ranging anywhere from 6 months in Creutzfeldt-Jakob disease to up to 20 years in Alzheimer's disease (Alzheimer's Association, 2013; U.S. National Library of Medicine, 2012).

Estimates of median survival length of those with Alzheimer's disease range from 1.9 to 8 years from onset of symptoms (Alzheimer's Association, 2013; Larson et al., 2004; Rait et al., 2010). Of these years, approximately 40% of time with Alzheimer's disease is spent in the third and final stage, which is more than any other stage (Arrighi et al., 2010). Individuals in this stage have extensive caregiving needs and are significantly more likely to require assistance toileting, bathing, feeding, dressing, getting in and out of bed, and managing incontinence than older people without dementia.

Impact of Caregiving

On average, caregivers provide anywhere from 22 to 63 hours of care each week (Alzheimer's Association, 2013; Fisher et al., 2011). Caregivers tend to be female and are often married, employed, and have their own children (Bouldin & Andresen, 2010). Their priorities are divided, usually for years at a time. On average they provide care for significantly longer than those providing care to people without dementia, with 43% providing care for 1 to 4 years and 32% providing care for more than 5 years (Alzheimer's Association, 2013). The impact of caregiving is holistic, and impacts the caregiver's social, financial, emotional, spiritual, and physical wellbeing. Caregivers express guilt, anger, grief, and isolation. Caregiver grief begins before death of a loved one and is exacerbated at the end of loved one's life, which adds to the emotional toll and burden (Diwan, Hougham, & Sachs, 2009; Givens, Prigerson, Kiely, Shaffer, & Mitchell, 2011; Holley & Mast, 2009). In the next section, I will review qualitative studies to provide a summary of the lived experience of caregiving for a loved one with dementia.

Experience of Caregiving for Persons with Dementia

Several qualitative studies explore the experience of caregivers of persons with dementia. Together, these studies paint a picture of caregivers adapting to a constantly changing life and

trying to regain control of their own lives. Caregivers also cope with a changing relationship with the care recipient. These studies highlight the inadequacies of support for caregivers.

Living with change.

Prorok et al. (2013) conducted a meta-ethnography to synthesize qualitative research studies on experiences of caregivers of those with dementia and found that caregivers live in a state of role transition and change. Several studies describe this constant state of change. Lin, Macmillan, and Brown (2012) conducted a grounded theory study of caregivers in Taiwan and found that the core category was “my life changed,” focusing on ways that the caregiving journey affected the caregiver’s everyday life. In their grounded theory study, Clissett, Porock, Harwood, and Gladman (2013) found that caregivers struggled with a disruption from routine when loved ones were hospitalized, and they coped by attempting to gain control of the situation.

Besides changes to everyday life, relationships between caregivers and care recipients also changed. Hellstrom, Nolan, and Lundh’s grounded theory study revealed a three-phase process of “sustaining couplehood,” “maintaining involvement,” and “moving on” (2007). Sustaining couplehood involves talking things through, making the best of the situation, keeping peace, and being appreciative. In moving on, spouses may view the relationship as “remaining a ‘we’,” while others “become an ‘I.’” Hibberd, Keady, Reed, and Lemmer (2009) asked caregivers to take photographs and write narratives to describe their experiences caregiving for a loved one with dementia. These data were then analyzed by a focus group of caregivers of loved ones with dementia and themes were derived. Caregivers described recognizing the existing relationship between caregiver and care recipient, transforming to adapt to new roles, stabilizing as an ongoing process as needs changed, and moving on after the death of a loved one.

In Sanders and Power’s phenomenological study of husband caregivers, participants described developing new ways to find intimacy, adjusting to personality changes in their

spouses, coping with the unexpected, and recognizing that the relationship was ending (2009). Similarly, Gillies (2012) found that caregivers deal with the simultaneous loss of a loved one to dementia while trying to preserve the parts of that person that are continuous.

Losing this loved one before death often invokes fear in caregivers looking towards their own futures. An interpretive phenomenological study revealed that caregivers of those with young onset dementia live in denial, struggle to maintain control, and worry about their own futures (Lockeridge & Simpson, 2013). A phenomenological study of caregivers in Iran revealed that caregivers reminisced about the past and feared the future (Navab, Negarandeh, & Peyrovi, 2012).

Landmark, Aasgargaard, Svenkerud, and Fagerstrom (2013) conducted a content analysis of focus group interviews and found that loved ones also feel like they are unable to escape the situation of caregiving. A phenomenological study of focus groups of Chinese caregivers of persons with dementia yielded similar themes, with caregivers reporting confusion, emotional impact, difficulty coping with behaviors of the care recipient, and demanding circumstances (Chan, Mok, Wong, Pang, & Chiu, 2010).

Experiencing inadequate support.

In addition to caregiving demands, caregivers often describe feeling that they must live up to expectations of others, including care recipient, other family members, and health care providers. An interpretive phenomenological study of Australian caregivers of persons with dementia by Benedetti, Cohen, and Taylor (2013) revealed themes of fulfilling family responsibility, trying to live up to expectations of care, dealing with the impacts of caregiving on physical health, emotions, autonomy, and social life, and managing role strain. In a descriptive qualitative study of focus groups of Canadian caregivers of persons with dementia, Lilly, Robinson, Holtzman, and Bottorff (2012) found that caregivers felt forgotten and abandoned,

and felt that expectations of their ability to care were unrealistic. Caregivers felt that their role was taken for granted by health care professionals and by family members, and it was up to them to find help from within themselves and to protect themselves from the effects of stress and caregiving. Brown and Alligood (2004) explored caregivers' experiences of help seeking and found that caregivers take one day at a time. Caregivers must first realize and accept that something is wrong before they are willing to accept advice and help from others.

The experience is similar for caregivers of persons with dementia living in nursing homes. Hennings, Froggatt, and Payne (2013) conducted a longitudinal narrative study on interviews and diaries of spousal caregivers of persons with dementia living in nursing homes and found that caregivers feel as though they are living in ambiguous roles in two worlds, one in the nursing home and one in the larger world. An interpretive phenomenological study of caregivers of persons with dementia living in nursing homes in England revealed themes of identifying self as a spouse versus as a caregiver, making sense of change, visiting relatives as a means of surveillance of care, and looking towards the future with hope versus despair (Mullin, Simpson, & Froggatt, 2013).

Support is seemingly inadequate throughout the process of caregiving, including at the end of life. Shanley, Russell, Middleton, and Simpson-Young (2011) conducted a descriptive qualitative study of family caregivers of persons with dementia at the end of life. Caregivers in this study described challenges of finding formal and informal support, learning to trust others with care, managing loneliness and isolation, watching their loved one disappear, handling the death of a loved one, and re-establishing life afterwards. Kim (2009) conducted a phenomenological study of eight Korean-American caregivers' experiences of caregiving after their loved one had passed away. Themes included accepting and understanding the disease, assessing one's own abilities to provide care, caregiving as a family, sharing caregiving

experiences with other caregivers as a coping mechanism after the death of a loved one, and looking back at inadequate services in the formal care system.

Burden

The caregiving experience is dynamic and lonely. Living in this ever-changing chaos, caregivers are susceptible to burden, depression, and decreased quality of life. Caregiver burden is a negative physical or emotional response to the stress and demands of taking care of someone. A descriptive cross sectional study of caregivers revealed that caregivers of those with dementia experience higher levels of burden than caregivers of those with cancer or schizophrenia (Papastavrou et al., 2012). Burden may higher among some types of dementia than others. While some studies indicate that caregiver burden, stress, depression, and anxiety tend to be higher among caregivers of frontotemporal lobe dementia and Lewy body dementia than among caregivers of Alzheimer's disease and vascular dementia (Lee et al., 2013; Mioshi, Bristow, Cook & Hodges, 2009), another study shows no differences between these groups (Nicolaou, Egan, Gasson, & Kane, 2010).

Caregiver burden tends to be higher among females than among males and among spousal caregivers than among adult-child caregivers (Kim et al., 2012; Poysti et al., 2012). Living with the care recipient also tends to correlate with higher levels of burden (Kim et al., 2012; Raccichini, Castellani, Civerchia, Fioravanti, & Scarpino, 2009). Working full time and experiencing inflexibility in work roles also increases role strain, burden, and depression among caregivers of persons with dementia (Wang, Shyu, Chen, & Yang, 2011).

Worsening severity of dementia tends to lead to the care recipient requiring more assistance with activities of daily living and hours of caregiving required. As dementia progresses to severe stages in the care recipient, degree of caregiver burden and incidence of depression and anxiety increase among caregivers (Kim et al., 2012; Liu et al., 2012; Turro-

Garriga et al., 2013). Increased behavioral problems are also predictive of increased caregiver burden (Bass et al., 2012; Leggett, Zarit, Taylor, & Galvin, 2011; Mohamed, Rosenheck, Lyketsos, & Schneider, 2010; Ondee et al., 2013). Burden among caregivers may decrease if the caregiver feels in control (Bruvik, Ulstein, Ranhoff, & Engedal, 2013) or if the caregiver feels forgiveness towards the care recipient (Cheng, Ip, & Kwok, 2013).

Quality of Life

Many caregivers also report poor quality of life. In a phenomenological study of quality of life among caregivers of persons with dementia in Italy, caregivers shared that fearing for the future and having to provide continuous care worsened quality of life, while receiving help and support from family and formal services, finding satisfaction in caregiving, having financial support, and having more free time improved quality of life (Vellone, Piras, Venturini, Alvaro, & Cohen, 2012). A descriptive cross sectional study of caregivers of persons with dementia in Canada revealed that decreased patient function and increased depressive symptoms predicted lower quality of life ratings (Naglie et al., 2011). Cordner, Blass, Rabins, and Black (2010) also found that increased behavioral problems among care recipients correlated to lower quality of life scores among caregivers at the end of life. Quality of life was improved when care recipients had higher cognitive function and were receiving pain medication.

Depression and Suicide

Besides burden, caregivers are at high risk for developing depression. Up to 75% of caregivers show signs of significant psychological illness (Prince & Jackson, 2009) and 39% to 44% have clinically diagnosable major depression due to the high stress and burden of caregiving (Fisher et al., 2011). In a cross-sectional descriptive correlational study of caregivers of those with dementia, Wang, Robinson, and Carter-Harris (2013) found 20% of caregivers under age 65 had depression, compared to 4% of the general population in this same age group.

These younger caregivers were also significantly more likely to have co-morbid chronic illnesses.

Depression and burnout are significantly correlated with decreased quality of life among caregivers of those with dementia (Takai, Takahashi, Iwamitsu, Oishi, & Miyaoka, 2011).

Depressive symptoms are negatively correlated with an overall positive caregiving experience (Semiatin & O'Connor, 2012). Caregivers had increased symptoms of depression and anxiety if they perceived their physical health to be poor or if they reported feeling that their income is inadequate, regardless of household income (Alma et al., 2010; Cucciare, Gray, Azar, Jimnez, & Gallagher-Thompson, 2010).

Caregivers show increased depressive symptoms when patients experience depressive symptoms (Ornstein et al., 2013). Depression in the person with dementia and depression in the caregiver are significantly correlated with higher unmet needs for both the caregiver and the patient (Black, Johnston, Lyketsos, & Samus, 2013).

Depression and burden may lead to thoughts of suicide among caregivers. In an online cross sectional study of caregivers of persons with dementia in the United States, United Kingdom, and Australia, 26% of caregivers reported that they had thought about suicide more than once in the last year (O'Dwyer, Moyle, Zimmer-Gembeck, & De Leo, 2013). These caregivers reported higher levels of burden and incidence of depression, as well as greater use of dysfunctional coping strategies. Through a qualitative analysis of caregivers of persons with dementia in Australia about suicidal ideations, O'Dwyer, Moyle, and van Wyk (2013) brought to light that caregivers considered suicide out of a need for reprieve, not out of a desire to die.

Physical Symptoms

Caregivers may also experience physical side effects from the stress of caregiving. Several studies indicate that caregivers of persons with dementia are likely at greater risk of

developing cardiovascular disease than non-caregivers. In a nation-wide longitudinal study of spousal caregivers, caregivers showed a 35% increased risk of cardiovascular disease as compared to general population risk after adjusting for demographic and health risk factors (Capistrant, Moon, Berkman, & Glymour, 2012). Though this sample was not limited to caregivers of those with dementia, those caregiving “long term,” or greater than a 2-year period, were nearly twice as likely to develop cardiovascular disease as those in the general population.

In another longitudinal study, Mausbach et al. (2012) reported finding lower brachial artery flow-mediated dilation, indicative of impaired endothelial function and potential cardiovascular disease, in caregivers with low satisfaction in leisure activities, increased stress, and increased time spent caregiving. Level of impairment of endothelial function of the caregiver was also associated with increased dementia severity of the care recipient (Mausbach et al., 2010). Caregivers of those with dementia reporting low engagement in pleasure activities and high activity restriction have significantly higher blood pressure than those reporting high engagement in pleasure activities and low activity restriction, even after accounting for demographics, comorbidities, and use of anti-hypertensives (Chattillion et al., 2013). Greater numbers of behavioral problems in Alzheimer’s care recipients and negative reactions to those behaviors by the caregiver were correlated with chronic low-grade hypercoagulability among caregivers (von Kanel et al., 2010). Lower satisfaction with leisure activities among spousal caregivers is associated with higher plasma levels of norepinephrine and epinephrine (Chattillion et al., 2012).

Caregiving may also impact kidney function. In a longitudinal study of glomerular filtration rate on caregivers of persons with dementia versus a control group, von Kanel et al. (2012) found no differences in kidney function between groups, but did observe impaired kidney function among caregivers with major caregiving transitions, such as nursing home placement.

Loss of sleep due to caregiving responsibilities may also cause physical health deficits and contribute to poor emotional health. More than half of caregivers report that they have poor sleep quality and are frequently awoken from sleep to provide care (Cupidi et al., 2012; Simpson & Carter, 2013). Poor sleep quality is further associated with increased incidence of depression and decreased quality of life.

Relationship Changes

Besides its impact on the caregiver, caregiving changes the relationship between caregiver and care recipient, as well as relationships with other family members. Caregiving may lead to family conflict, especially when there is an underlying family conflict prior to caregiving (Peisah, Brodaty, & Quadrio, 2006). The state of the relationship prior to caregiving impacts how the caregiver will respond to this role change. If the caregiver and care-recipient had a positive relationship in the past, they tend to report greater rewards from caregiving than those who did not have a positive relationship (Cooper, Selwood, Blanchard, & Livingston, 2010). Caregiver burden, role strain, and depression are mediated by having a positive relationship between caregiver and care recipient, caregivers feeling more prepared for their role, and caregivers feeling able to balance their own needs with the needs of the care recipient (Shyu et al., 2010).

Caregivers may try to hold on to aspects of the relationship they had before caregiving or may let go of prior expectations of the relationship. Walters, Oyebode, and Riley (2010) conducted an interpretive phenomenological study of six wives caring for husbands with dementia. Findings from this study reveal differences in how wives view their husbands, with some seeing them as different people than before and others seeing them as still essentially the same. Participants also described feeling guilt and empathy due to their own reactions to their husbands' behaviors. O'Shaughnessy, Lee, and Lintern (2010) conducted an interpretive

phenomenological study of seven spousal caregivers of those with dementia in the United Kingdom and found overarching themes of “connectedness and separateness,” “tension between meeting own needs and meeting needs of a spouse,” “knowing and not knowing the future,” and “seeking control.” Caregivers describe finding new ways to bond with loved ones while still feeling lonely over the loss of the old relationship.

The change in perception of the relationship between the caregiver and care recipient is especially evident among married couples. Caregiver burden is associated with lower perceived marital satisfaction (Fitzpatrick & Vacha-Hasse, 2010). Couples in which one partner has frontotemporal dementia tend to rate marital satisfaction as lower than those in which one partner has Alzheimer’s disease or in which neither partner has dementia (Ascher et al., 2009). Positive communication patterns between spouses are correlated with decreased caregiver depression (Braun, Mura, Peter-Wight, Hornung, & Scholz, 2010).

Impact on Institutionalization

Caregiver health and perception of relationship greatly impact the care that the care recipient receives. Along with an increase in psychiatric symptoms of dementia, high levels of caregiver burden is one of the two most common causes of institutionalization (Gaugler et al., 2011; Miller, Rosenheck, & Schneider, 2012; Waldemar et al., 2007). Other significant predictors of institutionalization include caregiver depression, non-spousal relationship, increased need for assistance with activities of daily living, negative perception of caregiver’s own health, use of adult day services, increased cognitive or functional impairment in the care recipient, use of a paid caregiver instead of a family caregiver, lower level of caregiver education, and fewer hours spent by the caregiver caring for the care recipient (Gallagher et al., 2011; Habermann, Cooper, Katona, & Livingston, 2009; Nikzad-Terhune, Anderson, Newcomer, & Gaugler, 2010). McLennon, Habermann, and Davis’s (2010) qualitative content analysis

revealed that caregivers tended to institutionalize loved ones when they were anticipating the inevitable, knowing they could not continue to provide care for much longer, and reaching the limit.

Burden, distress, and depression do not dissipate after placement and may even increase among some populations of caregivers. Gaugler, Mittelman, Hepburn, and Newcomer (2009) conducted a cross sectional descriptive quantitative study of 1,610 and 1,116 caregivers of persons with dementia 6 months and 12 months after nursing home placement and found that caregivers tend to have increased burden and depressive symptoms post placement if they have higher pre-placement burden and depression, overnight hospital use, and if they are spousal caregivers. Nikzad-Terhune et al. (2010) reported similar results, finding that increased pre-placement burden was associated with high burden after a loved one was placed in a nursing home. Other studies indicate that wives, daughters, and husbands of loved ones with dementia tend to experience increased burden and depression post-placement (Bramble, Moyle, & McAllister, 2009; Gaugler et al., 2009; Schulz et al., 2004).

Those with dementia are more likely to be institutionalized than those without dementia. By an age of 80 years, nearly 75% of individuals with Alzheimer's disease have been admitted to a nursing home, while only 4% of those in the general population are admitted by this age (Arrighi et al., 2010). Similarly, at time of death, 67% of those with dementia die in nursing homes as compared to 20% of cancer patients and 28% of those with all other conditions (Mitchell, Teno, Miller, & Mor, 2005). They are also more likely to be hospitalized, most commonly for falls, syncope, and trauma (Rudolph et al., 2010). Hospitalization also leads to increased incidence and severity of burden, depression, and grief among caregivers when compared to caregivers in the outpatient setting (Epstein-Lubow et al., 2012).

Coping skills

In the face of these challenges, caregivers must find ways to cope. Several studies explore profiles of caregivers based on different ways of coping. In a qualitative study using combined methods of narrative analysis and grounded theory, Corcoran (2011) describes four caregiving styles, including: facilitating, where caregivers focus on the emotional health and meaningfulness of the care recipient; balancing, where the caregiver tries to meet the needs of both the care recipient and the caregiver without causing one to sacrifice too much for the other; advocating, where the caregiver is vigilant in observing and assessing the care recipient; and directing, where the caregiver is focused on the physical health of the care recipient.

A qualitative study by Sanders, Butcher, Swails and Power (2009) used “ethnomethodology” to describe the characteristics of four basic “portraits” of caregivers of patients with dementia receiving hospice care at the end of life. They describe the disengaged caregiver, who focuses on self and is minimally involved with the patient; the questioning caregiver, who denies the severity of the illness and has confusion over hospice involvement; the all-consumed caregiver, who is detail-oriented, overwhelmed by caregiving and fears losing the support of hospice; and the reconciled caregiver, who feels ready for the death of the patient and maintains a personal life while still interested in caregiving. Hospice was involved in these cases, and in some instances, still did not provide what caregivers saw as adequate support.

Quantitative studies explore the consequences of different coping strategies. These studies tend to focus on typologies of coping, including avoidance or disengagement coping, such as denial and wishful thinking, versus active coping, such as acceptance and participating in support groups. Other studies examine differences between emotion-focused coping, where the individual attempts to positively reframe his emotions towards the situation, and problem-focused coping, where the individual attempts to change the situation causing the stress.

Caregivers may also use dysfunctional coping strategies, such as avoidance, substance abuse, or aggression.

Caregivers who used emotion-focused coping showed improved mental health compared to those who used problem-focused or dysfunctional coping (Tan & Schneider, 2009; Wong & Wallhagen, 2014). Caregiver use of disengagement coping strategies is associated with increased symptoms of anxiety and depression among caregivers (Garcia-Alberca et al., 2012; Lim, Griva, Goh, Chionh, & Yap, 2011; Piercy et al., 2013; Wilks, Little, Gough, & Spurlock, 2011). Papastavrou et al. (2011) conducted a cross-sectional correlation study in Greece with similar results, finding that those using wishful thinking coping had increased burden and depression, while those using positive coping strategies, such as looking for the positive or being positively changed by the experience, had decreased burden.

Avoidance coping leads to lower life satisfaction and increased caregiver burden, while deliberate coping leads to higher life satisfaction (Sun, Kosberg, Kaufman, & Leeper, 2010). Increased problem behaviors of the care recipient can lead to activity restriction and avoidance coping among caregivers, which may lead to increased depression (Mausbach et al., 2012). This may be a vicious cycle, as individuals with dementia tend to exhibit more behavioral and psychological symptoms when caregivers are depressed, more burdened, or using disengagement coping strategies (Garcia-Alberca et al., 2013; Lee, McKeith, Mosimann, Ghosh-Nodiyal, & Thomas, 2013). Lockeridge and Simpson (2013) conducted an interpretative phenomenological analysis of younger caregivers of those with early onset dementia and found that this population is prone to the use of denial as a coping strategy, which may subsequently lead to poorer quality of care delivered and increased incidence of caregiver depression.

Coping strategies of the caregiver can impact the care that they provide. In a study of caregiver characteristics and quality of care, McClendon and Smyth (2013) found that caregivers

who are agreeable, open, conscientious, or neurotic are more likely to provide high quality care. However, caregivers who are neurotic tend to be more burdened and depressed (Melo, Maroco, & de Mendonca, 2011). Those who are extroverts or who cope by wishful thinking or avoidance tend to provide poorer care (McClendon & Smyth, 2013), but those who are extraverted or agreeable tend to be less burdened and depressed (Melo et al., 2011).

Finding Meaning

Caregivers who cope positively may be more successful in finding meaning in caregiving and building self-efficacy. Caregivers who are able to find meaning and purpose in their role tend to have positive outcomes (Shim, Barroso, Gilliss, & Davis, 2013). McLennon, Habermann, and Rice (2011) reported that those who are able to find meaning through caregiving experienced decreased burden and improved mental health.

Caregivers are more likely to find meaning in the caregiving experience if they had a positive relationship with the care recipient prior to caregiving, if they currently have a positive relationship with the care recipient, if they exhibit high religiosity, if they have high intrinsic and extrinsic motivation for caregiving, and if they experienced low role captivity (Quinn, Clare, McGuinness, & Woods, 2012; Quinn, Clare, & Woods, 2012). In Lee and Bronstein's (2010) study of Korean-American caregivers of those with dementia, caregivers were more likely to find meaning in caregiving if they were caring for a parent than if they were caring for a spouse.

Abusive behaviors by the care recipient affect the caregiver's ability to find meaning. Resilience among caregivers tends to lead to a more positive care experience. However, aggressive behaviors among care recipients tend to lead to decreased caregiver resilience (Wilks et al., 2011). In a cross sectional study in the United Kingdom, more than a third of caregivers

report being abused by the care recipient “at least sometimes” (Cooper et al., 2010). Caregivers reported finding care more rewarding if there was less abuse.

Self-Efficacy

Caregivers are also more likely to report a positive caregiving experience if they have higher self-efficacy (Semiatin & O’Connor, 2012). Increased self-efficacy is predictive of decreased caregiver depression and burden (Alma et al., 2010; Au et al., 2009; Lopez, Romero-Moreno, Marquez-Gonzalez, & Losada, 2012; Rabinowitz, Mausbach, & Gallagher-Thompson, 2009; Romero-Moreno et al., 2011; Romero-Moreno, Marquez-Gonzalez, Mausbach, & Losada, 2012). Increased problem behaviors can lead to decreased self-efficacy and personal mastery (Mausbach, Roepke, et al., 2012).

Support and Intervention

Intervention Studies

Many small-scale intervention studies have been conducted to improve caregiver burden and distress among caregivers of persons with dementia. These studies are primarily focused on staff education, informal caregiver education, support groups for caregivers with coping education, creating peer support programs for current caregivers with past caregivers, and promoting bonding activities between caregivers and care recipients. Several studies trial new technologies in promoting interventions, including Internet and videophone versions of in-person training programs. While many of these studies show significant results, small sample sizes prevent these studies from promoting clinical changes in practice. Several randomized controlled trials have been tested with moderate sample sizes, which will be discussed in this section.

Livingston et al. (2013) conducted a randomized controlled trial in the United Kingdom to test the impact of an eight-session psychology program on affective symptoms of 260

caregivers, including hospital anxiety, depression, and quality of life of the carer and care recipient. Sessions provided education about dementia, ways of managing dementia, and coping strategies among other topics. Caregivers receiving the intervention scored an average of 1.8 points lower out of a possible 21 on an anxiety and depression scale ($p = 0.02$) when adjusted for age, sex, neuropsychiatric score, and burden.

Huang et al. (2013) conducted a randomized controlled trial in Taiwan to test an individual home-based training program on managing behavioral problems for 129 informal caregivers. In this study, compared to the control group, the intervention group showed increased preparedness ($t = 2.72$, $p < 0.01$), competence ($t = 4.77$, $p < 0.001$), and self-efficacy ($t = 3.81$, $p < 0.001$) in a 3-month follow up.

Bass et al. (2013) conducted an intervention study to compare the effect of a Partners in Dementia Care program to a matched site control group on unmet needs of caregivers, caregiver strain, caregiver depression, and support resources utilized in a sample of 486 caregivers of veterans with dementia. The intervention program included a coaching service for caregivers to work on specific issues identified by the caregiver in an initial assessment and continued follow up over 12 months. The intervention group showed significantly decreased unmet need ($B = -2.24$, $p = 0.01$) and depression ($B = -0.69$, $p = 0.047$) compared to the control group. Largest differences were seen in the first 6 months.

Bakker, Duivenvoorden, Olde Rikkert, Beekman, and Ribbe (2011) conducted a randomized controlled trial to compare the effect of an integrative psychotherapeutic nursing home program to standard nursing home care on neuropsychiatry symptoms of 168 individuals with cognitive impairment including dementia and on caregiver burden. The intervention program included a 13-week multidisciplinary team of specialists on a designated psychiatric-skilled nursing home unit. The effect of this program on neuropsychiatric symptoms was

statistically significant, though not clinically significant as rated by nurses and caregivers of these individuals. The program did, however, effectively decrease burden by an average of 17.69 points on a 100 point scale ($p = 0.001$). This decrease was not only sustained, but continued over time, with caregivers scoring an average of 24.76 points lower than control groups in a 6-month longitudinal follow up ($p = 0.001$).

Fortinsky et al. (2014) conducted a study of 31 dyads of individuals recently diagnosed with dementia and their caregivers on the effect of supplementing care provided by a primary care physician with care by a nurse practitioner. In the intervention group, a nurse practitioner specializing in geropsychiatry provided 12 hours of care in the homes of patients and family caregivers over a 12-month period. Individuals were interviewed at onset of the study, 6 months later, and 12 months later. There was no significant difference between baseline and 12-month follow up in either intervention or control groups in neuropsychiatric symptoms, quality of life, caregiver depression, caregiver self-efficacy of caregivers in symptom management or support service, or caregiver burden. However, on a four-point satisfaction scale, all participants reported high levels of satisfaction, with individuals with dementia ($n = 13$) averaging 3.9 ($s = 0.4$), caregivers ($n = 19$) averaging 3.9 ($s = 0.3$), and primary care physicians ($n = 18$) averaging 3.8 ($s = 0.4$).

Caregivers may find respite and support through support groups and adult day care facilities. Chien et al. (2011) conducted a meta-analysis of 30 controlled trials of the effect of support groups on caregivers of those with dementia and reported that participation in support groups significantly reduced burden (Hedge's $g = -0.23$, $p = 0.286$) and depression ($g = -0.40$, $p < 0.001$), and improved mental health ($g = -0.44$, $p < 0.001$) and social outcomes ($g = 0.40$, $p < 0.001$). Use of adult day care services led to fewer depressive symptoms among 341 female

caregivers than those not using adult day care services ($B = 3.77$, $p < 0.01$) (Kim, Zarit, Femia, & Savla, 2012).

Unmet Need and Low Service Use

Despite the positive results of these studies, most caregivers continue to report high levels of burden and unmet need. In a cross-sectional study of community-dwelling patients with dementia and their informal caregivers, 97% of caregivers reported having unmet needs, with highest unmet needs including resource referrals and caregiver education (Black et al., 2013). In another cross-sectional study, Rosa et al. (2010) reported that highest unmet needs of caregivers included medical knowledge of the disease, better knowledge of the exact diagnosis, learning how to communicate with a loved one, how to handle cognitive and behavioral disorder, and managing feelings of anxiety, rage, and guilt.

Yet, service use remains low among caregivers (Hirakawa, Kuzuya, Enoki, & Uemura, 2011). In a cross sectional secondary analysis of national data of White well educated caregivers of persons with dementia, Robinson, Buckwalter, and Reed (2013) found that 73% of caregivers did not attend support groups, and 79% did not use respite services. These non-users tended to be older, more depressed, and received less social support than those who used these services. In a cross sectional survey study in Australia, 44% to 60% of caregivers did not use respite services despite reporting unmet need (Phillipson et al., 2013).

After death of a loved one, service use remains low. Approximately one third of caregivers use bereavement services, including counseling, support group utilization, or psychotropic medication, after death of a loved one with dementia (Bergman, Haley, & Small, 2011). Those who experience depression, anxiety, and complicated grief are more likely to seek

counseling and use of psychotropic medications, though these factors are not significantly correlated to increased participation in support groups.

There are several barriers to use of services among caregivers, including time required to acquire help, financial restraints, stigmas about caregiving expectations, or fear of leaving a loved one under the care of a stranger. In a descriptive qualitative study of caregivers of those utilizing and declining use of adult day care services, Robinson et al. (2012) found that the most influential reasons for refusing day care services were feeling confused about access to day care and feeling that the care recipient would be unsafe in a day care program.

Lim, Goh, Chionh, and Yap (2012) conducted a cross sectional questionnaire study of caregivers in developed Asian countries and found that the greatest barrier to use of services among caregivers was lack of time. Cuesta-Benjumea's (2010) grounded theory study of respite among caregivers also adds insight, as participants expressed a need for legitimate rest to relieve burden, which could only occur when they did not feel that they were abandoning a loved one, when others were not hurt by their rest, when getting rest was imposed by others, and when it is acknowledged as their right to have rest.

Linguistically and culturally diverse caregivers experience even greater unmet need. Shanley et al. (2012) found that lack of familiarity and awareness about services was an additional barrier to their use among ethnic minorities. Similarly, Chinese American caregivers are limited by a lack of culturally and linguistically appropriate support (Zhan, 2004). Caregivers who are gay or lesbian experience high levels of unmet need even when services are utilized (Price, 2010).

End of Life Support

This prolonged period of stress impacts how caregivers manage at the end of life. Caregivers of those with dementia are more likely to require bereavement services after patient

death than those caregiving for patients with other conditions (Jones, 2010; Li, 2012), and they are more likely to develop post-loss depression if social support is not adequate (Burton et al., 2008; Gaugler et al., 2004; Lee & Choi, 2013).

Few interventions are effective in consistently decreasing caregiver burden among those caring for individuals with dementia (Levy, Lanctot, Farber, Li, & Hermann, 2012; Waldemar et al., 2007), and an interdisciplinary approach is most effective (Crooks & Geldmacher, 2004; Dartington, 2008; Mayhew, 2005). Successful interventions include providing respite care, providing counseling to caregivers, encouraging advance care planning, and providing engaging education to both the caregiver and the patient in the home settings (Ivey et al., 2013; Thinnes & Padilla, 2011; Waldemar et al., 2007). These strategies are an integral part of hospice care, which is an end of life program that focuses on palliation and family support when cure-oriented care is no longer appropriate.

Palliative care and hospice care programs are interdisciplinary approaches to alleviate symptoms such as pain, dyspnea, and agitation. Palliative care can occur with any disease process at any time in the lifespan, and refers to any treatment that focuses on symptom management rather than cure. Individuals receiving palliative care may also receive curative care concurrently. Hospice is a type of palliative care. Hospice is a specific insurance benefit program that can be initiated when prognosis is estimated to be 6 months or less and requires patients to opt out of curative or life-prolonging treatments.

Benefits of Hospice

Though there are no significant differences in caregiver perception of pain management among those with dementia receiving hospice care and not receiving hospice care, hospice recipients are more likely to die at home, which is associated with fewer psychiatric symptoms and less discomfort than institutionalized death (Bekelman, Black, Shore, Kasper, & Rabins,

2005; Shega, Houghham, Stocking, Cox-Hayley, & Sachs, 2008). When individuals with dementia receive hospice care, caregivers are significantly more likely to report that they had a “good death” (Shega et al., 2008).

In a retrospective study of 4,344 persons with advanced dementia who died in nursing homes, Miller, Lima, Looze, and Mitchell (2012) explored differences in treatments of those who received hospice care versus those who did not. Individuals receiving hospice care were less likely to die in a hospital and less likely to encounter burdensome interventions at the end of life, including injections, feeding tubes, intravenous fluids, and therapy services, than those who did not receive hospice care. Caregivers of those who receive hospice are also less likely to report unmet needs and are more likely to report higher quality of care and quality of dying for a loved one than those without hospice care (Teno et al., 2011).

Caregivers show a preference for palliative care prior to receiving hospice care. Torke, Schwartz, Holtz, Montz, and Sachs (2013) report using a grounded theory methodology to explore focus groups of family caregivers’ perspectives on cancer screening for loved ones with dementia. In this study, caregivers opt for quality, not quantity, of life. They also report having to fight professional caregivers to stop cancer screenings, as they do not want to put family members through the ordeal and expense of continued testing, particularly since they would opt not to treat if cancer was found. Caregivers report feeling relieved when health care professionals bring up screening cessation. I also conducted a phenomenological study on caregivers of persons with dementia on the experience of seeking hospice and found that caregivers showed preference for palliative care over curative care long before physicians discussed these options and before prognostic indicators allowed for the initiation of hospice care (Lewis, 2014).

Limited Access to Hospice

Despite these benefits and caregiver preference, the Medicare Hospice benefit is limited to those with a 6-month or less prognosis. Over the last decade, hospice use among nursing home residents with dementia is increasing, though overall use remains lower than for other diseases (Li, Zheng & Temkin-Greener, 2013; Miller et al., 2010). Hospice tends to be used less frequently among those of older age, male gender, and Black race (Karikari-Martin, McCann, Hebert, Haffer, & Phillips, 2012). In a nationwide survey of hospice and palliative care program directors, Torke et al. (2010) found that greatest barriers to hospice and palliative care access among those with dementia were lack of awareness about palliative care by informal caregivers and referring physicians, greater need for respite services, and difficulty obtaining reimbursement for services in this population than for those with other diseases.

The denial of the terminality of dementia by providers as well as the inability to accurately predict prognosis contribute to a lack of end of life support for individuals with dementia and their caregivers (Covinsky & Yaffe, 2004; Thune-Boyle et al., 2010; van der Steen, Onwuteaka-Philipsen, Knol, Ribbe, & Deliens, 2013). Providers continue to neglect the need for early advance care planning and palliative services, and often guide families towards inappropriately aggressive treatment plans and burdensome interventions at the end of life (Di Giulio et al., 2008; Kieley, Givens, Shaffer, Teno, & Mitchell, 2010; Mitchell et al., 2004; Mitchell et al., 2009; van der Steen, Albers, Licht-Strunk, Muller, & Ribbe, 2011).

The impact on patients and families is intensified by the fact that there are currently no tools that adequately predict prognosis near the end of life (McCarty & Volicer, 2009). The scale most commonly used by hospice agencies, the Functional Assessment Staging (FAST) scale (Reisberg, 1988), continues to fall short, with studies showing that as few as 22% of those with dementia who died within a 6-month period met criteria for hospice according to Medicare guidelines using the FAST scale (Mitchell et al., 2004). Providers rarely encourage caregivers of

those with dementia to seek hospice care, and patients are often deemed to be inappropriate for hospice care even if services are sought (Covinsky & Yaffe, 2004; McCarty & Volicer, 2009; Treloar, Crugel, & Adamis, 2009).

Grounded Theory Studies on Caregiving in Dementia

Since few effective interventions exist and even fewer are available and accessible to caregivers at the end of life, the current study aims to explore the problems caregivers face at the end of life and how they attempt to resolve that problem. This research question is consistent with grounded theory methodology. Many researchers claim to have used grounded theory methodology to explore caregiving for persons with dementia, but few use rigorous methodology and none explore caregiving during the end of life period. Few studies used classic Glaserian grounded theory, while most opted for Strauss and Corbin's method of grounded theory or Charmaz's constructivist grounded theory. This section will critically review existing grounded theory studies on this topic and will describe how the current study is unique.

Several researchers used method-slurring, in which they applied different methodology to data collection than to analysis and presented findings that were inconsistent with the stated method. Mamier and Winslow (2014) conducted a qualitative case study of three cases to compare the placement decision-making experiences of the caregiver from the perspective of family caregivers and professional caregivers. They claim to use a grounded theory approach for data analysis. However, researchers report that the goal of this research was to describe the experience of caregivers, and since producing a theory was not the desired outcome of this study, only the initial steps of a grounded theory method were used. Results are presented as "categories."

Corcoran (2011) claimed to have conducted a grounded theory study of narrative data of caregivers of individuals with dementia and video-recorded interactions between caregivers and

care recipients to explore caregiving styles. The researcher began this study by creating a “qualitative codebook” based on literature and preliminary data in an attempt to ensure reliability in coding the data. Axial and selective coding were used to examine multiple “core codes” which were sorted into categories. Finally, entire interviews were sorted into four “caregiver profiles” based on standard questions asked in all interviews. No theoretical sampling, theoretical coding, memoing, or emerging core category was discussed.

Mistic (2008) conducted a grounded theory study on caregivers of persons with dementia in nursing homes. Interviews were conducted using the same questions for all participants and focused on determining how individuals define quality nursing home care. Mistic describes using a combination of thematic analysis and constant comparative analysis to derive both themes and categories. Findings are presented as a theory of the basic social process of “coming to terms,” in which caregivers take on the caregiving role and then relinquish that role as they place a loved one in long-term care.

In a qualitative focus group study of Filipino and non-Hispanic White caregivers, Ivey et al. (2013) report using phenomenology as a research method, but also report using axial coding, developing codes and memos, and using constant comparative method for data analysis. Findings are presented as themes. Gillies (2012) conducted qualitative study of interviews of family carers of persons with dementia in the United Kingdom using a “derivative of a grounded theory tradition” (p. 658). Gillies describes a process of exploring pre-determined themes through line-by-line coding of interview transcripts.

Other studies also refer to pre-determined ideas that drive the research question, rather than allowing the core to emerge from the data. Brown and Alligood (2004) claim to use a grounded theory methodology but describe an antecedent core category derived from a pre-determined theoretical framework. Researchers used theoretical sampling and simultaneous data

collection and data analysis through the constant comparative method. There was no mention of memoing, open coding, selective coding, or theoretical coding, and only interview data were analyzed.

McHugh, Wherton, Prendergast, and Lawlow (2012) claimed to use grounded theory to extract themes from interview data with a predetermined topic of determining how information and communication technology may be used to reduce caregiver burden. Researchers report using open, axial, and selective coding to group categories into themes. This study was conducted in Ireland. Santiago (2012) reports exploring the experience of family caregivers of persons with late stage dementia using grounded theory methodology, but reports that no new theory emerged from interview data. Therefore, a pre-existing theoretical framework was applied to data to derive themes to describe the experience.

Others begin with inappropriate research questions for grounded theory methodology. Jurgens, Clissett, Gladman, and Harwood (2012) report using a grounded theory approach to examine caregiver satisfaction with hospitalization of individuals with dementia. Researchers report collecting interview data as well as non-participant observation data and using the constant comparative analysis to derive themes. This study took place in the United Kingdom. Egdell (2012) claimed to use Strauss and Corbin's method of grounded theory to explore how caregivers create a support network. Interview data were analyzed using three levels of coding to extract themes. This study was conducted in Canada. Theoretical sampling, theoretical coding, memoing, and discovering a core category were not mentioned.

Lin et al. (2012) reported using a grounded theory approach to explore interviews with six spousal caregivers in three phases at predetermined time intervals over 18 months. Researchers had predetermined research questions and aimed to explore how carers defined their roles, what their experiences were, and how those experiences changed over time. Theoretical

sampling was not used. Researchers cite Strauss and Corbin and report using constant comparative analysis, open coding, axial coding, and selective coding to discover a core category and its properties. A core category is identified and other categories are described in reference to the core category to create a “theory of caring.”

Many researchers claimed to use grounded theory but were missing some elements of grounded theory that are integral to the integrity of the method. Clissett et al. (2013) conducted a “qualitative interview study” in which they claim to use Strauss and Corbin’s method, including a constant comparative analysis. This study examined how family caregivers respond to hospitalization of a loved one with cognitive impairment. Findings are reported as a core problem and a core process. Purposive sampling was used for recruitment, and data were from interviews only. There was no mention of theoretical sampling, differentiation between open coding, selective coding, and theoretical coding, and no memoing.

Torke et al. (2013) also claim to use grounded theory methodology to explore caregivers’ perspectives on cancer screening. Researchers collected data from focus groups, and though they mention “open coding” of data, there was no mention of using theoretical sampling, identifying a core category, moving to selective coding or theoretical coding, or memoing, and findings are reported as themes. Gallogly (2008) conducted interviews of caregivers of persons with dementia and developed a theory of symbiosis between caregiver and care recipient. Data were analyzed using a software program to create analytic diagrams in addition to open and axial coding and the constant comparative method. There was no mention of an emerging core category, though findings are presented as a theory.

Molyneaux, Butchard, Simpson, and Murray (2012) conducted a constructivist grounded theory study using Charmaz’s method in the United Kingdom to explore couplehood in individuals with dementia and their spousal caregivers. Researchers conducted interviews with

couples until saturation was reached and describe a process of line-by-line coding and memo writing. They also kept personal reflective journals as part of the constructivist framework, which were incorporated into memos. Researchers did not mention theoretical sampling, concurrent data collection and analysis, or use of the constant comparative method, and findings were presented as themes.

Pastor and Vogel (2011) claimed to use a grounded theory methodology to explore long term care placement decision making among spousal caregivers of those with dementia. Researchers report using snowball sampling and using the same interview guide for all participants. They report using the constant comparative analysis to discover themes.

Some researchers describe appropriate steps that are consistent with grounded theory methodology, but these studies focus on unique areas of caregiving that do not overlap with the current study. Cuesta-Benjumea (2010) conducted a grounded theory study of interviews of caregivers of persons with dementia on finding rest and respite in Spain. Interviews were conducted in waves, with data analysis via constant comparative analysis in between interviews. Open coding, “focused coding,” selective coding, theoretical sampling, and memoing were used to uncover a core category. This study focused specifically on seeking rest among caregivers.

Botsford, Clarke, and Gibb (2012) used a constructivist grounded theory to explore the experiences of caregivers of individuals with dementia of minority ethnicities in England. Researchers aimed to be theoretically sensitive and used theoretical sampling, coding, and memo-writing. Researchers concurrently collected and analyzed data.

Hellstrom et al. (2007) conducted a constructivist grounded theory study of couples in which one partner has dementia, tracking and interviewing 20 couples over a 5-year period in Sweden. Constant comparative method was used to analyze each interview prior to the next

interview, and researchers describe “co-constructing” meanings with participants. From this analysis, a theory of “sustaining couplehood” emerged.

Daly, McCarron, Higgins, and McCallion (2013) conducted a classic grounded theory study of the social interactions of informal carers of individuals with dementia in Ireland. Data were limited to interviews, but researchers otherwise utilized Glaser’s method appropriately to discover a theory of “sustaining place.” Carers coped with an identified problem of “living on the fringes” by nurturing self and care recipient and by carefully choosing social relationships to sustain their social place.

Though many grounded theory studies have been conducted, as described, few of these studies were conducted with the rigor required of a classic Glaserian grounded theory. Of those that did use all elements of classic grounded theory, none were conducted in the United States. Also, none of these studies explore the end of life period for caregivers. The current study fills a unique niche in that it rigorously investigates the process caregivers use to overcome challenges at the end of life.

Summary

This chapter reviewed current literature on caregiving for an individual with dementia at the end of life, including an exploration of qualitative research on the experience of caregiving and quantitative research on the prevalence of burden and depression. Dementia is a terminal illness and prevalence is growing exponentially. Those caregiving for loved ones deal with stress and burden as they cope with physical, emotional, and financial demands that may last several years, exacerbated by the end of life. End of life support is often limited due to poor prognostic indicators and lack of recognition of terminality. This population of caregivers faces drastic unmet need. The area of caregiving for persons with dementia at the end of life has been relatively unexplored from a qualitative standpoint, and even positive interventions to aid

caregivers trialed in quantitative studies have been unsuccessful in meeting widespread need without a qualitative backbone.

For this reason, a grounded theory methodology will be used to provide a foundation on which to base future research in this field. Understanding the underlying primary issue that caregivers face and how they are currently processing is a crucial step in moving forward to provide support to caregivers at the end of life. The next chapter will provide an overview of grounded theory, including the background of the method and the general steps involved in using this method. It will also describe how the grounded theory methodology was applied in this study.

CHAPTER 3: METHODOLOGY

A classic Glaserian grounded theory method was used to develop a substantive theory that explored the experiences of caregivers of loved ones with dementia at the end of life. The aim was to uncover the chief concern of informal caregivers of those with dementia at the end of life and to discover the process by which they attempt to resolve this problem. This chapter will explain the ontology of the researcher, followed by the roots of classic Glaserian theory and the context in which this method emerged. An overview of the elements of grounded theory methodology will then be provided, followed by a description of how the method was applied in this study.

Ontology

Personal World View

According to Glaser, through conceptualization of data and abstraction rather than description, personal worldview should not affect the final outcome of research in a true grounded theory study. However, it is still necessary to acknowledge the influences and beliefs that influence the researcher's view of truth and knowledge. Even if these views do not affect research findings, they inevitably guide the way in which she conducts research, including what she chooses to study and what not to study. This section will discuss my own personal worldview.

My ontology is rooted in humanity. I believe reality can only be perceived insofar as a human perceives it. Given this view and the nature of dementia, rather than asking the question: "what defines reality?" it becomes more important to examine the question: "what defines a human being?" In today's culture, the value of Man is often judged by his usefulness and ability to contribute to society. If this is how we define Man, persons with dementia become useless, and thus cease to be human. I believe persons with dementia absolutely retain their humanity,

despite their inability to communicate or even to create independent thoughts at the end of life. I have adopted the philosophy of Viktor Frankl (1984), a psychiatrist who survived the Nazi death camps, to define Man and His purpose. According to Frankl, humans retain their human dignity even if they experience a loss of usefulness, and dignity is a greater measure of value than his usefulness.

In the case of persons with dementia, dignity must be put in context. In the traditional sense of the word, many believe that those with dementia do indeed lose their dignity. Those with dementia may undergo many humiliating circumstances, such as becoming incontinent, stripping themselves of clothing, or becoming angry and belligerent towards loved ones. Similarly, those in death camps were often forced to urinate and defecate themselves, stripped of their clothing, and forced to make humiliatingly selfish decisions to defend their own lives. The dignity that Frankl refers to is the ability to choose one's attitude towards one's circumstances. Even in this case, one may argue that in late stages of dementia, individuals no longer have the capability to control their attitudes. To this, Frankl says, "A residue of freedom, however limited it may be, is left to man in neurotic and even psychotic cases. ... An incurably psychotic individual may lose his usefulness but yet retain the dignity of a human being" (1984, p. 156).

This confusion between values of usefulness and dignity is rooted in a learned nihilism throughout our society. Rather than being a victim of biology, society, and circumstance, Frankl argues that Man is self-determinant because He retains the freedom to choose how to respond to His circumstance. Contrary to nihilism, Frankl argues that Man may find meaning under any conditions. Frankl asserts, "To be sure, a human being is a finite thing, and his freedom is restricted. It is not freedom from conditions, but it *is* freedom to take a stand toward the conditions" (p. 153). Man may find meaning in three ways: (1) in creating a work or doing a deed; (2) in encountering someone, or in other words, through love; or (3) in his ability to endure

his suffering. This last avenue is most profound, as it implies that man may find meaning despite, and in fact even because of, the most intolerable circumstances. To proclaim that life may have such unconditional meaning, one must also recognize the real and unconditional value of every human being.

My own respect for the dignity of human life is also rooted in a belief in Catholicism. I subscribe to a belief in *imago Dei*, which means that I believe that humans are made in the likeness of God and that God is manifest in humans. Thus, if humans should love God, they should also love their fellow human beings. I further believe that the body is a temple that houses the soul. Even if cognitive and moral capacities fade away, the body holds significant value and should not be destroyed.

Healthcare Ethics in Dementia

It is necessary to consider the principles that guide healthcare ethics in caring for, making decisions for, and researching this vulnerable population. Cognitively impaired individuals may be compared to infants in their capacity. They may not be capable of reasoning, rationalizing, or understanding, and they often require surrogate decision makers. Yet, like infants, they retain their moral status. According to Beauchamp and Childress (2013), having moral status means that one “deserve[s] at least some of the protections afforded by moral norms” (p. 64). They describe five theories that, together, determine which entities hold moral status. These theories include: human properties, or being an organism with a human genetic code; cognitive properties, or having mental awareness and the ability to think and understand; moral agency, or being able to judge right from wrong; sentience, or the ability to experience such things as pleasure and suffering; and having relationships with others. Each of these properties grants an individual some level of moral status. Therefore, though infants or individuals with dementia

may not possess all of these properties, they possess enough to be protected and treated with dignity and respect.

In dementia, a person may lose the ability to consciously search for meaning. However, the loss of this motivational driving force does not imply a loss of dignity. Without this belief, one may justify euthanasia of persons with dementia who have lost usefulness, as they have lost their personhood, and may also logically defend the killing of thousands of men and women in gas chambers for their own lack of usefulness to society. It is this value for human life that motivates me to explore ways to improve the quality of life for all humans, including individuals with dementia and their caregivers.

Context of Grounded Theory

Grounded Theory Roots and Symbolic Interactionism

Grounded theory emerged in a strong positivist context. Sociological research had trended away from theory generation and towards grand theory verification with the sophistication of quantitative methods. As Glaser and Strauss wrote in *Discovery*, “Currently, students are trained to master great-man theories and to test them in small ways, but hardly to question the theory as a whole in terms of its position or manner of generation” (1967/2010, p. 10). The grand theories that existed at the time did not sufficiently cover all of the content of sociology, and did not always “fit” where they were being used. Glaser and Strauss argued that a renewed movement towards systematic theory generation was necessary to the field of sociology. Thus, the methodology of grounded theory was proposed.

Symbolic interactionism is said to be one of the frameworks on which grounded theory was discovered. Herbert Blumer introduced the term “symbolic interactionism” with influence from George Herbert Mead and John Dewey. Symbolic interactionism is the process of interaction between individuals and the way that individuals make meaning from those

interactions. According to this theory, humans act based on the meanings they have assigned to individuals and objects. Humans interact with one another through symbols via language to negotiate these meanings. Individual interpretation of the symbols occurs through thought, which influences the meanings assigned to a person or object (Blumer, 1969/1998).

Strauss studied at the University of Chicago and was trained by Herbert Blumer and Everett Hughes, both influential in Strauss's perspective toward symbolic interactionism. Strauss later discussed these roots in his works with Corbin (2008). Glaser uses the term "symbolic interactionism" infrequently, though in some of his later works he does acknowledge the influence of Strauss's background in symbolic interaction on the discovery of grounded theory (1998). Glaser writes of learning about symbolic interaction from Strauss, "I learned that man was a meaning making animal" (1998, p. 32). He further says, "Thus there was, it seemed to me, no need to force meaning on a participant, but rather a need to listen to his genuine meanings, to grasp his perspectives, to study his concerns and to study his motivational drivers" (1998, p. 32).

Classic Glaserian Grounded Theory

With this true-ness to the meaning of the experience in mind, grounded theory was originally introduced by Glaser and Strauss in 1967 and is a method in which a theory is discovered from data. Data are constantly compared to allow significant concepts to emerge. Discovering patterns in the data allows the researcher to move from description of these concepts to abstraction, capturing relationships between concepts and properties of concepts (Glaser, 1978, 2001, 2002). The goal is to discover a theory that conceptualizes the phenomenon or process of interest that is grounded in data.

In this method, interpretation of data by the researcher is viewed as an inappropriate intrusion on data collection (Glaser, 2002). Through triangulation of data collection and passive

listening in interviews, Glaser states that data should not be co-constructed by interviewer and participant, but should instead be heard exactly as they are presented. The only interpretation of data should be that of the participant telling the researcher how to view the data correctly. Since, ideally, the researcher should be collecting data objectively without imposing his own beliefs, biases, and thoughts, grounded theory recognizes that the participant's impact on data is more significant than the researcher's impact. The researcher is human, and may not be able to avoid imposing his own views on the data, but the repetitiveness and interview strategies required in grounded theory should correct this bias and objectify the emerging theory. The goal of the researcher is not to objectively describe the data, but to objectively describe patterns within the data. This objectivity and abstraction allows grounded theory to overcome many of the pitfalls that have become critiques of qualitative data analysis, including issues with accuracy and trustworthiness.

The goal of this method is to allow a theory to emerge as it is truly experienced. Though no specific philosophical underpinnings are acknowledged, on the one hand, traces of pragmatism can be found in the emphasis on "all is data" and data as the driving force, as well as in the pragmatic background of the concept of symbolic interactionism, used to extract a basic social process from the data. On the other hand, traces of postpositivism and realism can be identified in the passivity of the researcher and the quest for objectivity. These perspectives are likely derived from Strauss's previous work with pragmatism and Glaser's work with quantitative methodology.

In terms of theoretical underpinnings, applying a theoretical framework would be counterproductive since the goal of grounded theory is to generate a theory. Glaser maintains that there should be no preconceived notions when beginning the research process. "All is data," and theories are no exception. Unlike other qualitative methods, data analysis and theory

generation must occur during and throughout data collection. Existing theories must be compared to the generating theory during data collection. Glaser and Holton write, “Contrasting the generated theory with extant other theories to prove, improve or disprove one or the other neglects or ignores constantly comparing the theories for category and property generation” (2004, para. 19). It is essential that theories be compared prior to the conclusion of theory generation in order to gain the insight that they have to offer as data.

Based on the state of research and my personal worldview, I have selected a classic Glaserian grounded theory methodology. This methodology calls for the researcher to be guided only by data, not by a preconceived philosophy or theory. Throughout this study, I attempted to leave behind all preconceptions, including previous literature reviews, existing theories, and personal biases to remain open to the emergence of the basic social psychological problem and the core variable of meaning to caregivers of those dying with dementia.

Method of Inquiry: General

A classic grounded theory methodology allows the researcher to examine the following general research questions:

1. What is the chief concern of the general population of interest?
2. What accounts for most of the variation in processing the identified problem?

These research questions are intentionally broad for the purpose of allowing the core variable to emerge. In this way, as is the cornerstone of grounded theory, the participants themselves can define the research problem. To aid in this process, data are concurrently collected and analyzed throughout the research process. Rather than discuss sampling, data collection, and data analysis as three separate procedures, the following sections will discuss the integrated process of conducting a grounded theory study. The sections below will review several of the tenets of

grounded theory, including theoretical sampling, viewing all as data, recognizing a core variable, and constant comparative analysis.

Theoretical Sampling

Theoretical sampling is used to select participants for a grounded theory study. In *Discovery*, Glaser and Strauss write:

Theoretical sampling is the process of data collection for generating theory whereby the analyst jointly collects, codes, and analyzes his data and decides what data to collect next and where to find them, in order to develop his theory as it emerges. This process of data collection is *controlled* by the emerging theory. (1967/2010, p. 45)

To begin, an initial purposive sample of individuals is selected from within the substantive area of interest. Individuals are asked broad, open-ended questions and allowed to tell their stories. Data are constantly analyzed as they are collected, and this analysis guides future sampling. After the first interviews, the researcher selects future participants based on the emerging theory. The goal is not to select the “right” group and to ask the “right” questions from the start. Instead, the goal is to use this population to get an idea of who the “right” group is and what the “right” questions are. Each population should guide the researcher closer to the emerging core variable (Glaser, 1978, 2001). The researcher begins to focus in on the core variable once he is sure it has emerged.

Based on the inductive conclusions from comparing and analyzing the initial interviews, the researcher deductively selects the next participants based on their theoretical relevance to the emerging categories. According to Glaser and Strauss, “The researcher chooses any groups that will help generate, to the fullest extent, as many properties of the categories as possible, and that will help relate categories to each other and to their properties” (1967/2010, p. 49). For example, this may include interviewing individuals going through a similar but different experience, or

individuals undergoing a specific part of a larger experience, or may include the same participants as the initial sample. It is not possible to predict sample size, which groups will be interviewed, or how many groups will be interviewed. Glaser and Strauss instruct, “data collected according to a preplanned routine are more likely to force the analyst into irrelevant directions and harmful pitfalls” (1967/2010, p. 48). Selecting the next group of participants requires that the research be “theoretically sensitive,” or open to the conceptual ideas that are emerging from the grounded data (Glaser, 1978, 2001).

Theoretical sampling continues until theoretical saturation is reached, which can only be achieved through concurrent collection and analysis. Saturation occurs when the researcher is confident that no new properties of the core variable are emerging from the data. At this point, both data collection and data analysis should be complete and the researcher should continue memo sorting and writing.

“All is Data”

Grounded theory is not limited to the use of qualitative data or to formal interviews. Casual conversations, quantitative data, secondary data, theories, and participant observation are all commonly used in grounded theory. Again, one of the tenets of grounded theory is that all is data. In this way, even biases themselves are data, and these become variables within the study according to Glaser. Conceptualization leads to abstraction of person, place, and time, which leads to a neutral grounded theory. Since the theory generates concepts, not facts, the researcher need not worry about “troublesome data” that would distort the results in a purely descriptive study (Glaser, 2001, 2003).

Grounded theory is also not limited to qualitative data. Glaser and Strauss (1967/2010) provide a history of qualitative and quantitative data, proposing that differences between them are based on whether the primary aim is to generate or to verify theory. They conclude that

“there is no fundamental clash between the purposes and capacities of qualitative and quantitative methods or data... We believe that each form of data is useful for both verification and generation of theory” (pp. 17-18). Therefore, grounded theory utilizes both aspects of quantitative and qualitative research as needed to produce a theory that objectively conceptualizes the phenomenon or process of interest. Diverse data are advantageous in that they lead to triangulation and help ensure that the researcher has reached saturation.

Core Variable

The main goal in a grounded theory is to discover a *core variable*, also called a *core category*. This core variable is the central focus of the emergent theory. In essence, it is the short answer to the research questions above. Once the basic social problem has been identified by the substantive population of interest, the core variable is the process this population uses to resolve that problem. The core variable should be easily recognized in the data due to its *grab*, its explanatory power, its inter-relatedness with other categories, and it should be repeated throughout the data as a point of emphasis (Glaser, 1978).

It is important to note that the core variable is not always a process, but may be a context, a condition, degrees of something, or an order, just to name a few. The core variable can be any kind of *theoretical code*, which is a term that describes how two substantive codes relate to one another. According to Glaser (1978, 2001, 2003), the core variable will emerge from the data if the researcher allows it to be discovered. Researchers may miss it or may select an inappropriate core variable if they are focusing on preconceived ideas or if they begin selective coding too early. If they are theoretically sensitive and open to the data, though, the core should become obvious when it emerges.

Constant Comparative Analysis

To discover the core variable, a constant comparative analysis occurs throughout the research process (Glaser, 1978, 1998, 2001, 2003, 2005, 2011; Glaser & Strauss, 1967/2010). Data are continuously compared to ideas, and ideas are compared to other ideas. It is through this comparison that the researcher can discover what is consistent and what varies among data, both of which are valuable contributions towards identifying a core variable and defining its properties. There are several layers of “coding” that occur in this type of analysis.

Substantive coding of data involves constantly reading, sorting, resorting, and comparing data. Initially, open coding is used, in which all data are coded to look for the core variable and its major dimensions. Once the core variable has emerged, selective coding is used to code only data relevant to the core variable. At this point, the researcher begins to define the properties of this concept by conducting more targeted interviews that focus on the core variable. Different populations may be interviewed and observed to clarify what is and what is not unique to the population of interest in order to further define the properties of the core variable.

Throughout coding, as data are collected and compared to other data, the researcher makes *memos*, which are stream-of-consciousness writings that attempt to turn facts into concepts. The goal is to discover conceptual properties that transcend a particular instance or example. The researcher then conducts *theoretical sorting*, or sorting of the memos themselves. Sorting and coding must be done by hand, as computerized sorting will never yield the same creativity and flexibility in results and will only lead to full conceptual description instead of a true grounded theory (Glaser 2003, 2005).

Theoretical coding occurs as the researcher searches for the relationships among substantive codes. This phase is extremely important, as the outcome should be the theory itself. Theoretical coding also requires sensitivity to emergence, and like all other phases should not be forced. Glaser warns that the researcher must resist the urge to select a “pet theoretical code,” or

a code that has a lot of grab that may not actually fit the data. Glaser also states that there are cases in which no theoretical code emerges, but encourages that the method will still produce a conceptual outcome worth sharing (Glaser, 2005).

When complete, the core variable, its properties, and the relationships among the properties operate as a theory with great generalizability. To be considered a theory that is truly grounded in data, the theory should meet several criteria. It should have: fit, where it makes sense with the data; grab, where it is attractive because it resonates; workability, where it serves a purpose to describe, predict, or explain something; and modifiability, where it can be adjusted to accommodate future data (Glaser, 1978).

Method of Inquiry: Applied

Understanding the method of grounded theory is to understand that relatively little can be pre-planned to apply the method correctly. The substantive population of interest was selected prior to beginning the study and included caregivers of loved ones with dementia at the end of life. Only this initial purposive sample was planned in advance of the study. All sampling and interview content after this was guided by the emerging theory. This research study aimed to explore the following research questions, as applied to the population of interest:

1. What is the chief concern of caregivers of loved ones with dementia at the end of life?
2. How do caregivers attempt to resolve this problem?

Face-to-Face and Online Interviews

This study began with a purposive sample of individuals who were primary caregivers of individuals who passed away in the past 10 years with a self-reported primary diagnosis of dementia. Interviews were conducted post-mortem to ensure that caregivers had undergone the experience of interest and would be able to provide insight into the entire experience rather than

on a single phase of the end of life period. Anticipated sample size was projected to be approximately 25 to 40 participants.

The first group of participants was recruited by word of mouth and from fliers to the general public in towns throughout Connecticut, including senior centers, coffee shops, grocery stores, libraries, and cultural centers. Targeted letters to agency leaders with attached fliers were also emailed to nursing homes, adult day care centers, hospice agencies, and support groups to be posted. See Appendix A for samples of recruitment letters to agency leaders and Appendix B for recruitment fliers. Inclusion criteria included self-defined primary caregivers of individuals who had died within the last 10 years, who, according to caregiver self-report, had a primary diagnosis of dementia. Participants were limited to English speaking individuals over age 18 years. Initial recruitment efforts yielded a small sample of 5 participants. One participant reported that she met inclusion criteria, but upon interviewing her, I identified her as a formal caregiver rather than an informal caregiver. The interview continued as planned, and her perspective was included in analysis as a point of comparison to the perspectives of primary caregivers of loved ones.

Data collection began with formal interviews of these participants, who were asked a grand tour question: “Please tell me what it was like to care for your loved one with dementia at the end of life.” If needed, participants were probed with follow-up questions including, “What challenges did you face during your time of caregiving at the end of life?”; and “Please describe an average day/especially challenging day caring for your loved one at the end of life.” Interviews also included clarifying questions. Demographic information was also collected, including gender, age, age of loved one at time of death, relationship to loved one, length of time since loved one passed away, type of dementia, place of death, involvement of hospice, religious affiliation, and race/ethnic background.

As the student investigator, I conducted all formal interviews. Interview questions changed based on the developing grounded theory. See Appendix C for examples of interview questions. Interviews were audio-recorded to allow for the involvement of the principal investigator, both as a co-coder when needed and as a mentor throughout the research process. Interviews were conducted in quiet public locations chosen by the research participant, including libraries, retirement homes, and coffee shops. During one interview, a participant also shared voice messages that her husband had left her while he was in a nursing facility, which we discussed at length. Interviews lasted 30 minutes to 90 minutes.

Due to poor response rate to initial recruitment strategies, online recruitment was initiated. A website with general information about the study was created. Appendix D includes snapshots of the study website. This website included a link to an online version of interview questions via an SSL encrypted website through <https://www.psychsurveys.org>. With permission from site leaders, online recruitment notices were posted to online message boards and forums for the general public, for the elderly, and for caregivers, as well as to support groups for caregivers of those with dementia. Recruitment notices were also emailed to site leaders with requests to forward study information via listserv to organizations with an interest in dementia research. Appendix E includes a sample of online recruitment notices.

Through the study website, participants were asked to answer open-ended questions as well as demographic questions, as they would have in an in-person interview. Participants were also asked to indicate whether or not they would be willing to be contacted again to answer more questions and, if so, to include contact information. Participants were invited to skip any questions they did not wish to answer and were given space to add comments at the end of interview questions. Online interview questions changed as data were analyzed and selective coding began, and continued to evolve as selective coding continued. See Appendix C for

interview questions that were posted to the study website as the study evolved. Participants were also emailed follow-up questions and clarifying questions as the study progressed if they indicated that they were willing to be contacted during the initial online interview. One participant who completed the online interview was excluded from the sample because she reported that she was a current caregiver and did not believe that her loved one had reached the end of life at this time.

Books and Blogs

During the process of online recruitment, one participant reported that she had written a book about her experiences as a caregiver. This prompted a new source of data to emerge, as I began to search for data from memoirs of caregivers and blogs about caregiving experiences. For books, inclusion criteria included books that were written by informal caregivers of persons with dementia who had passed away within 10 years. Books were excluded if they were published more than 10 years ago, if the caregiver resided outside of the United States, if the books were not in English language, if they were informational books rather than memoirs of a personal experience, or if the care-recipient was not reported to be deceased within the book.

To find published memoirs, this phase of recruitment began with a search on Amazon.com for “dementia* caregiver* memoir” and “Alzheimer’s* caregiver* memoir.” The term “memoir” was included in this search due to the large volume of informational books found in initial searches. All books within this list as well as books listed under “Customers who bought this item also bought” were considered for inclusion. Google.com was also used to search for “dementia* caregiver* memoir” and “Alzheimer’s* caregiver* memoir” and was searched until search lists became repetitive. Books were also considered for inclusion if they were mentioned within other books or on blog websites.

Within books selected for inclusion, pages or chapters were analyzed only if they discussed the last 1-year of the care recipient's life or if they discussed time after death. Discussions of past memories, informational passages that were irrelevant to the personal caregiving experience, or passages written prior to the final year of life were excluded from analysis. If the last year of life could not be identified but the care recipient's death could be verified within the book, the entire book was analyzed. Books with multiple authors describing multiple caregiving experiences were included in the sample, but only chapters meeting inclusion criteria were analyzed.

Blogs were identified in a similar way, with inclusion criteria including English language blogs that were written by informal caregivers of persons with dementia who had passed away within 10 years. Blogs were also excluded if they were published more than 10 years ago, if the caregiver resided outside of the United States, if they were informational blogs rather than accounts of a personal experience, if they were forums with open postings, or if the care-recipient was not reported to be deceased within the blog. To find blogs, recruitment began with HealthLine's list of "25 Best Alzheimer's Blogs of 2013." On each of these blogs, lists of "recommended blogs" were considered for inclusion. A google.com search was also used to search for "dementia* caregiver* blog" and "Alzheimer's* caregiver* blog" and was searched until no new blogs appeared in searches. Blogs were also considered for inclusion if they were mentioned within other blogs or in books that were analyzed.

Within blogs selected for inclusion, entries were analyzed only if they discussed the last 1-year of the care recipient's life or if they discussed time after death. Using the date stamp on blogs, entries were included in the sample beginning one entry prior to 1 year before the death of the care recipient through the completion of the blog. The entire blog was included if the care recipient died within 1 year of the initiation of the blog. Discussions of past memories,

informational entries that were irrelevant to the personal caregiving experience, or entries written prior to the final year of life were excluded from analysis.

Through these published memoirs and blogs, many caregivers communicated using forms other than written word. Caregivers shared photographs of themselves and loved ones, artwork, obituaries, eulogies from funerals, and meaningful prayers, song lyrics, or links to videos. These sources were all considered data and were analyzed as appropriate.

Participant Observation

In addition to these data sources, participant observation was also incorporated into data collection, though access to this population was difficult to obtain. A contact list of support group leaders in Connecticut was obtained from the Alzheimer's Association website, including bereavement groups and groups for current caregivers. Group leaders were contacted by phone and/or email depending on contact information listed. Recruitment was unsuccessful for the following reasons: group leaders did not return contact via phone or email; group leaders reported there were no bereaved caregivers of individuals with dementia currently attending groups; or group leaders did not agree to allow my presence in support group meetings.

I also contacted agency leaders from nursing homes, assisted living facilities, adult day care facilities, and hospice agencies around Connecticut to request participant observation opportunities. Again, most of these attempts were unsuccessful. Few agencies returned initial contact via phone or email, and none of those returned contact a second time to follow up with plans to arrange observations. Several agency leaders were unwilling to accommodate my presence. One agency assisted me in gaining entrée in the field by coordinating participant observation within their facility. This agency serviced a day care center, assisted living facility, and a nursing home, and observations were coordinated in each of these settings.

After meeting with agency leaders from this facility to discuss the study, representatives from the facility selected and contacted potential participants. If individuals were willing to participate, they were put in contact with me to schedule a time for observation. Inclusion criteria for participant observation included English speaking individuals 18 years of age or older who perceived themselves to be current primary caregivers of an individual with advanced dementia. Participants were encouraged to select a time that they would normally visit their loved one. During participant observations, I typically met caregivers in the facility lobby. We usually began with an informal, unstructured interview about their loved one's state in the disease, their caregiving history with their loved one, and their perceived current role. We then went to the loved one's community or floor and continued casual conversations about their experiences while they visited. Observations typically took place at meal times based on caregivers' routines, but also took place during exercise and music activities and during quiet times of rest. Aside from caregivers of individuals in this facility, one individual caring for a loved one at home who was known to me prior to this study also allowed participant observation in his home. Inclusion criteria for participant observation included English speaking individuals 18 years of age or older who perceived themselves to be current primary caregivers of an individual with advanced dementia. Demographic information was not collected on this sample. Observations lasted 45 minutes to 2 hours each. No personal identifying information was collected during these observations and field notes were recorded during and immediately following observations.

Agency leaders also assisted me in gaining entrée into a support group for current and past spousal caregivers of persons with dementia. This support group meets weekly, and the support group leader serves as a chaplain at the facility. Members of the support group were notified in advance that I would be present, and due to the intensive nature of these meetings, the

group leader requested that I attend only one meeting so as not to disrupt the attendance of individuals who may be uncomfortable with my presence. I worked closely with the support group leader to select a week in which attendance would not be low due to winter weather conditions or conflicting events, which required last minute rescheduling several times. This support group meeting lasted 5 hours, which is a typical length for this particular group.

Analysis

Concurrent analysis of books, blogs, interviews, and participant observation data guided selective coding in formal and informal interviews once the core category emerged. Interviews became more targeted as specific questions about the core variable and its properties became relevant, and interviews became shorter as they continued. Memos were written throughout this process as data were collected and coded. Theoretical codes emerged through data analysis and illuminated the core category and its properties. Together, coding resulted in an underlying theory of the basic social process of “rediscovering,” which will be discussed in Chapter 4.

Coding occurred line by line, and substantive codes gave way to theoretical codes as analysis continued. For example, the following quote from one online participant was categorized as “asking for help”:

Ask for "professional help" in care giving. It's much too stressful on the family. I had "support" from the hospice team of professionals. When I accepted that my dad needed 24/7 care in a secured facility, I was able to work on myself and mature.

“Stress on the family” was a cause of asking for help, and “accepting that he needed 24/7 care” was a condition of asking for help. “Working on myself” and “maturing” were consequences of asking for help. “Receiving support from the hospice team” was a context of asking for help. Building theoretical codes to connect substantive codes ultimately revealed an explanatory theory.

Throughout this study, I attempted to leave behind all preconceptions, including previous literature reviews, existing theories, and personal biases to remain open to the emergence of the basic social psychological problem and the core variable of meaning to caregivers of those dying with dementia. Literature review and exploration of existing theories occurred after the core category emerged but prior to the completion of the study, and these were considered data to be examined with reference to the emergent core.

Glaser (1978) warns that the final theory should be abstract and should earn integrity and credibility based on grab and fit rather than on descriptive proof. In other words, quotes from participants should be integrated into the write-up of theory to illustrate aspects of the theory, not to comprise or prove the theory. Glaser argues that abstract concepts derived from constant comparison of cases serve to generalize the process far better than words from a single participant. Relying on these quotations rather than on abstraction forces the researcher into a method of full conceptual description.

To avoid the inappropriate use of quotations as description of an experience rather than as illustrations of abstract ideas, several drafts of this theory were constructed prior to the version presented in Chapter 4. Early representations of this theory were diagrams using gerunds and concepts derived from constant comparison. As these concepts became fuller, memos were combined to create written drafts of the theory, in which quotes and case descriptions were excluded. I continued to compose drafts of this theory without including specific examples until concepts and their properties were sufficiently developed. Quotes and examples were added to the theory at the end to serve as “illustration” and “imagery” (Glaser, 1978, p. 134).

Rigor and Trustworthiness

Within qualitative research, there are many philosophies on how to determine the rigor of naturalistic studies. Strauss and Corbin have developed their own means of evaluating grounded

theory studies, but Glaser (1992) says of their evaluation technique, “Research is put back into wrestling with the canons for judging quantitative method research which are inappropriately applied to grounded theory” (p. 116). As described in the general method of inquiry section, according to Glaser (1978), a theory truly emergent from data should be deemed “credible” and “generalizable” if it has fit, grab, workability, and modifiability. However, these terms are more useful to outside judgment of a reported theory than for the researcher to evaluate his own theory.

To evaluate my own results, based on Mackey’s (2007) description of types of evaluation criteria, I have opted to use Lincoln and Guba’s (2005) classic criteria to ensure “trustworthiness” of results. Lincoln and Guba describe “trustworthiness” as the researcher’s way of building a case to show that these results deserve attention. Trustworthiness is based on “credibility,” “transferability,” “dependability,” and “confirmability.” Each of these will be discussed in this section to describe how they applied in this study.

Credibility is analogous to internal validity of quantitative studies. Credibility ensures that the data reflect true results of the experience and are not simply erroneous. To ensure credibility, I utilized Lincoln and Guba’s techniques of prolonged engagement in research, triangulation of data sources, peer debriefing, and member checking. Prolonged engagement involved collecting and analyzing research over a 6-month period in which I was immersed in data and in the topic of dementia caregiving in my personal and professional life. I spoke to family members, coworkers, and friends about this topic constantly and kept a journal of my experiences. I spoke to participants on the phone, in person, and online in preparation for interviews. I spent time talking to and emailing a graduate student studying dementia who contacted me after seeing a recruitment poster, who also happened to be personally caregiving for her mother with dementia at the time. I spent months collecting and analyzing data and

memoing. Participant observation in particular took place over a 2-month period. Before even beginning observations, I spent several hours meeting with staff representatives and the support group leader, discussing and planning visits with staff that allowed me to gain entrée, and touring the facility. This time invested was critical in earning the trust of staff, which translated to participant trust. It was also important that, by the time observations occurred, I had become a familiar face to most participants in this study.

I also used triangulation of data sources to ensure credibility by collecting data from various samples of caregivers undergoing this experience. Data were expressed through different mediums and means of communication, were collected during and after caregiving experience, and were collected formally and informally. This sample primarily included in-person and online interviews, books, blogs, and participant observation. Peer debriefing was completed with my major advisor, who is an expert qualitative nurse researcher with experience in grounded theory methodology. Original drafts of the theory were also discussed and verified with professional clinical experts from the nursing facility where participant observation took place.

Member checking occurred continuously as new questions were developed based on the constant comparative method. Formal member checking was also used to report findings back to participants in the study to determine whether the emergent substantive theory adequately captured their experiences. Changes were made to the theory as appropriate to reflect feedback from these participants until participants agreed that their experiences were reflected in this theory. For example, earlier on in analysis, I had believed the basic social process to be “reclaiming identity.” It was through feedback from participants on these initial ideas that I came to discover that reclaiming identity was actually a stage within the process of “rediscovering.” Member checking was particularly useful in understanding patterns of variation

among participants within the process of rediscovering. For example, when I presented the theory back to participants towards the end of analysis, several reported experiencing multiple breaking points and feeling like they had repeated the process many times throughout their time caregiving. Further exploration of the idea of repetitiveness within the process revealed that this was a common variation to the process, but it was not the mainstream experience. Member checking allowed me to capture a more complete picture and to maintain credibility.

Transferability is the second criterion for evaluating qualitative studies and is analogous to external validity. This refers to the extent to which results can be applied to the general population of interest. To establish transferability, I used the technique of thick description (Geertz, 1973). I provided rich and detailed data and descriptions of data to allow readers to determine whether or not findings may be transferred to future populations of interest. Initial purposive sampling and theoretical sampling were also used to select participants with diverse experiences. This led to a diverse sample in terms of geographical backgrounds within the United States, care settings, ages, relationships between care recipients and caregivers, and types of dementia. Racial and ethnic diversity was lacking from this sample.

The third criterion for evaluation is dependability, which captures consistency and is analogous to reliability. Again, triangulation of data sources builds a case for dependability as it does for credibility. I also kept an audit trail of raw data, substantive coding, theoretical coding, memoing, and drafts of theory generation, which were reviewed by an expert qualitative researcher to examine the process and product of inquiry. See Figure 1 for a partial audit trail of the construct of “missing the past.” Appendix F also includes examples of memos from different phases of this study.

Confirmability was the final criterion for evaluation. This refers to the researcher’s lack of bias and is analogous to objectivity. Glaser and Strauss (1967/2010) describe that the

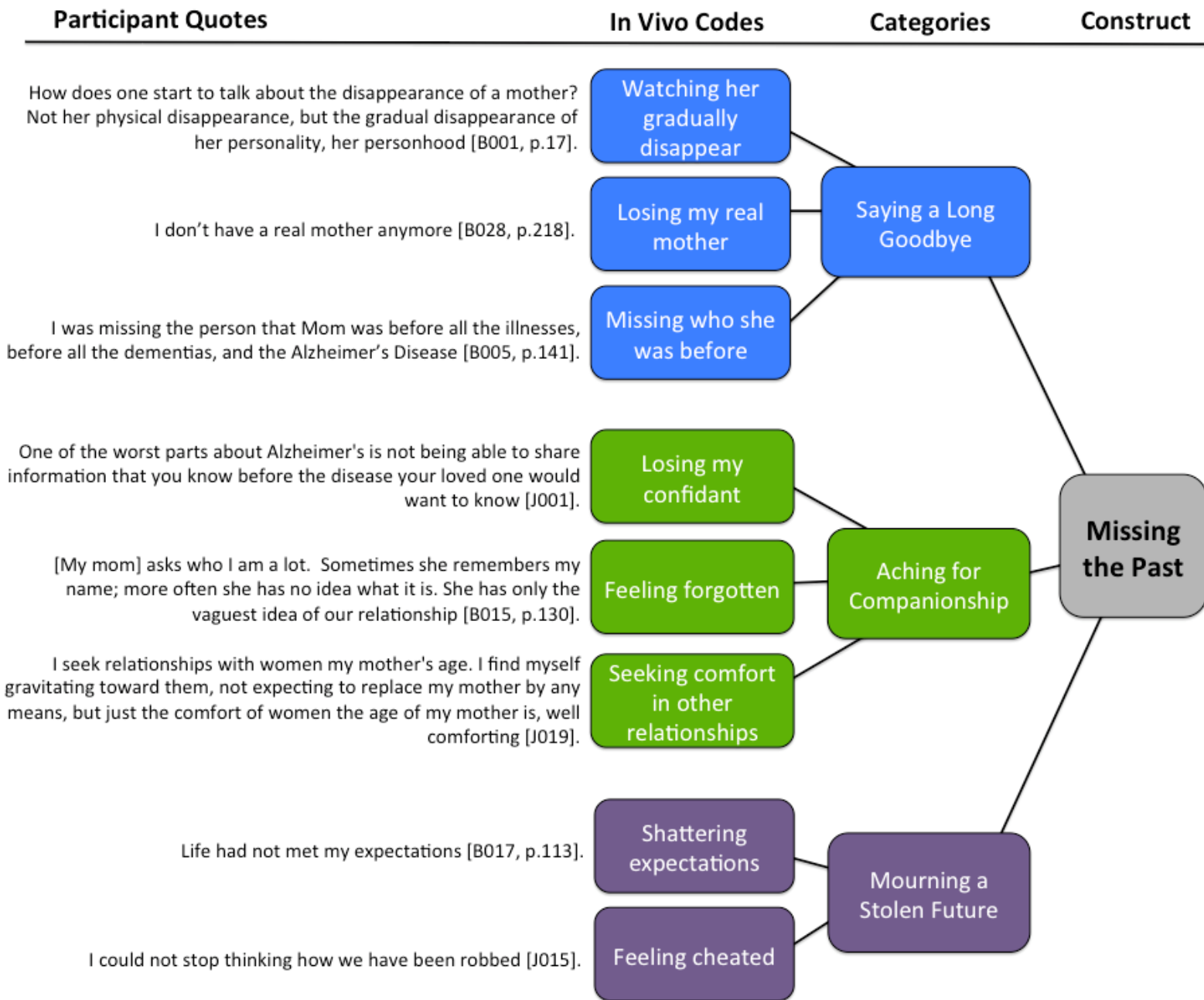
researcher is able to correct biases and inaccuracies through the constant comparative method, in which biases are treated as data and are eliminated as the theory is conceptualized through abstraction. Utilizing an expert researcher to review the audit trail from raw data through analysis also ensured confirmability of results. Using guidelines by Lincoln and Guba (1985), I made attempts to ensure that the use of this method was rigorous to produce a credible, transferable, dependable, and confirmable substantive theory.

Other Considerations

This study was approved by the Institutional Review Board prior to recruitment. Informed consent was obtained prior to all in-person interviews. Process consent was also obtained, as participants were given the opportunity to add or delete anything from the audiotape at the end of the interview. An information sheet was posted on the study website, and participants were asked to indicate online that they had received the information sheet and consented to participate in this study. All individuals observed during participant observation were given an information sheet about the study prior to participation. No informed consent was obtained for use of books or blogs, as these were publically available.

Participants were identified using an assigned identification code, and transcripts of interviews and field notes did not contain any personal identifiers. Demographic information was coded with this same participant-specific identification code. Data collection and analysis occurred concurrently over a 6-month period.

Prior to beginning this study, I underwent rigorous training, both in a classroom setting and independently, on grounded theory methodology. I also attended a grounded theory seminar by Barney Glaser during the planning phase of this study. In addition, I operated under the supervision of an expert qualitative researcher with experience in grounded theory methodology throughout this study.



Summary

Figure 1. Partial audit trail for the construct of “Missing the Past.” This chapter reviewed my ontology and personal worldview, which affected the decision to use a grounded theory method. It also discussed the context in which grounded theory was

discovered by Glaser and Strauss and the work of Glaser on developing this method since its discovery. A classic Glaserian grounded theory methodology was used to theoretically sample a population of primary caregivers of loved ones who passed away with dementia. Major data sources included in-person and online interviews, books, blogs, and participant observation. Open coding, selective coding, constant comparative analysis, concurrent data collection and analysis, memo-writing, and theoretical sorting were used to uncover a substantive theory that explains how this population resolves its chief concern. The next chapter will describe the findings of this research study and the emergent substantive theory.

CHAPTER 4: RESULTS

This chapter will describe the results of the grounded theory study of caregivers of persons with dementia at the end of life. Caregivers face a concern of being trapped in an inescapable role. They attempt to resolve this concern by rediscovering their loved one and themselves. A substantive theory of the basic social psychological process of “rediscovering” has emerged from the data. This chapter will describe the research sample, the main problem that caregivers face, and the theory of rediscovering.

Sample

Theoretical sampling was used to recruit a sample of participants through multiple sources. The sample included participants from face-to-face interviews, online, interviews, published books, blogs, and participant observation. Each sample will be discussed in this section. The total sample of individuals participating in formal online or in-person interviews, books, or blogs included 83 caregivers who described taking care of 86 loved ones with dementia at the end of life. An additional 18 participants were observed in a support group setting and/or on an individual basis. Including participant observation, 101 individuals describing 104 cases were included in this sample. Informal interviews and casual conversations are not captured in this sample, though field notes and memos were impacted by these experiences.

Formal face-to-face interviews were conducted with five individuals. Interviews were conducted after the loved one had passed away. One of these individuals was a private-duty aide and not a family caregiver. One individual in this sample was interviewed twice, for a total of six face-to-face interviews.

Online interviews were conducted with 31 individuals, but one interview was excluded because the participant stated that her loved one was still alive and was not yet at the end of life. Two individuals described experiences of caring for two loved ones. In total, this sample

consisted of 30 participants who discussed 32 cases. Participants were interviewed one to four times each for a total of 60 interviews conducted in this sample.

The sample of books consisted of 26 books, which were written by 30 caregivers describing 31 cases of caring for a loved one with dementia. The sample of blogs consisted of 18 blogs. A reference list of all books and blogs used in the sample is included in Appendix G.

Participant observation consisted of observations of 18 caregivers. Observations took place over a 2-month period and total time spent observing was 19 hours. Working with this sample was invaluable, as it allowed me to informally interview individuals at all stages of this process to learn more about the stage as it was being currently experienced.

At the advice of the support group leader, demographic characteristics were not collected on this population to protect the privacy of those participating in the support group setting and to encourage open participation. This is the only sample in which some participants were actively caring for loved ones at time of participation. Twelve spousal caregivers were observed during a support group meeting, including six males and six females. Of those, four were caregivers to someone who had already passed away; one was a caregiver to a loved one who was actively dying; six were caregivers to a loved one in the advanced stage of dementia; and one was a caregiver to someone in the middle stage of dementia. One-on-one observations with loved ones took place with ten individuals, though four of these individuals also participated in the support group. All of these individuals were caring for loved ones in the advanced stage of dementia, and nine of the ten were caring for a loved one who lived in a nursing home. One individual was caring for a loved one at home. Of these individuals, six were males caring for wives, one was a male caring for his mother, three were females caring for husbands, and one was a female caring for her mother.

Participants also expressed themselves via photographs, artwork, videos, poetry, and recipes. Others shared artwork, videos, poems, and songs that were meaningful to them but that they did not create. One participant asked me to listen to five voicemail messages that her husband had left her when he was living because she felt that they captured that time for her. Still others shared obituaries of their loved ones or eulogies, prayers, or readings that were read at their loved ones' funerals. All of these data sources were considered in analysis and memo-writing.

Informal interviews and casual conversations also contributed to the discovery of this theory. Through the recruitment process and time spent in the assisted living, adult day care, and nursing home facility, I was privy to the opinions of informal non-primary caregivers, current caregivers of individuals in the early stages of dementia, individuals with dementia, nursing facility staff, support group leaders, and professional experts in dementia care. These individuals were not considered participants as they were not the primary population of interest and did not consent to participate. However, it is worth note that these experiences influenced my thought processes and may have impacted the questions I chose to ask in formal interviews and the memos I wrote. In the "all is data" mentality, these conversations gave context to the interviews and of observations in this sample.

Demographic Characteristics

Demographic information was collected from 83 participants, including those who participated in in-person interviews, online interviews, books, and blogs. Demographics were not collected from those who participated in participant observation. See Table 1 for demographic characteristics of the sample. Overall, this sample was primarily female (87%), White (92%), and Christian (77%). Twenty-eight states were represented in the sample, with highest representation from Connecticut (21%).

Table 1

Demographic characteristics of sample of in-person and online interviews, books, and blogs

	n	%
Total Sample:		
N = 83 caregivers, N = 86 care recipients		
Caregiver gender (N = 83)		
Male	11	13
Female	72	87
Care recipient gender (N = 86)		
Male	38	44
Female	48	56
Age of caregiver (N = 60)		
Mean: 58 years		
Range: 36-88 years		
Age of care recipient at time of death (N = 74)		
Mean: 80 years		
Range: 47-101 years		
Relationship of care recipient to caregiver (N = 86)		
Father	20	23
Father-in-law	1	1
Friend	3	3.3
Grandfather	1	1
Grandmother	2	2
Husband	15	17
Mother	38	44
Mother-in-law	3	3.3
Wife	3	3.3
Time from diagnosis until death (N = 72)		
Mean: 5 years		
Range: 3 months-21 years		
Time since death (N = 80)		
Mean: 3.9 years		
Range: 3 days-10 years		
Type of dementia (N = 83)		
Alzheimer's Disease	53	64

Frontal Temporal Lobe	5	6
Lewy Body	7	8
Parkinson's	1	1
Vascular	6	7
Wernicke-Korsakoff	1	1
Mixed	3	4
Unknown	8	9
Place of death (N = 83)		
Care recipient's home	20	24
Caregiver's home	12	17
Home of another family member	2	2
Assisted living	7	8
Nursing home	31	37
Hospital	8	10
Inpatient hospice facility	2	2
Enrolled in hospice at time of death (N = 80)		
Yes	57	71
No	23	29
Time enrolled in hospice (N = 46)		
Mean: 109 days		
Range: 1 day-2 years		
Religious affiliation of caregiver (N = 57)		
Buddhist	3	5
Catholic	17	30
Christian (not otherwise specified)	13	23
Jewish	1	2
Protestant	14	24
Unitarian Universalist	1	2
Unaffiliated	8	14
Caregiver racial background (N = 75)		
White	69	92
Hispanic	3	4
African American	3	4
Caregiver state of origin (N = 67)		
Arizona	2	3
California	3	5

Colorado	2	3
Connecticut	14	21
Delaware	1	1
Florida	5	7
Georgia	1	1
Illinois	2	3
Maine	1	1
Maryland	1	1
Massachusetts	2	3
Mississippi	1	1
Missouri	1	1
Nevada	1	1
New Jersey	2	3
New York	5	7
North Carolina	3	5
North Dakota	2	3
Ohio	2	3
Pennsylvania	2	3
Rhode Island	1	1
South Carolina	1	1
Tennessee	1	1
Texas	4	6
Virginia	5	7
Washington	2	3
Wisconsin	2	3
Wyoming	1	1

Caregivers had a mean age of 58 years at time of data collection. The average age at time of death of care recipients was 80 years. Participants were most frequently caregivers to mothers (44%), fathers (23%), and husbands (17%). It is worth noting that, though demographic characteristics were not collected for the participant observation sample, the observation sample primarily consisted of males caring for wives.

Care recipients most commonly had Alzheimer's disease (64%), though a wide variety of types of dementia was represented in the sample. Loved ones in this sample most often died in nursing homes (37%) or in their own homes (24%). Most did receive hospice care (71%) with an average enrollment of 109 days. Six individuals mentioned that loved ones were discharged from hospice at some point during care but were readmitted at time of death.

In both books and blogs, it is worth noting that the demographic characteristic of "time since death" is different from other samples. Those blogging and several participants writing books used journal entries or emails as parts of text and thus were written in "real time" of caregiving. Others wrote about their experiences years later looking back. In either case, "time since death" was recorded as time of death compared to current time. For example, if the author wrote an entry in 2010 on the day that a loved one died, "time since death" was recorded as 4 years, not 1 day. Since it was difficult to capture time between the event and the writing in most cases and since the author had the opportunity to edit and rewrite after the event had passed, I made a choice to capture the age of the data provided, not the time that passed between the event and the data creation.

Basic Social Psychological Problem: Role Entrapment

Throughout the data, caregivers described a feeling of irreplaceability that trapped them in their caregiving role. Caregivers felt bound to loved ones emotionally, mentally, and often physically. This may have been out of love, out of duty, out of respect, or out of a belief in some moral code. With or without help from others, caring for this person occupied much of the caregiver's time, thought, and energy. The primary caregiver believed that he or she held qualities that could not be replaced by another caregiver, including information, skills, experience, relationship power, or love for the family member. Even if tasks could be outsourced to others, the caregiver believed that his or her role was nontransferable. The only

escape could be through the death of a person that he or she loved. This section will describe the basic social psychological problem of role entrapment, which is the main concern of caregivers of loved ones with dementia at the end of life.

Participants had different motivations for taking on the role of caregiver for a loved one. Some felt that they had no other choice but to be there, since no one would take over in their absence. One participant stated, “I didn't feel there was anyone else who could step in” [P027]. Another said, “I was trapped. I really had no one to take my place. I was an only child with few options since just leaving my mother to fend for herself would have likely resulted in me going to prison” [P017]. Others were motivated by love. One participant caring for his mother-in-law said:

...I got sick and tired of hearing some variation of the comment “You’re a saint for doing this.” ... I knew I was not a saint. I did not do this out of some kind of religious belief. I did it out of simple, intense love and respect – both for my wife, and for her mother.
[B027, p. 222]

A woman caring for her husband said, “It was always love. Not duty” [J004].

Yet, another woman caring for her life partner experienced terrible guilt as she asked herself, “How could I visit him only out of a sense of duty – not love?” [B032, p. 181]. Many adult children caregivers described a strong sense of duty, saying, for example, “It is what a son should do” [P045].

Religion, marital vows, and moral codes were also motivating. One daughter, who described a rocky relationship with her mother, said:

It is less about the fact that my mother is my mother – in truth, forgetting our long history makes it easier for me to relate to her – and more about the fact that my mother is a fellow human being in need of my help. [B029, p. 126]

For some, the transition to caregiver occurred without intentional choice. One daughter said, “I never actually chose to take care of my mother. It just happened” [B015, p. 181]. Most participants described a combination of motivating factors.

Even with help, caregiving was consuming. Caregivers thought about care constantly. One daughter caring for her mother wrote, “I really can’t even focus right now, she’s just on my mind constantly” [J003], and a son caring for his father said, “The situation occupied the majority of my thinking day and night” [P007]. Many discussed the sacrifices of time and energy, and most discussed feeling mentally, physically, and emotionally exhausted. One daughter said, “Mom was pushing the limits of my energy, every muscle in my being screamed for release” [B018, p. 567]. These feelings were consistent among caregivers, regardless of care settings.

It is telling that nursing home admission or in-home health aides did not alleviate these feelings of overwhelming exhaustion. This is likely because even when tasks of care could be delegated, as in the nursing home setting, caregivers believed themselves to be irreplaceable as the primary caregiver. As the coordinator of care, these individuals had insight into the “big picture” that others could not grasp. One son-in-law summarized this feeling:

You gain solid confidence that you and you alone understand what is really happening.

You know all about the meds, all about doctors, all about the needs of your loved one for whom you are caring. You have gotten used to the responsibilities involved, and will likely resent it if anyone tries to interfere or impinge. [B028, p. 79]

One daughter described this as feeling “perpetually responsible” [B017, p. 110].

Many caregivers were afraid to leave a loved one with someone else, fearing that others would not provide good quality care or that their loved one would not feel safe and comfortable. One said, “I did allow others to come and care for him so I could get a break, but usually came

back to substandard care issues and an extremely unhappy and confused father” [P014]. Another daughter said, “I knew that I knew Mom and I knew how to take care of her and make sure everything was okay, and I frankly didn’t believe nor trust that anyone else could or would do that for her” [B005, pp. 136-137]. Caregivers continued to feel accountable for coordinating, supervising, ensuring quality, and, in many cases, physically providing care.

One son described a similar experience, but acknowledged that these feelings were self-inflicted. He said, “I’ve developed the common caregiver’s illusion that only I can look after my father” [B006, p. 158]. Even acknowledging that this was an illusion, though, this son described incredible guilt when he did not uphold his own expectations.

Since it could not be delegated to others, this nontransferable role could only end through the death of the care recipient. Several caregivers admitted this truth with extreme guilt. As one son said, “He has to die so I can have my life back” [B006, p. 170]. One daughter went so far as to title her memoir *When I Married my Mother* because she and her mother were together “until death do us part” [B031]. Whether or not caregivers hoped for the death of a loved one, the knowledge that this role was inescapable until death led to caregivers feeling trapped.

Caregivers used profound imagery to describe the feeling of being trapped. Several described being in prison, carrying weights, and being tied down. One daughter said, “...home is my prison and caregiving is my jailor...” [J011]. Another said, “For several years I was yoked to my mother” [B015, p. 7]. A son said, “My father is going downhill, and I am tied to his decline” [B006, p. 110]. Many caregivers simply used the word “trapped” to describe their situations.

It is important to note that role entrapment did not typically result in resentment toward the care recipient. Many regretted the situations that caregiving created, but this usually caused anger toward the disease or circumstances, not the care recipient. One wife wrote, “I was raised

not to hate anything, but 'by golly' I hate Alzheimer's with a passion" [J013]. Others admitted with guilt that they did resent the care recipient, particularly if the relationship prior to caregiving was poor.

Feeling trapped in this irreplaceable role emerged as a main concern for caregivers at the end of life. Once caregivers took on this role, they developed a perspective on the whole picture of care that could not be transferred to other individuals. This perspective required them to be bound to their loved one's care until death. Tasks of caregiving could be delegated to paid professionals or other family members, but whether realistically required or self-inflicted, only the primary caregiver could fill this role.

Substantive Theory of Rediscovering

Based on the perspectives of the participants in this sample, it seems that remaining in this irreplaceable role is simply a fact of caregiving. It cannot be alleviated by professional support or by receiving help from others or even by respite. However, feeling "trapped" in this role may be overcome through a process of rediscovering. Filling the caregiver role often caused primary caregivers to view themselves strictly as "caregivers" due to restrictions on time and energy. The caregiver is unable to escape constant thoughts, worries, and tasks required of him or her. By rediscovering their relationship with the loved one, the relationship that exists outside of the caregiver-care-recipient dyad, caregivers can find some relief. Due to the nature of dementia, caregivers must also rediscover the care recipient. They must discover the parts of their loved one that remain intact and also discover the parts that are new since the disease has taken over. As importantly, caregivers must rediscover themselves, remembering their identities that exist outside of caregiving. Through rediscovering, caregivers are able to remain in the irreplaceable role without feeling trapped in it.

The process of rediscovering consists of five stages that emerged from the data. Figure 2 depicts this process, and Figure 3 shows the categories within each stage of this process. The first stage is missing the past, in which the caregiver grapples with the loss of the person they once knew while the care recipient is still living. The second stage is sacrificing self to caregiving, where the caregiver typically begins to lose sight of the world and relationships outside of providing care. The next stage is yearning for escape, in which the caregiver reaches a breaking point and begins to look for care alternatives. Stage four is reclaiming identity, in which the caregiver adapts to the changes in himself, the care recipient, and their relationship. The final stage is finding joy, in which the caregiver rises from acceptance to finding purpose and peace in his role.

Theoretical codes also emerged that linked categories within these stages to one another in the process of rediscovering. Categories in the stage of missing the past provided a context for the second stage of sacrificing self. Categories in the second stage were causes of the third stage. In the stage of yearning for escape, categories were consequences of the loss of self. Stage four categories included strategies that caregivers used to reclaim identity. The last stage includes the consequences of the previous stage, which resulted in finding joy. Each stage and its categories will be described in the following sections.

Stage 1: Missing the Past

The first stage that caregivers underwent in the process of rediscovering was missing the past. Categories in this stage included saying a long goodbye, aching for companionship, and mourning a stolen future. Caregivers slowly lost their loved ones as dementia stole memories and personality piece by piece. Complicated emotions accompanied the loss of a loved one who was still living. Caregivers had to cope with missing the person they once knew and loved and

the relationship they had with this person. They also had to cope with broken dreams of a future with this loved one.

Saying a long goodbye.

As the care recipient vanishes one piece at a time, the caregiver misses the person he or she once knew and loved. Many caregivers describe their years of caregiving as “saying a long goodbye.” One caregiver said, “...With dementia, loss comes in bits and pieces and drags on and on for many years long before the person even dies” [B032, p. 175]. Another wife explained, “When someone you love is slowly dying, you mourn for every lost function. You give up one thing at a time” [B021, p. 112].

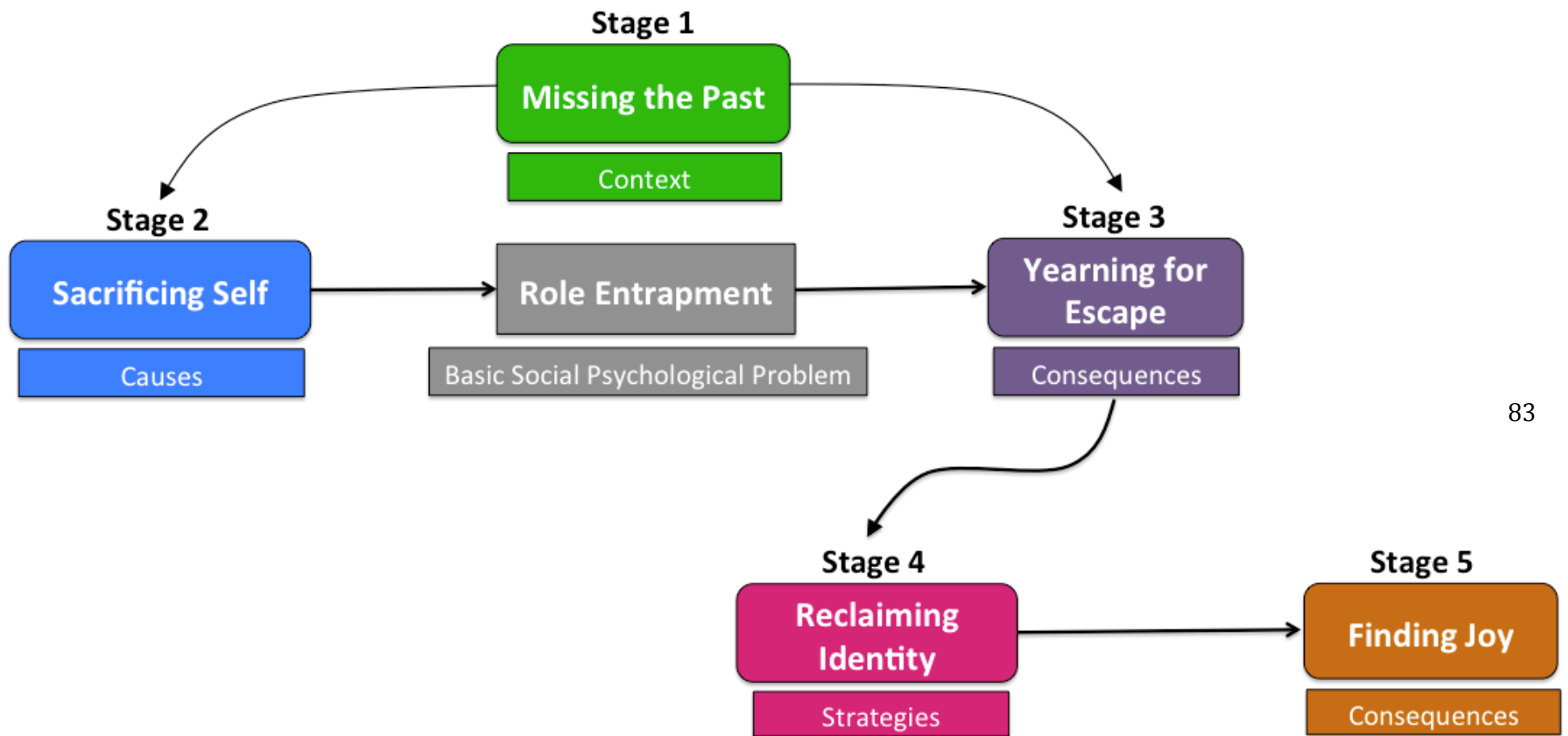


Figure 2: The Basic Social Psychological Process of Rediscovering to Resolve the Basic Social Psychological Problem of Role Entrapment

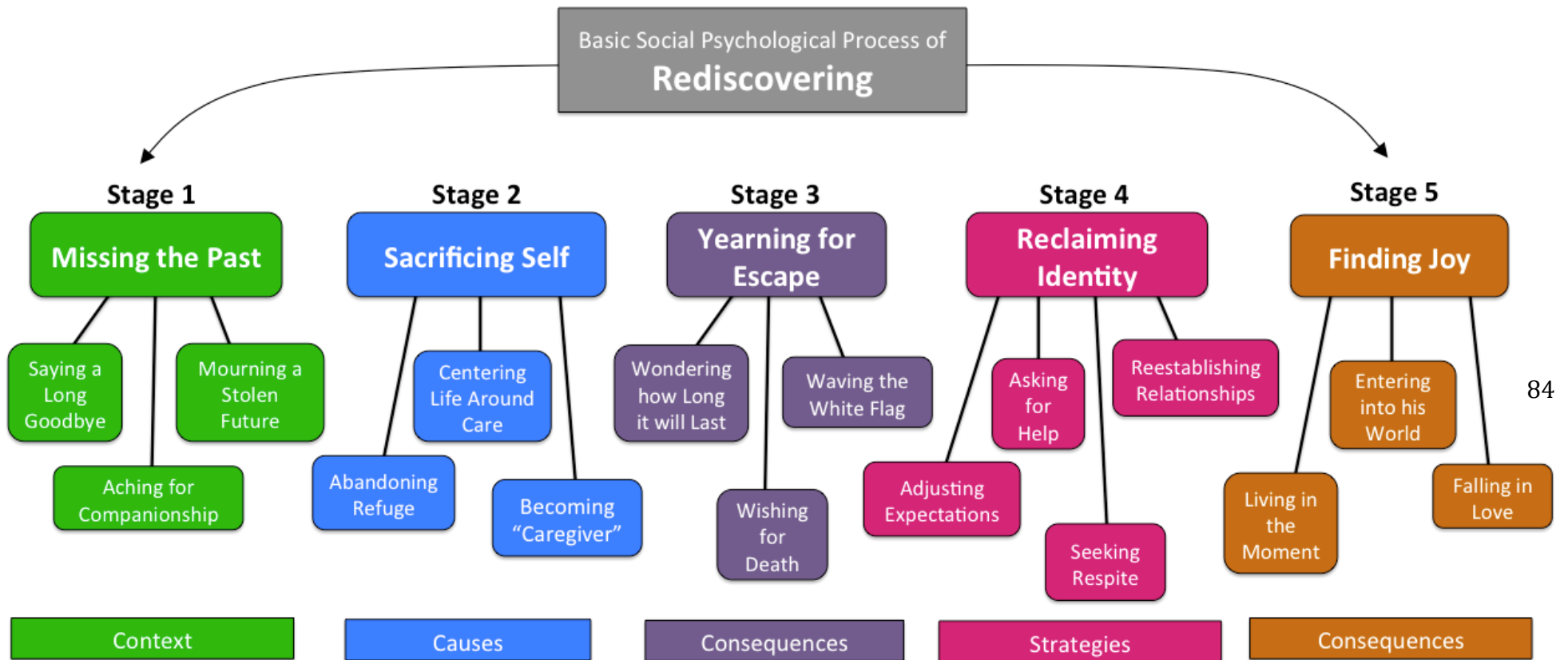


Figure 3: Categories within the Five-Stage Process of Rediscovering.

Some caregivers used the term “lasts” to describe this experience, comparing it to the “firsts” of a newborn, and others use the term “little deaths.” One wife wrote, “Little deaths may sound strange, but for me each time [he] lost an abilityit felt like a small death. I quickly learned when he lost an ability it was gone, no turning back.....gone forever” [J013]. One daughter writes of the challenges of grieving for these deaths in someone who is still alive. She says, “We sit there every day and watch her die. Our lives are on hold while her death is on hold. We can not mourn and yet we are forced to grieve every day as another piece of her dies” [J015].

Others also described the odd sensation of losing a person who was still alive. As pieces of this loved one faded away, the care recipient became less and less like him or herself. One daughter wrote, “I lost my mother long before her death” [B011, p. 153], and another, “There she was and there she wasn’t, in front of me but no longer there” [B007, p. 278]. One daughter lost her father while taking care of her mother and wrote, “My parents are no longer here, I am an emotional orphan” [J001].

By the end of life, the caregiver may no longer recognize the person whom they once loved. A wife said of her husband, “He was not the same person I was married to for 58 years” [P021]. A husband losing his young wife to frontal temporal lobe dementia said, “...the true [her] that we all knew and loved has for the most part vanished due to this dreaded disease” [J012].

Losing this person to the disease was “heartbreaking” and “depressing.” One caregiver wrote, “I felt utterly alone. Never in my entire life had I felt so alone” [B032, p. 179].

Caregivers missed their loved ones intensely even though they had not yet died. One caregiver said, “I missed my grandma the way she was” [P009]. A wife said, “A number of things made me miss [him] so much, but I do realize I am missing ‘the [him] that was’” [B008, p. 241].

Another wife described her still living husband, saying, “There's such an emptiness because

David isn't here with me. I miss David's sweet smile (he no longer smiles). I miss his voice (he seldom talks). I miss his presence” [J013]. She went on to list many of his features that she loved that went missing long before his death.

Aching for companionship.

The loss of this loved one to disease created a void in caregivers who missed not only the person, but the relationship they used to have with that person. One daughter said, “Really what I wanted to do is to take her to Disney with my children or stay up talking about life. Share my frustrations, successes, dreams, hopes for my kids. Really I just want my mom back” [J015]. Others described experiences of wanting to share good or bad news with loved ones, but knowing this was no longer possible. One daughter, who had previously lost her father and was caregiving for her mother, describes hearing of a death of a friend named “Mary”:

I immediately wanted to call Daddy and Mom and tell them. I even had the phone in my hand for a brief second. ... [but] I can't tell Mom, she most likely would not know who Mary even was. ... Even sharing tragedy, is not possible. [J001]

Feelings of losing a relationship were often made worse by the fact that the care recipient may no longer have recognized the caregiver. Most caregivers described facing this harsh reality at some point, and many described having to remind loved ones who they were. One wife shared her story:

We were lying in bed holding hands. I told [him] I loved him, and he gave me a few small kisses. Then he looked at me and said, “We should get married!” I usually tried not to correct [him], but this time I felt a need to do so. I said, “Honey, we’re already married.” He responded with, “No, I said we should get married.” I simply said, “OK.” [B016, p. 86]

A daughter described reminding her father of her mother’s death:

I explained Mom passed away fifteen years ago, and he was shocked to hear the news, as if it had happened yesterday. ... Dad asked me how she passed away, so I told him the story, just as he had told me. [J010]

As the care recipient lost memory of these relationships and events, some caregivers described feeling replaced in their loved ones' eyes by nursing home staff or aides. One daughter said, "But here is the true heart wrench ...when an aide or nurse walks in, I see that look in her eyes for them. They have become her pride and joy" [J019]. A husband who took part in participant observation shared that his wife had found a "new boyfriend" when she entered the nursing home. He described the deep pain that this brought him before he was able to accept her disease. As he fed her, he explained to me that she no longer knew who he was, "but she knows I am one of the people who loves her." Some felt that their loved ones did not even know that much. One daughter wrote of a visit with her father, "I sat there and held his hand and knew he had no clue who I was, or that I was familiar, or that he even knew he was holding my hand" [J002].

"Feeling forgotten" caused emotional turmoil, especially the first few times that it happened. Participants described feeling "shocked," "scared," and "sad." Some also felt "hurt" and "angry." One life-partner wrote, "There were times when I resented people suggesting I focus on trying to find a way to reach *him*. Couldn't they understand I also wanted him to reach *me*?" [B032, p. 181]. Another wrote, "I felt like a child, chasing after my mother as she walked away. I just wanted to be loved, for her to take an interest in me, her daughter" [B023, p. 192].

Some caregivers felt forced to seek aspects of this relationship elsewhere. One wife wrote, "I also have to get emotional support elsewhere, because [he] is just not capable of it at this stage in his illness" [J009]. Another said, "I knew I could never replace [him], but I had to

find *someone* with whom I could spend time on the phone” [B032, p. 179]. A daughter summarized the impact of the loss of relationship after her father’s death:

Grief is a selfish thing. We're sad ... because we have a hole in our lives shaped like the one we've lost. The hole in me where my dad was isn't even dad-shaped. It's just a blob. As my dad wore away, I became less dependent on him. I needed him less because I was forced to go to others for the things he used to do for me. [J002]

Others were unable to find support elsewhere, and simply suffered in “loneliness” and “despair.”

Mourning a stolen future.

Missing a loved one and a relationship was compounded by missing a future that should have been. When considering the future, many participants blamed the disease for “stealing” or “robbing” from them. One wife wrote, “Dementia brutalized him and stole the love of my life from me. It altered him, us, and me” [B012, p. 3]. A daughter said, “My heart once again aches there are so many things that Alzheimer's steals” [J001].

Caregivers describe “shattered dreams” and “life not living up to expectations.” One wife grieved a loss of quality time with her husband, saying, “I am starting to be more aware of how much we are missing in retirement, not being able to enjoy each other” [B008, p. 241], and another, “..... it isn't what I'd hoped and dreamed our life would be at this time in our life...” [J013]. Another wife said, “I feel that [he] was cheated, and we were cheated; we were not allowed to grow old together” [B016, p. 103]. Yet another said, “I had imagined our middle age to be a wonderful time together. But it was not to be” [P018].

Adult-child caregivers shared these sentiments. One daughter said, “This was not the script I had envisioned in my mind. What was the script? I don't know....just not this!” [P010]. Another daughter said, “Life had not met my expectations, nor [his]” [B017, p. 113].

For many caregivers, unmet expectations were not limited to the quality of time with a loved one, but also included unmet expectations for their own futures. Caregivers missed their own lives before caregiving. Many participants sacrificed relationships, jobs, and homes to be present to a loved one. One said, “I felt ‘robbed’ of some continued type of quality to my personal life and a little independence ...” [P016]. As caregiving continued, these sacrifices became greater, which brought caregivers to the second stage of the process of rediscovering.

Throughout the first stage, caregivers yearned for what they had lost. They missed the person whom they used to love, the relationship they had with that person, and the future they had hoped for with that person. Grief for the past and continued loss created a context in which the caregiver began to sacrifice his or her own needs, and eventually identity, to caregiving.

Stage 2: Sacrificing Self

The second stage in the process of rediscovering was sacrificing self to care. Categories in this stage included abandoning refuge, centering life around care, and becoming “caregiver.” The context of missing the past laid the groundwork for caregivers to devote themselves to trying to minimize losses and control the “downward spiral” of their loved ones. In doing so, caregivers abandoned their own comforts and needs. Life began to revolve around tasks of caregiving. Ultimately, the identity of the caregiver became dependent on this role, and sense of self outside of caregiving was lost.

Abandoning refuge.

In turning themselves over to caregiving, participants lost careers, homes, time with their own families, friends, vacations, privacy, and downtime. They lost those parts of their lives that

brought them relief. These sacrifices were often made consciously at first, but typically amounted to be much greater sacrifices than the participant had initially expected.

Caregiving itself became a full time job for many by the end of life period. Many caregivers described “career disruption,” “job strain,” and unexpectedly retiring or quitting jobs to make time for caregiving. One son said, “As the end got closer we got several false alarms that he was beginning his final slide towards death. This continued to put a strain on my job (as it had for years)” [P007]. This also had financial implications, as several “worried constantly about money” but felt that leaving work was the only way to provide appropriate care to a loved one. One daughter said, “It's only now that I realize I spent those years constantly on edge waiting for the next crisis, worrying about money, worrying about my own job due to having to miss work” [P013].

Some participants lost their jobs because they needed to relocate to provide care, which also caused “geographical disruption” and “loss of home.” This further impacted financial wellbeing. One daughter said, “Financially we lost a great deal of money due to giving up jobs and having to purchase a home in [her state] prior to selling our home in [a different state] (we still own both homes)” [P015].

Another daughter described having to move abruptly to manage her mother’s care and wrote, “My own concept of home started to fall apart” [B017, p. 71]. Home disruption could occur through any major home change. Some caregivers moved across the country to be closer to a loved one, while others moved in with a loved one or invited a loved one to move in with them.

Inviting professional caregivers into the home had a similar impact. One wife described the disruption of sharing her home with her husband’s 24-hour caregivers:

Nothing was “ours” or “mine” anymore. I shared the house with [my husband] and with his caregivers. The kitchen, the bathrooms, the living room, the bedroom were theirs. I had virtually no privacy unless it was in the middle of the night and [my husband] was asleep. The dishes, the drawers, the cupboards were no longer just ours, even the newspapers. ... I had wanted him home – but I didn’t have a home of my own any more, and that was part of the price I paid. [B012, pp. 150-151]

Caregivers lost the refuge of their own sense of home.

More detrimental than work or home disruption was family disruption, particularly for adult-child caregivers. Caregiving required large amounts of time, pulling adult-child caregivers away from their own spouses and children to be present for a parent. Caregivers worried about how these changes would affect their families. When moving her mother in with her, one daughter wondered, “Will she put my family at risk?” [J003].

Adult-child caregivers often struggled with balancing the needs of their children with their parent care-recipient. Many caregivers described putting themselves second to the care recipient, but these “sandwich generation” caregivers truly struggled with how to prioritize the needs of their children with those of a parent. One caregiver wrote, “The term ‘sandwich generation’ is ridiculously inadequate to describe those of us caught between raising our own children and caring for an elderly parent. I’ve got a better one: the ‘vice-grip generation’” [B009, p. 31]

This same caregiver described handling her daughter’s acute illness and hospitalization in the midst of caregiving for her mother. She felt extreme guilt for inadvertently overlooking her daughter’s needs as she provided to her mother. She wrote:

I've spent every lucid moment taking care of my mother. My own child needed me and I didn't pick up on it. ... I sat there, stunned, not ever having fully realized the impact of Mother's care on my children's lives. [B009, p. 131]

Another caregiver whose mother lived with her described balancing young children and caregiving and wrote, "I was in the thick of it, juggling the urgent and conflicting needs of two short, crazy people and the forgetful gray-haired lady who used to be my mom" [B007, p. 249].

Marital relationships between adult-child caregivers and their spouses were also affected by caregiving. One daughter wrote, "We didn't discuss it openly very often, but we both felt the tension. He still didn't like having to be our sole financial provider, and he didn't seem to understand exactly what I was providing" [B007, p. 248]. She described an argument in which "...[my husband] ... quietly told me, 'This is not what I signed up for'" [p. 251]. Another daughter described facing her husband's "festering resentment" [B017, p. 30].

Even when spouses understood and accepted the demands of caregiving, these couples had limited time together. One daughter said, "My marital relationship was 'on hold' during this time" [P026]. Another daughter lived together with her husband and her mother and said:

It sure would of been nice to allow my husband and myself just a few hours once in a while to breathe some fresh air, escape the confines of our home, to simply go somewhere together to talk, to laugh, to enjoy a meal just the two of us. Oh, what a blessing that would of been to us ... but I realized that this was a dream, never to become a reality for my husband or myself. [P016]

One daughter wondered, "How long do my children and husband have to sacrifice their nights without me?" [J015].

Caregivers described total upheaval of their home lives and familial relationships outside of caregiving. While currently caregiving, one exasperated daughter wrote, "I cry because

there's dirt under my refrigerator. My husband surely wonders why he married me. My son keeps his distance. My brother thinks I'm ridiculous" [J016]. She later reflected on the choices that she made to be present for her father and wrote, "I hope when this is all over I still have friends. And a husband. I hope [my children] still have a mom with a sense of humor, and my happiness gene reappears intact" [J016]. Many participants used the term "putting life on hold." Comfort and security were abandoned to make time for caregiving.

Centering life around care.

Life became all about caregiving. As one daughter said, "I was full-on in the caregiving role" [P012]. Decisions became about needs of the loved one, not about needs of self. Another daughter said of caregiving, "You have to remember in this scenario that it's not really about you. It's about your loved one(s) and what they need and what's best for them is the only option" [B005, p. 137]. Many participants used the phrase "centering my life around [him/her]."

Even in nursing home care, caregivers operated on the routines of the care recipients. One participant said that her husband was the center of her life, and when remembering placing him in a nursing home she said, "But even then he was the center of my life: I planned my activities around him" [P021]. This was also noticeable in planning participant observation opportunities. Caregivers knew when their loved ones would be eating, napping, and participating in events and planned their days around finding opportune times to visit. One participant wrote, "Our days became all about her calendar" [B002, p. 102].

Caregivers also described "living on duty." Participants said, "I was on duty or on call 24/7" [B017, p. 79], and "It just seemed like I was always on call" [P023]. At home, this often meant listening to a baby monitor at night. In a nursing home, this meant carrying a phone and being ready to "drop everything" to be there in a moment's notice. One son said, "I would get a

call at any time of the day or night and had to get to the nursing home as soon as possible” [P007].

This could last several years by the time the care recipient reached the end of life. One daughter wrote, “My roll as her caregiver was full time, twenty four seven for two years. I had no outside life during my role as a caregiver. My life, was her life” [P016]. It did not take long for this grueling job to become an identity.

Becoming “caregiver.”

Giving up their own lives and taking on the tasks, worries, and responsibilities of caregiving forced caregivers into a shift in self-identity. Being a “caregiver” became part of who they were at the core, and in many ways, defined them. It also came to define the relationship between the caregiver and care recipient.

Participants described “wearing many hats” within caregiving. One daughter wrote, “I’m on a twenty-four hour schedule, vacillating between the roles of wife, mother, daughter, maid, cook, and nurse” [B009, p. 30]. Another daughter explained that she was not able to be a daughter in the midst of all she was doing for her mother. She said, “I was so busy with being a caregiver for my mom ..., housekeeper, transportation manager, cook, personal shopper, medication aide and anything else that I often didn’t have the energy or the capacity to be a daughter” [P035]. Participants reported serving as “coach,” “cheerleader,” and “spiritual midwife” in helping the care recipient through the end of life.

One in-home caregiver with 24-hour care reported that her husband’s aides began to see her as an aide instead of as his wife or their employer. She wrote, “I had become another aide and a poor one at that” [B012, pp. 136-137]. To improve her skills and to gain respect among the aides involved in his care, this wife went so far as to audit course to become a certified nursing assistant.

Both spousal and adult-child caregivers described becoming “parents” to loved ones. One daughter said, “I’ve been thrust into the role of parent” [B029, p. 56] and another, “I became her caregiver, her parent, her mom” [J011]. Another daughter adjusted to the idea of becoming a caregiver and parent: “I am my mother’s caregiver. I’ve bathed her, fed her, clipped her toenails and changed her diaper. I’ve done everything that a mother would do for her child” [B026, p. 52]. One wife described that she and her daughter were “immersing ourselves in our new roles of caregiver and parent” [B016, p. 54]. Another wife said, “My whole adult life with him led to the last three years being in the role of his parent, not his wife” [P018].

Boundaries of previous relationships were shattered. One daughter wrote, “When Dad died, Mom lost her role as a wife, and she was losing her role of mother as I was losing mine as a daughter. We both had previously leaned on these identities for navigation with each other” [B017, p. 85]. As the identity of the relationship changed, so did the identity of the caregiver.

Participants became absorbed in caregiving. A son-in-law wrote, “You develop such tunnel vision – everything has to be considered in terms of one objective: being a care-provider” [B027, p. 193]. One daughter said, “The role reversal from daughter to caregiver had defined me” [P010].

Caregivers forget about their own wants and needs as they focus on the wants and needs of the care recipient. As one participant wrote, “I’m whisked away by the needs of my mother, my children, and a full house. I forget there’s a me” [B009, p. 114]. A son said, “I’ve had some fears about disappearing into the pocket of my father’s life, of being swallowed by his needs and routines” [B006, p. 30].

Many caregivers described this feeling of being “swallowed” or “consumed” by caregiving. One participant said, “I didn’t realize until Mom’s passing exactly how much her illness had consumed me over almost a decade. I don’t even remember what life was like before

Alzheimer's" [P013]. One wife argued that, without living through this experience, the effect of caregiving could not be truly understood. She wrote: "You may try and may even think you can put yourself in that place and understand all that it involves...but it will fall short of how consuming that role is in your life. It embodies heart, soul, mind and strength" [J019].

Through providing care to a loved one, caregivers set aside their own needs and focused all of their being on caregiving. Being a "caregiver" became part of the identity of these individuals. The former self was devoured by the role required of them. Eventually, sacrificing themselves caused these caregivers to wish for an end to this role.

Stage 3: Yearning for Escape

Sacrificing self to caregiving caused participants to yearn for escape. Categories in the third stage were wondering how long it will last, wishing for death, and waving the white flag. Caregivers grappled with loss without end in sight and wondered how much longer they would need to remain in this role. However, wishing for an end to caregiving was inextricably tied to wishing for the death of a person whom they loved, and this brought harrowing guilt. Caregivers reached a breaking point where they waved the white flag, realizing they could no longer continue to provide care.

Wondering how long it will last.

Prognosis of dementia is difficult to predict and a person can live with dementia for many years. Ambiguity toward the end of life period led to caregivers guessing when the end was near based on constant assessment of loved ones, wondering how long this would last. One participant said, "It is now at the point where I look at her and find myself wondering how long" [J015]. Rather than appreciating this time, caregivers feared what the future might hold if not

death. One daughter said, “I worry about how many more summers there will be” [B022, p. 101].

The end of life brought pain for both the caregiver and the care recipient. The caregiver was forced to bear witness to the suffering of a loved one. As one participant said, “The most difficult part - without question - was seeing her suffer so much toward the end. She seemed to be in such agony, not only physically but emotionally. It was heartbreaking and horrifying to witness” [P013]. Another said, “By the time Mama's life was ending ... I just didn't want her to have to suffer anymore” [P012]. Caregivers watched their loved ones undergo fate worse than death, and wondered how long they would need to suffer.

Caregivers also wondered how much longer their own suffering would last. Participants described seeing “no end in sight,” which took an emotional toll on those trying to get through the ordeal of caregiving. In an unsent letter to her mother, one daughter wrote:

I guess what I resent the most is the longevity of the situation. It's easy to be kind, loving and caring when there's a cutoff date. ... I fear the possibility of years of your existence, staring off into space, and randomly screaming while I change your diapers, sheets and nightgowns, wondering why. [B009, p. 124]

A son realized, “This will be my life as long as he lives” [B006, p. 30].

Some also described challenges of “dealing with a disease of indeterminate length” in financially planning care. Caregivers did not know how to plan for expenditures of care when care may be required for a range from a single year to twenty years. Spouses also worried about using their savings to provide care and leaving themselves with nothing: “At night I worried about money. What would we do if he outlived his long-term care insurance? How could I meet his expenses? ... What would happen to me, if we used up our assets for his care?” [B012, p. 145].

Some worried about when to call family members home and when to take time off from work. Several described feeling like they were “crying wolf” when “false alarms” caused them to prepare for death prematurely. These same participants described extreme guilt when they were disappointed in their loved ones’ recoveries from these “near death experiences.”

Wishing for death.

Many wished for death of a loved one to end the suffering of the loved one. Few caregivers admitted that they wished that their loved ones would die so they could have their lives back, but many implied that they had considered this thought. This brought extreme guilt.

Some considered that a death would benefit both the caregiver and the care recipient, though this was also accompanied by guilt. One daughter said, “I think the major feeling is guilt. My mother had dementia for a long time and there were times when I wished she would die and relieve everyone, including herself, of the slow torture of her fading memory” [P025]. Another daughter wrote, “When my dad is out of his misery and I’m out of mine – watching him in his – I hope I don’t waste too much time feeling guilty for feeling relieved that he is done suffering, and so am I” [J016].

Witnessing suffering of a loved one often motivated caregivers to wish for death. One daughter described a considerable change in her father after moving him to a new care facility:

I just want my Dad to be at peace. I can see fear in his eyes. And I just want it to be over for him. Watching him go through this is killing me. This was the first time that I so strongly wanted my Dad to leave this world. It was all I could think about. It's the only solution. [J018]

Another daughter said of her mother, “This is not living. Please God take her” [B026, p. 52]. In the midst of physical or emotional anguish, death seemed to be the only way out.

Some participants described knowing that their loved one had considered suicide since this diagnosis. Others grappled with hearing their loved one beg for God, or, in some cases, for their caregiver to take them from this world. One daughter wrote, “My dad wants to die. He said so again, last Saturday, when he realized he wasn't going to be able to come home again. He has said so many times: I'll kill myself. Just shoot me. Just kill me.”

When the end of life approached, several participants described an urge to assist their loved ones in expediting the dying process. This thought usually came from feeling complete “helplessness.” One daughter considered, “She will never get well, never again be the person she was. Can nothing I do help? Wouldn't it be merciful simply to end this suffering?” [B011, p. 144]. While watching her mother actively die for weeks, another daughter said, “I was taken by an overwhelming urge to finish this seemingly endless process for her. I had to leave the room so I would not put a pillow over her face” [B017, p. 118]. A son described finding a bottle of his father's pills in the earlier stages of disease that were not medically required, but that his father had intended to use for suicide. The son took them away from his father, but considered giving them to his father at the very end life: “The sight of them comforts me, the way a gun in a drawer might comfort a tormented soul: just to know there's a way out. I'm thinking about it again, thinking I should do this” [B006, p. 231]. Caregivers became desperate for an end to the suffering of a loved one.

Similarly, caregivers considered their own death as a potential way out of their own suffering. One caregiver wondered, “Does the caregiver die first because it's the only way out?” [J009]. She admitted, “Oh, how I long to be out of this [world] sometimes.” Another daughter also confessed, “I was alone in caring for my mother and often felt depressed and even suicidal a time or two knowing that I had no one to turn to with questions or for help” [P017].

Caregivers felt extreme guilt in admitting their defeat. They felt that they “should be able to handle [caregiving],” and their own death seemed easier to face than admitting that they could not be there for a person whom they loved. One daughter explained this strong aversion to asking for help:

I haven't got much more left to give. I can barely drag myself out of bed in the morning.

But I am selfish for asking, how dare I ask, because my MOTHER needs me, my

FATHER needs me, I can't ask for help for myself when they need me. [J002]

Another caregiver described reaching his breaking point one day:

And as I stood there at the sink, washing the dishes, thinking favorably on the option of having a heart attack, it sunk in that I was done. I mean, I'd been standing there, considering that a heart attack might be the best solution to my problems. Yeah, a heart attack. Hell, at 49, I'd probably survive it. It'd come as no surprise to anyone, given the kind of physiological and psychological stress I'm under. No one could blame me for no longer being a care-provider for someone with Alzheimer's. [B027, pp. 136-137]

Sleep deprived, emotionally exhausted, and with no reprieve in sight, caregivers struggled to look for rational solutions to the need for escape. This same caregiver who considered his own heart attack admitted, “I can't continue to do this. ... I don't like to fail at something. I don't like to set aside a job before it is done. But it beats having a heart attack” [B027, p. 137].

Waving the white flag.

When caregivers were able to step back and analyze the situation, many were horrified at their own thinking in considering death as a solution. They did, however, realize that they could no longer continue to give what they were giving and do what they were doing. Wishing for death was a result of total desperation. One caregiver wrote:

You start to become desperate for some kind of solution, some kind of help, some way to get out of this impossible situation. But your patient needs you more than ever, as the disease relentlessly progresses. You're caught in the perpetual crisis. [B028, p. 132].

Caregivers described "waving the white flag" and "throwing in the towel." Many felt "ashamed" to do this, as if they were "giving up" on their loved one or "abandoning" them.

Participants found themselves "questioning my ability to continue" and "not knowing if I can take much more." One daughter said that she had to learn to live "not knowing how much longer, or even if, you can hold out" [B011, p. 151]. Most participants eventually reached a point of "realizing I can't do this anymore." One wife said, "You find that what you are doing is tiring and you can't keep it up" [P040]. A daughter described a discussion with her husband, confirming, "We can't live like this anymore" [B018, p. 573]. Another daughter said, "[My husband] and I reevaluated our situation and realized had something had to give" [J015]. One daughter summarized her experience, saying, "I am drowning, I am choking, I am lost" [J002].

When caregivers reached their breaking point, they felt overwhelming "shame" and "guilt." Caregivers described reconsidering the reasons that they pushed themselves for so long to be where they were, and many were not comfortable putting their own health, wellbeing, or happiness above the health, wellbeing, or happiness of the care recipient. They discussed how they "should be" as caregivers, but felt that they simply could not live up to these expectations. Participants described emotional trauma in "letting down" loved ones and "accepting failure" as caregivers. As one daughter said, "Aiming for perfection is easy, really. Accepting imperfection, I've discovered, is a much tougher proposition" [B029, p. 158].

In this stage, caregivers faced the consequences of a total sacrifice of themselves to care and yearned for escape from this role. They wondered how much longer they would need to provide care, and at times some even wished for death of their loved one or themselves as a

means to end the suffering. Caregivers gave in to the fact that they could no longer continue and admitted that something had to change. In the next stage, caregivers began to strategize in reclaiming their own identities.

Stage 4: Reclaiming Identity

After caregivers reached the point of needing escape, they strategized to reclaim their own identities. This stage included categories of adjusting expectations, asking for help, seeking respite, and reestablishing relationships. Participants could not walk away from their roles as caregivers, as they were still irreplaceable and felt responsible for care. However, they did find ways to sustain themselves and to become individuals again outside of caregiving. In this way, they relieved themselves of feeling trapped in this role through adjusting their own expectations of themselves, asking for help from others, seeking respite, and reestablishing previous relationships.

Adjusting expectations.

Many caregivers had high expectations of themselves for providing care to loved ones prior to reaching a breaking point. For example, many believed that they should be the only ones providing physical tasks of care, that they should not burden other family members with requests for help, or that their loved one could only be cared for at home. It was not until these caregivers felt completely “physically and emotionally drained” that they accepted that they could not live up to these self-inflicted requirements.

Participants used terms “accepting,” “adapting,” and “adjusting.” One daughter said, “I’ve had to let go of some of my caregiving ideals” [J006]. A son-in-law had described a similar experience:

I am constantly at risk of falling into the trap that I should be doing more, should be stronger. ... That is a dangerous path. So, I do what I can, when I can, and try to cut myself some slack the rest of the time. [B027, p. 121]

One daughter recognized the importance of “losing my internal critics” [B017, p. 112]. A son advised future caregivers, “Try to be easy on yourself. ... Remember that you’re not supposed to get everything right” [B030, p. 269]. Another daughter wrote, “I’m relaxed into the reality that nothing I do will ever feel exactly right or perfect, but I can at least be kind to myself and real and go with the flow, wherever it takes me” [J006].

Caregivers in this stage focused on “forgiving myself,” “going easy on myself,” and “being gentle with myself.” Realizing the seriousness of his own despair in caregiving, one participant wrote, “It needs some tending – awareness, being a little more lenient with myself, a little more indulgent. ... Be as gentle with myself as I am with [my mother-in-law], at least for a while” [B027, p. 253].

Participants began to recognize self-care as essential to their survival as caregivers. One participant wrote that caregivers need to develop “patience and compassion towards ourselves” to survive [B023, p. 208]. Another reiterated this point, saying, “The only way I’ll get through this, I realized, is to go a little easy on myself [B029, p. 87]. Caregivers realized that they could not help loved ones if they did not regain personal strength. One caregiver said:

If you are to be effective as a caregiver, you then have to catch your breath, forgive yourself, and get on with the task at hand. None of us are saints. We’re all frail, fallible human beings. You have to accept that, if you have any hope of getting through this.
[B028, p. 144]

Caregivers had to change the demands they placed on themselves in order to reach out and ask for help.

Asking for help.

By changing their expectations for themselves, caregivers allowed themselves to ask for help from others. For many, asking for help was synonymous with failing to do it themselves. As one caregiver said, “I’ll just have to leave my ego in the wings and do it” [B023, p. 156]. Many could not accept help until they adjusted their own attitudes towards their role.

Accepting help was further challenging for caregivers who had been doing everything themselves for a long time. Participants described the challenges of “letting others in” to the intimate and private caregiving relationship. One daughter said, “My biggest challenge was letting go. ... I had to allow others to do what only I had done for Mom for a year” [P010]. Another said, “It was difficult for me to relinquish 'control' to someone else as I was always my mother's support, but I got better at enlisting other's help as the time wore on” [P026]. Several described that they needed to “learn how to ask for help.” One daughter said, “Asking for help is a skill? Apparently it is, and one that I am not very skilled in, yet!” [J011]. Many participants advised that future caregivers learn to ask for and accept help.

Some described the difficulty of “trusting others to provide good care.” One daughter said, “I had to let go and hope they would take good care of her” [B009, p. 80]. This also meant accepting that others may not provide care in the same way that caregivers did. One daughter explained, “You have to give up and let go and let someone else fill your shoes for awhile, even if they don't fill them like you think they should!” [J011].

Once participants accepted a need for change or help, however, many struggled to find it. Participants described rejection from hospice care, facilities refusing to take loved ones with behavioral symptoms, and ineligibility from services due to symptoms or, in some cases, young age. One daughter wrote of being denied hospice care:

I don't blame them, it's not hospice's fault, but why offer help only at the end? If she had had cancer or some other painful disease, I could have had help months ago. What asinine rule says that Alzheimer's families are better off and can manage any better than cancer families? [B009, p. 140]

Another daughter said:

Dementia offers many surprises to those who have it and to their families. One of the biggest ones, as far as I am concerned, is the sudden realization that even the most excellent standard health insurance doesn't cover care for people who need help because they were suffering from dementia. [B015, p. 120].

Cost was also an insurmountable barrier for many. One daughter sought to have her mother placed in a facility and said, "I basically spent a week fooling myself, thinking that I could find Mother decent care without bankrupting us" [B009, p. 132].

Caregivers exhausted their options and many were left feeling like they were on their own. One daughter admitted, "I've done all that I know to do. It feels like it's time to let go, but I don't know where to turn" [B009, p. 132]. Another daughter said, "I look at the craziness of my life and I realize that some how something must change but I cannot see how" [J015]. One daughter tried to bring in home health aides but found that the only individuals she could afford to hire were "incompetent" in dealing with dementia. She described a vicious cycle of not being able to work because she needed to provide 24-hour care, and not being able to afford help because she could not work. She said, "There was quite simply no help for me as I was caring for my mother" [P017].

Many participants were disappointed with the care they did receive. Caregivers knew that no cure was available to their loved ones, and they did not expect miracles from health care workers. They did, however, expect respect, understanding, and support, and many did not

receive it. A daughter of a physician said, “If doctors, nurses and aides remember that warmth and listening are essential to quality care – even if they cannot cure – perhaps my faith in my dad’s profession will be restored” [B012, p. 158]. One daughter wrote about what she wanted from health care providers after a disappointing visit from a hospice nurse:

You know what I want? Here’s what I want- for future reference: *I want you to tell me I’m doing the right thing. I want you to say ‘I’m so, so sorry,’ then be quiet for a minute. I want you to have the time to come here, and sit with me, and help me do things I don’t feel comfortable doing alone or asking my family to do. I want you to not be in a hurry. I want you to figure out if I need a hug or a cup of hot tea, or if I need you to tell me to go take a hot bath. I want you to just be here until I don’t need you to be here anymore. I want you to not ask ridiculous questions and act like some yuppie psychologist who just got her degree last week and knows the right buzz words to get people to respond properly. I want you to have the common sense, the compassion and gentleness that ought to be instinctual, not only to a woman, a nurse, and a daughter but most of all, a hospice caregiver for God’s sake! That’s what I want from you.* [B009, pp. 156-157].

Participants learned to “take what I can get” from their support systems, and most learned to rely primarily on informal supports.

Seeking respite.

If caregivers were able to find help, this gave them an opportunity to step back from caregiving and find time for themselves. Participants used respite time away to “recharge” and “prevent burnout.” After spending 2 days away from her husband, one participant said, “Honestly, those two days probably bought me another month of endurance” [J004]. A granddaughter said, “That time to recharge, regain perspective on the world and just breathe is important to keep up the strength to continue the work” [P009].

This time was essential for caregivers to maintain patience and love towards care recipients. As one participant said, “There are many, many times while caretaking I would find myself becoming very impatient. ... That is why it is so important to walk away and take time for you” [B019, p. 45].

Others described extreme examples of losing their patience with a loved one. During participant observation of the spousal support group, one husband who lost his wife several years ago shared a story of becoming frustrated with her during a road trip. He reported that her personality had changed and she had “turned on me.” After spending all day in a car with her, when they arrived in their hotel room and she continued her attacks on him, he described grabbing her by the neck and pinning her against the bed, yelling at her to stop. He told the story with extreme sadness, guilt, and regret, but said that he was sharing his story to show others the importance of stepping back and making time for self before reaching the point of lashing out at a loved one.

Besides allowing them to continue to provide care, respite time allowed participants to reconnect with who they were before caregiving. A son described leaving his father for a short time, saying, “What I really needed was to be held, to laugh and tell stories, and to know I still fit into my old life” [B006, p. 158]. Some participants spent time away catching up with other family members and friends, or simply catching up on errands and tasks to maintain their own homes. Others expressed the importance of doing something solely for themselves when they were away.

In all cases, caregivers carefully chose how to spend their respite time to get the most out of their limited time away from the care recipient. One participant said, “Be mindful of what you do with your free time. Do something only for you. THIS IS VITAL!” [P010]. Another caregiver discussed “squeezing the most out of me minutes” [J011]. Caregivers found respite in

coping activities such as writing and journaling, deep breathing, exercising and going for walks, joining support groups, praying, through music, and venting to friends. Through these activities, participants experienced “emotional release,” “expressed [themselves],” and restored hobbies from their lives before caregiving.

Reestablishing relationships

Caregivers spent time away from the care recipient reinstating sense of self through alone time or time with other family members. When they were with loved ones again, this critical respite time allowed participants to step back from the responsibilities of caregiving to redevelop bonds outside of the caregiver and care recipient relationship.

Participants in this stage found a way to “intertwine” roles of caregiver and loved one rather than choosing between them. One wife said, “The things I did as his caregiver were, to me, an extension of my role as wife” [P042]. Another said, “I liked the idea that I could still be his wife and not only his caregiver” [P024]. One son described reminding himself of the relationship that he had with his mother before caregiving. He said, “*This is my mother, I reminded myself. Gone is her laugh, gone are her devilish ways, gone is her swagger, but this is my mother. This is my mother*” [B030, p. 247].

Finding appropriate help allowed caregivers to give up some of the tasks of caregiving so that they could focus on the loving relationship rather than the responsible relationship. As one participant said, “At a time like this, being a daughter, son, or spouse is one’s primary role. It’s important to recognize this and to get all the help that is available” [B001, p. 20]. Another made a choice to get help so that she could enjoy more time with her husband. She said, “I knew that I wanted to spend more time as his wife so I called in the help I needed” [P040]. Another wife placed her husband in a nursing home and experienced an unexpected renewal of love from this

change, saying, “I was lucky enough to find a wonderful place that took care of the practicalities so that I could concentrate on just being his wife and being with him” [P018].

When caregivers spent quality time with loved ones, many described finding new relationships that were wonderful and fulfilling. One caregiver advised, “You will be given an opportunity to know your loved one in a way you never imagined. Embrace that!” [P010]. Another said of her experience caring for her mother, “I am grateful for getting to know my mother in a way I could never have possibly known her before” [P037].

Participants described finding old pieces of their loved ones that still remained that they had overlooked while being swallowed up by caregiving. One caregiver described an especially emotional day in which her mother was crying for her own mother. The caregiver wrote, “I WANTED MY MOTHER. I decided it might cheer me up to list a few of the special qualities she exhibited over the years.” After including a long list of her mother’s traits, she divided the list into three groups and said, “I realized that I still have a lot of the mother I was describing. Some of the qualities she still has herself. ... Some of the qualities reside in my brother. ... And some I have inherited.” [B015, p. 96]. She described feeling better knowing that not all of her mother was gone.

Others discovered new pieces of their loved ones. After placing her husband in a facility, one caregiver said, “Looking back, I realize that this is the time we’d finally accepted the behaviors associated with the disease. We were truly beginning to know ‘New [him]’ at another level, and our love grew even stronger.” [B016, p. 65]. Another participant said, “Gradually my need and desire for my ‘old [him]’ began melting away as I realized that I could bring joy to my ‘new [him]’” [B032, p. 195].

Caregivers were able to rebuild relationships that had been lost during the overwhelming period of focusing on caregiving. One daughter realized, “I began by writing about what I was

losing. Somewhere along the line I started writing about what I was finding” [B015, p. 197].

Parts of the care recipient had changed and could not be restored, but this did not prevent caregivers from finding a way to establish new relationships with their loved ones. One daughter admitted, “Only months ago, I thought [losing her in pieces] was awful, tragic. But now I am beginning to believe there is new possibility even in the midst of loss. In forgetting, we are offered an opportunity to forgive” [B029, p. 130].

Participants in this stage were able to reclaim their own identities by changing their expectations of themselves, getting help, finding respite, and reestablishing relationships with loved ones. They found themselves again. By using these strategies, caregivers were able to find joy and purpose in their role as caregiver.

Stage 5: Finding Joy

As a consequence of reclaiming themselves, caregivers were able to rediscover their loved ones and to find true joy in their roles. Categories in this stage included living in the moment, entering into his world, and falling in love. They were able to shift their focus from providing care to providing joy, and in doing so, found joy. One participant said, “I felt joy that I’d brought him so much joy” [B032, p. 189], and another said, “We focus on life’s joys as much as we can and in doing so somehow create joy” [B015, p. 182]. Joy was felt through being present in the moment, entering into the world of the loved one, and ultimately falling in love with the care recipient all over again.

Living in the moment.

Participants describe making a choice to “be present” in each moment with their loved ones. One caregiver described:

I’ve learned to live life with my mother her way, moment to moment. Of course, I still think and plan as best as I can for her future – and I feel compelled, still, to worry over it,

especially late at night. But when I am with my mother, it's like I am with the music. I am there, present and attuned. Mindful of the moment now, and yet mindless as the moment, passing, becomes past. [B029, p. 187]

Other participants also described learning this skill from the care recipient. A daughter explained, "Forced by my mother's pace to slow down, required by her needs to be focused on the moment, I grasped that being fully with her was more important than the end goal" [B017, pp. 25-26].

"Living in the moment" allowed caregivers to focus on life, rather than death, even at the end of life. One caregiver reported "opening [her] eyes" and "focusing on his remaining life rather than his impending death" [B032, p. 204]. Another summarized her experience with the following quote by Ida Scott Taylor:

One day at a time... this is enough. Do not look back and grieve over the past, for it is gone; and do not be troubled about the future, for it has not yet come. Live in the present, and make it so beautiful that it will be worth remembering. [J013]

Several described trying to make the present "beautiful" for a loved one. A daughter said, "I can string [moments] together into memory, and she cannot. But what I believe – what I have to believe – is that the quality of the moment matters, if only in that moment" [B029, p. 187].

Living in the present allowed participants to shift their goals towards finding joy in life. One daughter described her transformation: "My mind was always outside of the moment – tallying what needed to be done, rehashing history, inventing conflicts – never fully present with what was in front of me. I lost years to this fog of past and future" [B017, p. 25]. She later wrote, "I now measure success by my degree of awareness in the present moment. Achieving goals is secondary. The purpose of my life is simply the living of it" [B017, p. 26].

Living in the moment also included “dancing in the moment” [P043]. Participants reported using music to find joy with their loved one. In appreciating the present time, caregivers were able to “sit back and enjoy the music” [P045] in ways that they could not before. They used analogies to refer to singing or dancing, and also reported physically singing and dancing with loved ones, who were often able to respond to music when they could no longer respond in other ways. When listening to music with her life partner, one participant wrote, “His eyes sparkled, his whole face beamed, he sat up straight, and moved in time with the music. It was a joy to see him come to life like that” [B032, p. 228].

Similarly, laughter became a means of finding joy in the present. Many participants described “living and laughing in the moment” [P043]. Caregivers reported finding humor wherever they could. One participant said, “[Laughter] invariably made our burdens lighter and brought us together” [B015, p. 9]. During participant observation, one caregiver laughed at almost everything his wife said, though her speech was garbled and he admitted he could not understand her most of the time. She usually laughed when he laughed, and we spent most of our visit laughing together. He said to me, “I try to laugh as much as I possibly can every day.” Participants frequently mentioned humor and laughter together as a means of holding themselves in the moment and of finding joy. As one participant said, “As Alzheimer's descended into his life, we kept laughing, we kept dancing, we kept singing” [J018].

Entering into his world.

Participants also learned to enter into the world of the care recipient as a means of finding joy. Caregivers learned to stop yelling, stop correcting, and stop rationalizing. Instead, they “relaxed into [his/her] world.” One participant advised, “Enter into their world and you will be happier - if they say it's August and it's really December don't try to correct them. If they say they haven't eaten and they just ate give them a snack” [P024]. Another said, “We’ve now

decided to let [her] have her own little world, and accept that we're just visitors to it" [B027, p. 119].

In choosing not to argue, participants described "creating peace." One son said, "The important thing to remember is that if you live with the person in their reality, there can be much more harmony and connection" [B030, p. 284]. A daughter learned to use her mother's own strategy to grapple with her mother's forgetfulness of the dedicated care that she provided. She said, "I no longer feel the need to prod my mother's memory, to remind her, to prove that I am a dutiful daughter" [B029, p. 187].

Participants learned to take on the care recipients' perception of truth. One said, "I learned that reality was a relative term" [B017, p. 97]. Some caregivers even admitted to preferring this alternate reality, as it allowed them to "reprioritize." One daughter said, "I began to see life through her eyes, and to look for what was truly important" [B002, p. 102].

Similarly, caregivers learned to let go of frustrations towards care recipients and find comfort when they were able to put themselves in their loved ones' worlds. A daughter described her mother's habit of repeating phrases and questions. She said, "The cycle of repetition has the capacity to make me crazy – and often it does. But I've discovered recently that when I relax into it – cycle and recycle – repeat, respond, repeat – I understand there is comfort in the repetition" [B029, p. 153].

Participants also chose to "go with the flow." A daughter explained, "I live in time differently than I used to, floating along rather than swimming against the current" [B011, p. 151]. Another said she learned to "ride the waves of dementia" [J006]. In the face of an unpredictable future, caregivers were able to find joy when they could "relax a little with the unknown" [B017, p. 113].

Falling in love.

Through the process of rediscovering, the caregiver finds joy that truly rests in falling in love with the care recipient again. Some participants in this study clarified that they had “never stopped loving” care recipients, but they were not “in love” with them when caregiving took over as the priority. Adult-child and spousal caregivers alike found that, in this final stage, they rediscovered true love.

Caregivers focusing on “finding activities we could do together,” such as coloring, doing puzzles, reading books, listening to music, or just sitting together in a garden. When care recipients could not participate in activities, caregivers “relied on touch.” Participants described holding hands, giving massages, lying together, hugging, and kissing. Time was devoted to being together, not just to tasks of caregiving.

Caregivers also focused on ways to bring joy to their loved ones. One daughter said, “I felt an intense need to help Mother touch, smell, or hold everything she had loved. It became my mission to bring happiness to her life, and to make her remaining days meaningful” [B002, p. 102]. Another said, “I always told Mom that I was going to do my best to make sure her second childhood was better than her first one. And it was through this time of connecting, holding, talking, reading, and tucking in that I did my best during each day to keep that promise to Mom” [B005, p. 127].

Participants formed deep connections with their loved ones through the process of caregiving and created new bonds in their relationships. One daughter said, “I have come to care for my mother’s body and mind – and in this way have forged a connection soul to soul” [B029, p. 128]. Another daughter described:

[My sister] and I became closer to Dad than we had ever been and our love for each other grew stronger. As Alzheimer's descended into his life, we kept laughing, we kept dancing, we kept singing. We cried too, but got back up. Dad gave us a purpose. [J018]

These connections led to deeper love and understanding. Another daughter described a similar dance that led to her discovering her “new” mother and falling in love:

We became two people in a dance of spirit that included pain, grief, laughter, wonder, frustration, wisdom, and love. My concept of her was annihilated, and in its place I discovered a funny, sharp-witted, sensitive, grateful and loving woman who bore her grief and her trials with great patience and acceptance. She became my hero, my teacher, my model. And in that dance I fell in love with my mother. [B017, p. 86]

A son caregiving for his father wrote, “So far it’s been no different from raising my son: the more I take care of him, the more I love him” [B006, p. 7].

It became important to caregivers that care recipients knew that they were loved. One daughter said, “I made sure Mom knew that I wanted to do this and that I was happy to do it and that I loved her unconditionally. Because I was and I did. And I do” [B005, p. 105]. One daughter explained that her mother no longer knew who she was, but that this was unimportant to her now. She said:

I don’t let this bother me because there isn’t much I can do about it. I figure it’s my job to love her the way she is now rather than to pursue the thankless task of trying to make her revert to the way she used to be. [B015, p. 130]

In this final stage of rediscovering, caregivers were able to find love and happiness in their roles as caregivers. They found joy through living in the moment, entering into the world of dementia, and falling in love all over again. Finding joy in caregiving allowed caregivers to see their role as a blessing. One daughter concluded, “In short, a burden was transformed into a privilege” [B015, p. 197].

Process Variation

Individual experiences of caregivers varied greatly as they underwent the process of rediscovering. A majority of caregivers experienced each stage of this process in the order described. However, it must be stated that each experience was unique, and not all participants were able to complete the process through to stage five. Many participants described going through some of the stages and not others, and some described repeating these stages multiple times. This section will describe some of the patterns of variation in this process among this sample.

Many participants experienced the first three stages of this process but were never able to reclaim their own identities or to find joy in their roles. They felt trapped and wished for escape until their loved ones died and relieved them both of suffering. Adult-children who described this experience were typically providing care alone, without familial support. They usually described an upheaval of their entire lives, more often occurring when they cared for a loved one in a home-care setting. Spousal caregivers who described this experience felt as though they had fallen out of love with the care recipient because the person whom they loved had completely disappeared. These spouses tended to use nursing home care as an attempt at escape, though this did not relieve them of feeling bound to the care recipient. Both adult-child and spousal caregivers in these cases were riddled with guilt for feeling bound to a loved one purely out of obligation. They described feeling “burdened,” “depressed,” and “abused” by their experiences.

Other participants described experiencing all of the stages described except for stage three, which was yearning for escape. These caregivers claimed that they never wished for the caregiving to end. They did feel irreplaceable in their role and felt bound to a loved one, but they never felt “trapped.” One participant in participant observation explained, “I am not trapped. But I would never say that this role is voluntary!” Even without feeling trapped, these caregivers faced a problem of role entrapment as they struggled with exhaustion and grief to be

the “point person” and “everything to [a loved one].” They did sacrifice themselves to care, as in stage two of the process, but they were able to reclaim identity, as in stage four of the process, without ever reaching the stage three “breaking point.” Participants that described this experience tended to begin care with a lot of informal support. These participants described taking breaks and finding respite from the start of providing care, as they often had family and friends in place to help make this possible.

Still other participants described experiencing this process as a repeating cycle with each worsening phase of dementia. One participant said, “I would add that there are many 'breaking points' at different stages along the way. Just when you have got used to one set of symptoms/behaviors, another new set comes along” [P047]. Participants would rediscover the care recipient, find joy, and would then begin mourning the past all over again when their loved one “regressed” further into dementia. These participants would need to begin the process over again, once again rediscovering their loved one to move past a longing for escape and again find joy.

Though no two experiences were the same, this five-stage process of rediscovering captured the majority of experiences from this sample. Patterns of variation in this process within the sample can be summarized above. All participants who described themselves as being the primary caregiver experienced a concern with believing themselves to be uniquely essential to the care and wellbeing of their loved one. In this way, the basic social problem of role entrapment was ubiquitous.

Summary

Through constant comparative analysis of data from in-person and online interviews, participant observation, and caregiver memoirs in books and blogs, a substantive theory of rediscovery emerged. Caregivers used the process of rediscovery to cope with the basic social

psychological problem of role entrapment. In this process, missing the past became a context to caregivers sacrificing themselves to care. This loss of self caused a yearning for escape.

Caregivers strategized to escape by reclaiming their identities, and as a result were able to find joy in their roles. The irreplaceable role of caregiver could not be transferred or removed, but through rediscovery, caregivers could move from feeling trapped in this role to feeling honored to be in this role. In the next chapter, I will discuss how this theory relates to current literature and other theories. I will also discuss strengths and limitations of this study and implications for nursing practice.

CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS

Chapter 4 discussed the emergence of the theory of rediscovering from data. In this chapter, I will summarize how that theory fits into the context of current literature. This chapter will also discuss the implications of this theory for nursing practice, strengths and limitations of this study, and recommendations for future research. I will also discuss the benefits to participating in this study for caregivers.

Summary of Findings

A substantive theory of rediscovering emerged from analysis of in-person interviews, online interviews, books, blogs, and participant observation of caregivers of individuals with dementia at the end of life in this grounded theory study. Participants described a basic social psychological problem of role entrapment, in which they believed that they played an irreplaceable part in the care of a loved one and were bound to their loved one by the unique attributes that they held in this role. To overcome feeling trapped in this role, participants began a five-phase process of rediscovering their loved ones, their relationships with their loved ones, and themselves. In this process, they missed the past, sacrificed themselves to care, yearned for escape, reclaimed their own identities, and ultimately found joy in their roles.

Discussion of Findings

As the theory of rediscovering emerged from the data, previous literature and theories were analyzed as data using the constant comparative method. Reviewing the literature after the majority of analysis had taken place helped ensure that findings did not reflect “pet codes,” or ideas that were preconceived and forced into the data. In general, other qualitative studies capture single stages within the process of rediscovering. These studies shed light on experiences of caregivers in each of these stages. The current study provides a broader picture of

these stages within the process of rediscovering. In this section, findings will be discussed in the context of previous studies in this area.

Role Entrapment

“Entrapment” is a psychological term with roots in the biological concept of fight versus flight response in animals (Taylor, Gooding, Wood, & Tarrier, 2011). Gilbert and Gilbert (2003) describe entrapment as an arrested flight response. They explain that “a person may be highly motivated to get away from their current situation (aroused flight motivation) but is not able to” (p. 174). Entrapment may be internal, such as feeling trapped in one’s own thoughts, or external, such as feeling trapped in one’s circumstances (Gilbert & Allan, 1998). Entrapment is usually caused by a prolonged stress that is perceived to be uncontrollable and inescapable (Taylor et al., 2011). Gilbert and Allan (1998) developed an instrument to measure entrapment. According to this scale, external entrapment is based on such feelings as feeling trapped, feeling like one can’t get out, wanting to escape, and feeling powerless in a situation or relationship.

The term “role entrapment” has been used in sociology to describe the feelings of individuals who are trapped in a role by a group in power or by society at large. This construct is frequently used in literature on gender roles in society. In the case of this study, role entrapment does not necessarily refer to a position imposed on individuals by others. As discussed in Chapter 4, caregivers experience a range of motivating factors that hold them in the position of caregiver. For the purposes of this study, “role entrapment” refers to an external entrapment in the situational role of caregiver.

Within current research on caregiving in dementia, one descriptive quantitative study explored the construct of “entrapment” among caregivers. Martin, Gilbert, McEwan, and Irons (2006) measured entrapment using the scale developed by Gilbert and Allan (1998) and measured depression, guilt, and shame among 70 caregivers of individuals with dementia in

England. Entrapment was correlated to depression ($r = 0.602$, $p = 0.001$) and to shame ($r = 0.344$, $p = 0.01$) but not to guilt.

Previous qualitative studies also reference feelings that reflect role entrapment of caregivers but do not use this term. Landmark et al. (2013) conducted a content analysis of focus group interviews in Norway and identified the following three categories: “To be stuck in it – I can’t just leave”; “it assaults one’s dignity”; and “sense of powerlessness in relation to the fragmentation of relationships in home health care” (2013). Feeling stuck and powerless both reflect concepts within the construct of entrapment.

Other studies reflect a perception among caregivers that they are expected by societal standards to become caregivers out of duty. In a grounded theory study, Lin et al. (2012) described that caregivers felt a responsibility and duty to care, uncovering the sentiment, “It is what I do.” Lee and Smith (2012) reported similar findings in a qualitative study of Korean American caregivers using elements of phenomenology, case study, and grounded theory, finding that adult children are motivated by obligation and duty. Though not measured in these qualitative studies, caregivers who acted out of social obligation would likely report high levels of role entrapment.

Among caregivers in the current study, besides duty and obligation, participants reported feeling trapped by the feeling that only they could provide or ensure good quality of care for their loved ones. The belief that quality of care depends on the presence of a family caregiver is consistent with previous studies (Benedetti et al., 2013; Mullin et al., 2011; Phillipson et al., 2013; Shanley et al., 2011). Role entrapment emerged as the basic social psychological problem in this grounded theory study, and elements of entrapment imposed by society or self can be found in previous quantitative and qualitative studies of this population.

Rediscovering

Prior studies also reinforce the idea that caregivers resolve the problem of role entrapment through rediscovering. Individual stages of this process can be identified throughout the literature. This section will discuss how each stage of this process relates to previous research in this field.

The concept of “missing the past” is a repeated issue among caregivers. Many qualitative studies describe the experience of losing a loved one to dementia and losing a relationship with that loved one before losing them to death (O’Shaughnessy et al., 2010; Oyebode, Bradley, & Allen, 2012; Pastor & Vogel, 2011; Shanley et al., 2011). Losing the person and aching for companionship due to a lost relationship with the care recipient both emerged as categories within stage one of the process of rediscovering. Navab et al.’s (2012) phenomenological study of Iranian caregivers described a sense that caregivers were captured in time, reminiscing about the past and fearing the future. Looking back led to sadness and regret over what was lost and what may have been done to prevent the progression of the disease.

“Sacrificing self” is also a commonly described phenomenon among this population. Spousal caregivers in Pastor and Vogel’s (2011) grounded theory study reported feeling “eclipsed” by the care recipient, feeling that their own needs were being overshadowed and that they lost themselves. Massimo, Evans, and Benner (2013) report using interpretive phenomenology to explore the experiences of two spouses of individuals with frontotemporal dementia. Though this study was limited by a small sample size, findings reiterate the experience of changing not only roles, but also identities through the caregiving experience. Participants described “becoming caregivers” instead of wives. This same category was derived within the second stage of rediscovering.

In an interpretative phenomenological study, Mullin et al. (2011) found similar themes in their analysis, including unstable self-identity of spouses as they struggled to maintain their roles

as family members versus caregivers. Both adult children and spousal caregivers reported needing to take on a parental role toward a loved one with dementia in a qualitative content analysis by Simpson and Acton (2013). These studies echo the voices of participants in this grounded theory study.

Other studies repeated categories that emerged during the stage of “yearning for escape.” Caregivers in another grounded theory study expressed the challenges of having no end point except through death (Pastor & Vogel, 2011), and one narrative study revealed a theme of participants wishing for the death of a loved one (Hennings et al., 2013). O’Dwyer, Moyle, Zimmer-Gembeck, et al. (2013) reported that over a quarter of caregivers had considered suicide more than once in the past year. As in this current study, caregivers tended to consider suicide due to a need for emotional and financial reprieve (O’Dwyer, Moyle, & van Wyk, 2013).

The fourth stage of “reclaiming identity” can also be found in previous studies. Though few studies discussed recovering self-identity, many discussed retaining or discovering a relationship with a loved one with dementia, which aligns with the category of “reestablishing relationships.” At this point, most studies depict a divide among caregivers who view a negative relationship that is changed from the past, or a positive relationship that is retained from the past or is discovered. No studies capture the entire process, as outlined in this substantive theory, in which caregivers mourn the loss of a relationship and then reclaim a relationship later in the caregiving experience.

Flynn and Mulcahy (2013) discussed changes in relationships as an emerging theme in their descriptive qualitative study of seven caregivers of family members with early onset dementia in Ireland. Most caregivers in this study described a negative relationship change, in which one family member became dependent on the other and the partnership between them disappeared. As in the current study, though, others spoke of developing a new and different

relationship through this experience. Participants in Sanders and Power's (2009) phenomenological study described finding new ways to be "close and intimate" with their partners as the old relationship morphed into new one in the presence of dementia.

Botsford et al. (2012) conducted a constructivist grounded theory and uncovered a central process of "redefining relationships." Closeness of the bond and expectations of the relationship changed and developed with disease progression. Caregivers went through phases of recognizing, in which they found meaning in their new relationships, reacting, in which they dealt with behavioral changes, and adjusting, in which they reallocated tasks and found new ways to relate to the care recipient. Besides "reestablishing relationships," this study reiterates the category of "adjusting expectations."

In a constructivist grounded theory study, Molyneux et al. (2011) discussed a shift in the co-constructed identity of the couple among persons with dementia and their spouses. Participants attempted to "sustain couplehood" through maintaining the relationship they had prior to dementia and role sharing. In the current study, caregivers reported that they were unable to sustain previous relationships, and emphasized acceptance of new relationships over sustaining old ones. This difference may be due to the severity of dementia at the time of interview of the caregiver. It may be that, at the end of life, acceptance of change must replace sustainment as a priority.

The final stage in the process of rediscovery, "finding joy," is the least studied construct from this process. This may be because not all caregivers reach this stage, or it may be that this stage is more pronounced at the end of life. Shim, Barroso, and Davis (2012) conducted a qualitative content analysis of interviews of spousal caregivers of individuals with dementia. In this study, researchers examined differences between participants who described their overall caregiving experience as negative, ambivalent, and positive. Those who described a negative

experience focused on the loss of a relationship and on their own unmet needs, whereas those who described a positive experience were able to focus on what they still had. Caregivers rating the experience positively maintained a positive relationship with their loved one, finding positive experiences in moments of lucidity or in showing their own love rather than expecting something in return from the care recipient. Shim et al.'s study differs from the current study in that participants in the current study discovered new versions of self, relationship, and loved one. These new versions may have held pieces of their former versions, but retaining what had been before was not possible. Shim et al. describe holding onto something old, which may not be possible at the end of life.

This study introduces the basic social psychological problem of role entrapment, in which caregivers feel that they are unable to escape their role. They feel irreplaceably bound to their loved one due to the unique attributes that they have to offer. They feel tied to their loved one based on their own expectations for themselves as well as their perceptions of expectations of loved ones, other family members, and society. To resolve this problem, this study reveals the five stages of rediscovering, which are missing the past, sacrificing self, yearning for escape, reclaiming identity, and finding joy. Each stage in the process of rediscovering has been explored before, but never in the context of the whole picture. This current study adds to existing literature by highlighting how these pieces fit together to create the experience as a whole. This study also fills a unique niche in describing the end of life process, which has been previously unstudied qualitatively.

Implications for Nursing Practice

Understanding the problem of role entrapment and the process of rediscovering will provide nurses with insight and tools to help caregivers of individuals with dementia find joy and provide joy to loved ones at the end of life. Nurses can use this process to view the caregiver as

a patient, to recognize when caregivers reach different stages in this process, and to guide them through these stages as they are reached. This process provides insights into the specific needs of this population when they are in each stage. It also supports the need for a system change to improve accessibility and quality of palliative care earlier on in the dementia process. This section will discuss these implications for nursing practice.

First and foremost, this study reiterates many studies before it in the critical necessity of viewing the caregiver of an individual with dementia as a patient. Caregivers experience enormous physical and emotional burden, and their needs must be addressed to avoid the long-lasting impact of this burden on the caregiver or care recipient's health and wellbeing. One caregiver said, "The family involved is also a patient. They just don't get the spotlight, the monitoring of doctors, the strong medications and the cooked meals. Dad is just a piece of this large network of misery" [B022, p. 55]. As dementia advances, the needs of the caregiver grow. One participant in this study reported, "The early stages of Alzheimer's are hardest, I believe, on the person suffering from it. The later stages are hardest on the family" [B001, p. 18]. Nurses must understand that they need to care for both the person with dementia and, just as importantly, the caregiver of that person.

To properly care for the caregiver, nurses would benefit from being able to recognize where the caregiver is in the process of rediscovering. Many caregivers reported that they did not feel prepared for what was coming next. One caregiver said, "No one warns you enough about the emotional toll it takes to be the caregiver for a relative/friend" [P009], and another said "I had no idea what I was getting into. ... I didn't expect it to be easy but it was worlds more difficult than I could ever imagine" [P007]. By realizing their current stage, nurses could help caregivers prepare for the challenges they will likely encounter as they enter new stages of this process.

Recognizing the caregiver's current stage would also allow nurses to validate the feelings that the caregiver expresses and help caregivers anticipate what they may experience next. For example, caregivers who are sacrificing themselves completely to care should be warned that they might soon wish for escape from this role. Nurses may tell them that it would be normal for them to wonder how long this would last or even to wish for that their loved one would die to end the suffering. By acknowledging these feelings up front, nurses may help alleviate shame and guilt that often accompany these thoughts. Nurses should also know that caregivers in all stages are at risk for depression and suicide. Particularly in stage three, caregivers should be assessed for suicidal ideation.

Nurses may also realize that caregivers in the first three stages of rediscovering may not be ready to ask for or accept help. At this point, nurses must recognize the caregiver as the "expert" on their loved one and offer support in this role. They should offer information about the disease process and should make caregivers aware of the resources available to them. It is essential that nurses provide caregivers with information on respite opportunities and coping skills, as well as information on what to do in case of emergency. Caregivers can quickly reach a point of desperation, and it is essential that they are prepared with information on where to turn if they need immediate escape from their situation without risking the safety of the care recipient.

It is also important for nurses to be careful of the implicit expectations that they place on caregivers. Many caregivers feel trapped by expectations that they will care for a loved one independently and will provide care at home. Though these expectations are often self-imposed, previous studies indicate that caregivers may feel that these expectations are imposed on them by health care providers (Benedetti et al., 2013; Robinson et al., 2012). Nurses should make an effort to help caregivers reverse these expectations so that caregivers can reclaim their own identities in stage four.

The nurse must also realize how fragile the caregiver may be from the experience of caregiving and must understand when caregivers become angry, defensive, or ambivalent in the care setting. This “emotional rollercoaster” is unpredictable and exhausting for caregivers, and caregivers should not be judged for their reactions to any situation. In my own nursing care, I have noticed a change in my own reactions towards caregivers of individuals with dementia since this study. In particular, I recall being shocked and horrified to hear a daughter tell me that she wanted her father to “hurry up and die” after sitting by his bedside for 2 days. I remember being annoyed at another caregiver who called to check on her father repeatedly and became upset with staff if care was not provided exactly as she wanted. Both of these cases occurred during data collection and analysis, and I experienced a change of heart as I became able to identify their stages in the process of rediscovering. Understanding these caregivers instead of judging them changes the support that the nurse is capable of providing to them.

Lastly, the nurse should recognize that caregivers need support from the beginning of the process through to the end. For most participants in this study, this process lasted much longer than 6 months. The “end of life” for individuals with dementia is often prolonged, and thus so should end of life care be prolonged. Hospice programs introduced in the last 6 months or less based on prognostic indicators are inadequate for this population. One participant described that hospice would have been helpful earlier in the process:

[The hospice nurse] offered a lot of suggestions for us to consider, from a respite break ... to advice on how to better manage the stresses we’re under. None of it was useful. Oh, it was, in the sense that had we not considered those things, it would have been very beneficial to bring it up. ... But we’ve managed through these things long enough that I think, honestly, we’re doing about all that can reasonably be done to handle the stresses.
[B027, p. 275]

This reiterates the conclusion of my earlier phenomenological study of the experiences of caregivers seeking hospice care for loved ones with dementia (Lewis, 2014). In that study, findings suggested that hospice enrollment criteria should be based on caregiver needs and attitude towards palliation rather than on prognostic indicators. Introducing a palliative care program earlier in the dementia process would allow participants to have resources available to them before reaching a breaking point, which would aid both caregivers and care recipients in experiencing better quality of life throughout the entire end of life process.

Nurses can provide customized care to caregivers throughout stages of the process of rediscovering if they understand this process. Recognizing the individual stage of the caregiver would allow nurses to assess, understand, and validate the specific needs of caregivers in each stage. Extending end of life care programs to encompass this entire process would also benefit caregivers working their way through these stages and may help more caregivers reach stage five, which is finding joy in caregiving.

Strengths and Limitations

This study had several limitations. As with any research study, the experiences described in this study may be biased to represent a population more willing to participate in research. The content of this study may have been emotionally upsetting to some, which may have limited their willingness to participate. This sample was also limited in racial diversity. In an attempt to diversify the sample, fliers for in-person interviews were intentionally brought to cultural centers and to towns in Connecticut known to have greater populations of racial minorities. Despite these attempts, this sample consisted of a primarily White population. See Chapter 4 for demographic characteristics of the sample.

Limited access to participant observation opportunities also limited this study. Due to constraints on the researcher, total immersion into participant observation was not feasible.

Observation opportunities were also limited by a lack of response or willingness to participate from support groups and nursing home, assisted living, and hospice facilities. Only one facility was used for participant observation. This facility was open and accommodating to research and promoted a palliative mindset among its residents and their caregivers. This likely affected the experiences of these caregivers, and also likely created a bias towards those who opted to use a facility with palliative goals. Only one support group was used for observation as well, and similarly, the willingness of this group to allow the presence of a researcher may indicate a unique bias compared to groups that would not allow my presence.

The use of published memoirs as data may have also skewed results towards a more educated population. It is worth noting, however, that the diversity of writing styles and grammar usage appeared to indicate a spread of educational backgrounds. Many of these books were self-published.

Another limitation of this study may have been including both spousal caregivers and adult-child caregivers in the same sample. While this decision was consciously made to add breadth to the theory, the inclusion of both groups may have weakened the ability to construct a theory that specifically fit each population. Differences in these groups were reported as applicable in Chapter 4, and differences not relevant to the theory will be discussed in this chapter as areas of interest for future research.

Finally, the use of grounded theory methodology may neglect to explore some concepts that are significant to the experience of the population of interest. Once the core category emerged, selective coding began, and method dictated that this core become the focus of the research. However, there may be other categories that were not selected as the core that are still important elements of the caregiver experience and may warrant future study. Since development of a theory, not full conceptual description, was the goal of this study, those

categories were not further explored. Other categories that emerged through data collection and analysis that were not incorporated into the theory will be discussed in the section on future research in this chapter.

This study also had strengths that served to counteract some of its limitations. First, a wide variety of data sources were used. The research sample included in-person interviews, online interviews, participant observation, books, blogs, voicemails left behind for a loved one, artwork, photographs, obituaries, eulogies, poems, prayers, and songs. Triangulation of data sources strengthened the emerging theory by adding insight and objectivity that could not be possible from using one data source alone.

By collecting data in various ways, attempts were also made to ensure that this sample would not be biased to include only those with positive caregiving experiences. Participants were intentionally recruited from fliers hung in public locations, not limited to areas that provide services to caregivers, to avoid bias towards those who had their needs met. Similarly, online recruitment was not limited to websites providing support to caregivers. Conducting interviews face-to-face and online allowed for both older and younger populations to participate. In this way, the sample was neither limited to individuals who were computer-savvy, nor to individuals who had the time and preference to meet in person. Though face-to-face interviews and participant observation were geographically limited, conducting online interviews and analysis of books and blogs also allowed for a national representation in this sample. See Chapter 4 for demographics.

Strict adherence to grounded theory also strengthened this study. Prolonged engagement, triangulation of data sources, peer debriefing, and member checking should ensure credibility. Rich slices of data and purposive and theoretical sampling should ensure transferability, and inquiry auditing should ensure dependability. Examination of the audit trail and abstracting

rather than describing should greatly reduce biases, if not eliminate them. These techniques and rigorous use of the classic grounded theory methodology should lead to a theory that fits, grabs, works, and is modifiable.

Recommendations for Future Research

Use of the grounded theory methodology produced a substantive theory of rediscovering. This theory opens many doors for future qualitative and quantitative study within the substantive area of caregiving for loved ones with dementia at the end of life, which will be discussed in this section. This section will also describe categories that emerged from data that were not part of the basic social psychological process of rediscovering but that may warrant future research. I will also outline differences between spousal and adult-child caregivers that did not fit in this theory but that also may indicate need for further study.

The theory of rediscovering includes five stages. Each of these stages has been somewhat explored in qualitative literature. Further qualitative studies on transitions between specific stages may be beneficial to provide insight into how to help caregivers move through this process to reach joy in their roles. Qualitative studies should also explore applicability of this process to individuals from racial and ethnic backgrounds other than White caregivers.

This theory also provides a framework for future quantitative study. The emergent basic social psychological problem highlights the importance of role entrapment for caregivers. Measuring incidence and severity of entrapment may be helpful in assessing populations of caregivers at risk for depression. Severity of entrapment may also be useful as a measure of effectiveness of interventions to provide caregiver support at the end of life. For example, a customized intervention plan may target those with high levels of entrapment to deliver increased support during these times.

Other interventions for future study may focus on strategies that caregivers already use to transition from stage four, reclaiming identity, to stage five, finding joy. Interventions could be targeted towards caregivers experiencing the need for escape to aid them in adjusting expectations, asking for help, seeking respite, and reestablishing relationships. In these ways, this theory provides a foundation for future interventions to support and bolster those coping mechanisms that already exist among caregivers.

Future studies may also explore those categories that emerged from this study but that did not occur within the process of rediscovering. Caregivers in this sample faced an often traumatic experience of “bearing witness to suffering,” in which they watched a loved one suffer and fade away. Suffering was both chronic and acute, as participants described the everyday decline caused by dementia compounded by sudden and harsh experiences of loss of dignity, physical pain, and emotional torture. Though this category was tied to the category of “saying a long goodbye” within stage one of this process, it competed with “role entrapment” as a potential basic social psychological problem for this population.

Another competing problem was “life disruption.” Again, this problem was somewhat addressed in the second stage of the process, in which caregivers sacrificed themselves. However, the external effects of this disruption on a caregiver’s family members, marital relationship, parenting abilities, finances, employment status, home status, and physical health could not be fully explored in this study.

Participants also expressed concerns “navigating systems” as they struggled to manage and supervise care. This topic has been relatively well studied among caregivers of those in nursing homes in previous literature (Kim, 2009; Mistic, 2008). However, future study may be warranted on how caregivers navigate home care systems and enlist the help of private duty aides, social workers, and hospice care in the home care setting.

One other challenge for caregivers that was not addressed in this process was “filling the void” after the death of a loved one with dementia. This experience differed for caregivers depending on which stage of the process of rediscovering they were in when their loved ones died. Caregivers who completed all five stages of rediscovering often reported healthy grieving, missing their loved ones and their roles after the death of a loved one. Those who had lost a loved one during stage two or stage three described patterns of complicated grief that warrant further study. Caregivers who were in stage two, sacrificing self, when their loved ones died expressed a total loss of purpose with the loss of a loved one. Their own lives had been consumed by caregiving, and they did not know how to move on once they were no longer needed in this role. Those who had reached stage three, yearning for escape, struggled with extreme guilt and shame when their loved ones died. Many had wished that their loved ones would die, and felt ashamed that they were overcome with relief when their loved one did die. Future studies should explore the post-loss experiences of these caregivers who lost loved ones at earlier stages in the rediscovering process.

Besides these other challenges that caregivers faced, specific differences in spouses versus adult-child caregivers emerged that could not be captured in the process of rediscovering but may merit future study. Firstly, caregivers experienced lucidity very differently depending on their familial relationships to the care recipient. Adult-child caregivers pined for moments of lucidity, claiming that these moments in which their loved one “returned to [them]” were “rewarding” and “made it all worth it.” On the other hand, spousal caregivers described these moments as “torture.” One participant in the support group described his wife becoming alert for a moment, and he cried as he told the group that he “asked God to never let her have one of those again.” Spousal caregivers fixated on the fact that their loved ones became aware of what was

lost when they became lucid, while adult-child caregivers focused on the fact that they had “found” their loved ones again in these moments.

Another major difference for caregivers was in “fibbing.” Almost all caregivers described “learning tricks” to distract loved ones, to reorient them, or to calm them. Many of these tricks involved lying to a loved one. Adult-child caregivers understood that these “white lies” were necessary for the wellbeing of their parent and compared them to the lies that parents need to tell their children to protect them in childrearing. Spouses had a much harder time adjusting to telling lies to a spouse, as individuals described feeling that this was ingrained in their minds as socially and morally unacceptable. They had valued the honesty that existed in their marriages and felt like they needed to learn to abandon personal values to be able to lie to their spouses. Future studies may look at the comparative experiences of truth-telling in marital versus adult-child relationships of caregivers.

Finally, adult-child caregivers and spousal caregivers expressed differences in the experience of living together during dementia. Adult-child caregivers typically did not live with care recipients prior to the diagnosis and advancement of dementia. Those children who chose to live with their parents described being proud to fill a duty. They felt that they were honoring a loved one by choosing to live with them. Spousal caregivers, however, took for granted that they would live with a loved one when they became married. Rather than making an active choice to live together, as with children, spouses already lived together and thus could only make an active choice not to live together. Spousal caregivers in the support group described feeling like they were breaking their vow of “til death do us part” by parting with their loved ones in physical home and finding placement for them. These painful distinctions between adult-children “choosing to live with” and spouses “choosing to live without” may warrant future study on the effects of post-placement grief and guilt.

The emergent theory of rediscovering and its stages lay the groundwork for future quantitative and qualitative studies of caregivers of individuals with dementia at the end of life. This theory may be useful in proposing and trialing interventions based on caregivers' current attempts to resolve the problem of role entrapment. Future studies may also qualitatively explore emergent categories from the data that were not part of the process of rediscovering and differences in adult-child and spousal caregiver experiences.

Benefits of Participation

During data collection, many participants indicated that participating in this study was therapeutic for them. Several participants who were interviewed after death of a loved one indicated that they were able to "find closure" through interviews. One son wrote after the interview, "Meeting with you gave me some closure to the passing of my father. It was good to talk with someone like yourself who has also experienced the loss of a loved one to Dementia."

A few participants told stories that they reported they had never shared with anyone before. They had kept these stories from their children, siblings, or spouses in an attempt to protect the dignity of their loved ones. In this interview, they found a way to share their own experiences with a stranger without feeling that they were risking the dignity of the person whom they loved.

Participants also reported feeling validated based on their participation in this study. During an interview late in the interview process, one participant read a description of the theory of rediscovering and sent me an email afterwards. She said, "When I read things like this, though my mom has been gone for about 14 months, I still feel an incredible sense of validation. I'm not the only person who has felt these things or been through them... there's a comfort in that."

Many other participants reported that it “felt good to help others” [P045] through their participation in this study. Participants writing books or blogs reported the same satisfaction from sharing their stories. One participant wrote in her book, “I do pray that I can tell *our* story and help other caregivers who may go through this terrible disease with a spouse or loved one” [B008, p. 236]. Sharing their pain, their suffering, and their ability to overcome was therapeutic for caregivers participating in this study.

Summary

In this chapter, I reviewed the emergent basic social psychological process of rediscovering. This theory was discussed in context of previous literature on caregiving for loved ones with dementia. Based on this theory, recommendations for change in nursing practice and future areas of research were proposed. This section also described the limitations and strengths of this study and the benefits of this study to caregivers who participated.

Conclusion

This grounded theory study of caregivers of individuals with dementia at the end of life explored the emergent basic social psychological problem of role entrapment and the basic social psychological process of rediscovering as a means to resolve that problem. The process of rediscovering included five stages, which were missing the past, sacrificing self, yearning for escape, reclaiming identity, and finding joy. Caregivers who were able to work through this process were able to transcend providing care and were able to provide joy to the care recipient and themselves. Nurses must recognize and understand this process as a means to help caregivers overcome feeling stuck and trapped and move towards finding happiness again. Participants in this study described a journey of suffering and sorrow, heartbreak and despair, failure and triumph, and incredible resilience as they survived and conquered their roles with

profound love and purpose and rediscovered themselves, their loved ones, and the relationship they had once shared.

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Appendix A

Recruitment Letter to Agency Leaders

To Whom It May Concern:

My name is Laura Foran Lewis, RN and I am a PhD student in the School of Nursing at University of Connecticut. I am looking for your help to recruit participants for a study I am doing for my dissertation titled: Caregiving for Loved Ones with Dementia at the End of Life. The goal of this study is to learn more about what it is like for these caregivers when their loved ones reach the end of life, including the challenges they face and how they cope with these challenges. The Institutional Review Board at the University of Connecticut has approved this study.

I am wondering if you would be willing to post the enclosed flyer in your facility? If you have any questions or concerns, please do not hesitate to contact me by email a laura.foran@uconn.edu, or by telephone at (860) 486-0547.

Thank you,

Laura Foran Lewis, RN, MSN

Appendix B
Recruitment Flier
University of Connecticut

Volunteers Wanted for a Research Study

Caregiving for Loved Ones with Dementia at the End of Life

The purpose of this research study is to explore the experience of caregiving for a loved one with dementia and Alzheimer's disease at the end of life. Participation includes an interview up to 1 hour long with a nurse. Interviews will be scheduled at a time and place that is convenient for you.

To participate in this study, you must have taken care of someone with dementia or Alzheimer's disease who has passed away in the last 10 years. You may have cared for them at home, or they may have been in assisted living or in a nursing home.

To learn more about this research, please contact Laura Foran Lewis or Dr. Cheryl Beck. You may reach us by email at Laura.foran@uconn.edu, or by telephone at (860) 486-0547. This research is conducted under the direction of Dr. Cheryl Beck.

Student Investigator: Laura Foran Lewis, RN, MSN

Principal Investigator: Cheryl Beck, DNSc, CNM, FAAN

UConn IRB	
Approved On	10/4/13
Approved Until	10/4/14
Approved By	DMW

Laura Foran Lewis or Cheryl Beck Laura.foran@uconn.edu (860) 486-0547	Laura Foran Lewis or Cheryl Beck Laura.foran@uconn.edu (860) 486-0547	Laura Foran Lewis or Cheryl Beck Laura.foran@uconn.edu (860) 486-0547	Laura Foran Lewis or Cheryl Beck Laura.foran@uconn.edu (860) 486-0547	Laura Foran Lewis or Cheryl Beck Laura.foran@uconn.edu (860) 486-0547	Laura Foran Lewis or Cheryl Beck Laura.foran@uconn.edu (860) 486-0547
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Appendix C

Questions for Face-to-face and Online Interviews

Questions changed as the study progressed. The following are examples of questions that were asked in face-to-face interviews or were posted on the study website during the study. These questions were not all included in a single interview or posted online at the same time, but in progression, new questions replaced old questions as data collection and data analysis took place. Follow-up questions and clarifying questions were also included in face-to-face interviews and were sent to online participants on an individual basis via email.

Please tell me what it was like to care for your loved one with dementia at the end of life.

Please describe an average day taking care of your loved one or describe an especially challenging day.

What challenges did you face during your time of caregiving at the end of life?

What was the hardest part of caring for your loved one at the end of life?

What was your role as the caregiver? How did this affect your life outside of caregiving? Did you ever feel trapped in this role? Did you feel like others could take your place if you needed a break?

Did you feel like your primary role was to be your loved one's caregiver, to be his/her family member, or both? Did you feel like these roles were separate or did you feel like you could be both a family member and a caregiver at the same time? Did your view on this role change throughout your time taking care of him/her? If so, what brought about this change? Which role felt better for you? Which role felt like he/she got better care?

Did you feel bound to your family member emotionally, mentally, and/or physically? This may be out of love, out of duty, out of respect, or out of a belief in some moral code. If so, please describe this feeling.

Appendix D

Images of Study Website

Caregiving for a Loved One with Dementia

[Home](#)
[Informed Consent](#)
[Participate Here!](#)
[Questions?](#)
[About the Student Investigator](#)

Volunteers Needed for a Research Study!

[Participate Here!](#)



The purpose of this research study is to explore the experience of caregiving for a loved one with dementia (including Alzheimer's disease) at the end of life. To participate in this study, you must have taken care of someone with dementia who passed away in the last 10 years. You may have cared for them at home, or they may have been in assisted living or in a nursing home.

Participation includes answering a few questions about your experience as a caregiver. A consent form with more information about this study can be found by [clicking here](#).

Please feel free to ask questions via the [Questions](#) page on this website or email me directly at laura.foran@uconn.edu.

Thank you!

Laura Lewis, RN, MSN, Student Investigator
Principal Investigator: Cheryl Beck, DNSc, CNM, FAAN

Caregiving for a Loved One with Dementia

Home

Informed Consent

Participate Here!

Questions?

About the Student Investigator

The screenshot shows a web browser window with a document titled "University of Connecticut Consent Form for Participation in a Research Study". The document is from Scribd and is page 1 of 2. The text on the page includes:

Principal Investigator: Cheryl Beck, DNSc, CNM, FAAN
Student Researcher: Laura Foran Lewis, RN, MSN
Study Title: Caregiving for Loved Ones with Dementia at the End of Life

Introduction
You are invited to participate in a research study to explore the experience of caregiving for a loved one with dementia and Alzheimer's disease at the end of life. You are being asked to participate because you were a primary caregiver to someone with dementia who has passed away within the past 10 years.

Why is this study being done?
I am a graduate student in Nursing at the University of Connecticut. I am interested in finding out about what it is like to care for a loved one with dementia at the end of life.

What are the study procedures? What will I be asked to do?
If you agree to take part in this study, you will be asked to respond to questions about your personal experiences caring for a loved one with dementia via the Alzheimer's Association

Caregiving for a Loved One with Dementia

Home

Information Sheet

Participate Here!

Questions?

About the Student Investigator

Please click on the link below to participate in this study. The link leads to an online form that will ask basic questions about your caregiving experience. You can click on the link and look through the questions before deciding whether or not you would like to participate. Thank you for taking the time to share your story with me!

<https://www.psychsurveys.org/laura4n/caregiverstudy>

****If you are from Connecticut and would prefer to participate in a face-to-face interview, please contact me via the Questions page on this web page or by email at laura.foran@uconn.edu or contact Cheryl Beck via phone at (860) 486-0547 to schedule an interview at a time and place that is convenient for you!**

Caregiving for a Loved One with Dementia

[Home](#)

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[Participate Here!](#)

[Questions?](#)

[About the Student Investigator](#)

Questions?

If you have any questions or comments about this study, please post them here or email me directly at laura.foran@uconn.edu.

[Send an email](#)



Please enter your questions or comments below. The student investigator will contact you via email to respond to your questions. Thank you!

Name

First

Last

Email *

Comment *

Caregiving for a Loved One with Dementia

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About Laura Foran Lewis



My name is Laura and I am doctoral student in the School of Nursing at the University of Connecticut. I am also a cancer nurse at the University of Connecticut Health Center, where I have been working for the past 3 years.

I became interested in dementia care when my grandma was diagnosed with vascular dementia. I grew up across the street from her and was privileged to be there with her holding her hand when she passed away.

My experiences with her and with my family in handling her death brought me to where I am today.

It is my hope that this study will bring knowledge to the field of dementia care that may help future caregivers and individuals dealing with this disease. Thank you for your participation!

Appendix E
Online Recruitment Notice

Subject:

Caregiving for Loved Ones with Dementia Research Study

Post:

My name is Laura Foran Lewis and I am a doctoral student in the School of Nursing at the University of Connecticut. I am looking for individuals who may be willing to participate in a research study about caregivers. The purpose of this research study is to explore the experience of caregiving for a loved one with dementia (including Alzheimer's disease) at the end of life. I am looking for individuals who took care of someone with dementia who passed away in the last 10 years. You may have cared for them at home, or they may have been in assisted living or in a nursing home. Participation is entirely online and includes answering a few questions about your experience as a caregiver. It can take as long or short as you like, depending on how much you decide to share.

To find out more about this study or to participate, please see the study website:

www.caregiverstudy.weebly.com.

Thank you for your consideration!

Laura Lewis, RN, MSN, Student Investigator

Principal Investigator: Cheryl Beck, DNSc, CNM, FAAN

Appendix F

Examples of Memos

EXAMPLE 1

Memo: 12/4/13

Trying to decipher what the core category is – but I don't think it has emerged just yet... Here are my thoughts so far.

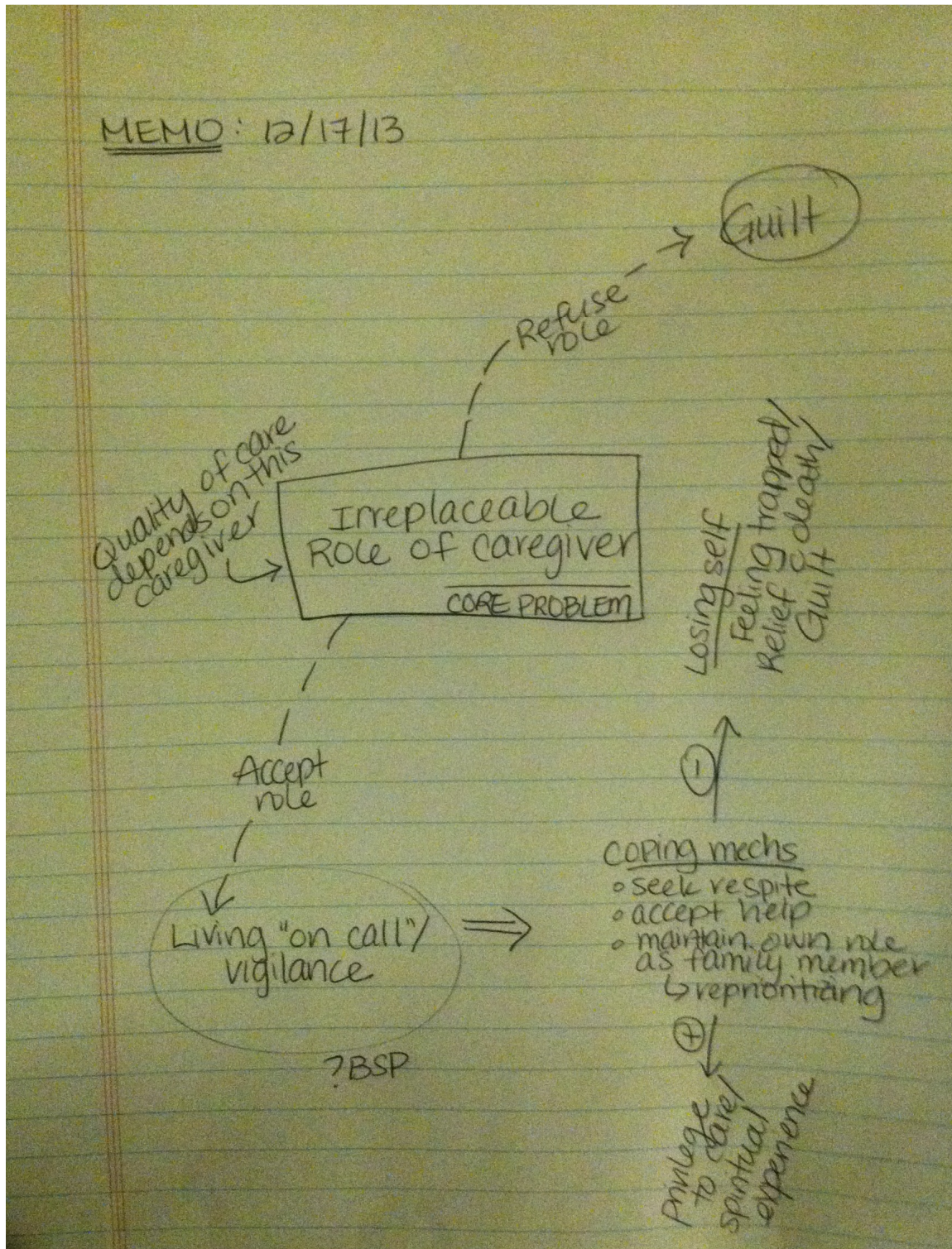
- 1) The need to be an advocate
...HAD to be there, mistrust when not there, nurse instead of family hat, struggle to navigate system
 - Self-advocating
 - Irreplaceable (had to drop everything to be there)
 - Question: irreplaceable in who's mind? Patients? Caregivers? Health care workers? Other family members?
 - "Vigilant gatekeeper"
- 2) Role reversal of parent/child relationship – unique to children caring for parents?
Challenge of seeing parents as weak/vulnerable/helpless –nothing I could do
 - Reversing roles
 - Redefining relationships – spouses report no longer sharing "marriage" relationship
- 3) Personal sacrifice/strain
Jobs, marriage, finances, physical health, high stress, reliving same thing over and over, heartbreak ... still losing the person you love, can't go anywhere
 - Giving of self
 - All-encompassing
 - Going through the motions
 - Isolation/loneliness

I feel like I may have hit on something with the irreplaceable piece. All others follow this – the caregiver is in a position to accept or reject the all-encompassing role, leading to either distress with acceptance or guilt if unable to become the sole, irreplaceable caregiver. Those who choose this role forewarn others to remember not to be a martyr and to use help, but they are not able themselves to see this when they are caregiving or to do anything about it if they can see it. Dementia & caregiving become their world, and everything else must take a backseat to fill this role to avoid guilt. It is like an unhealthy obsession forced on them. Inescapable until death, when relief finally comes.

Questions for future interviews:

- Did you feel like you were the only one who could do this?
- Did you ever feel trapped in this role?
- Did you feel like others could take your place if you needed a break?
- How did this affect your life outside of caregiving?

EXAMPLE 2
Memo: 12/17/13



EXAMPLE 3

Memo: 1/19/14

Possible that the main way of coping is “Living in the moment”? Caregivers talk about reprioritizing – you can’t look back and can’t look forward. You need to know there is an end in sight, but wishing for this to end means wishing for death. Looking back just brings sadness and grief. Instead, caregivers cope by learning to love the “new” person they are caring for and by reprioritizing to focus on the here and now and appreciating the small blessings that accompany this time. They learn to see it as a blessing only when they can learn to LOOK for the blessings in the now. Intertwining identities is a means to reprioritizing or vice versa? Either way, whether or not this is the core, it is central...

EXAMPLE 4

Memo: 2/1/14

Biggest Problem:

Role Entrapment

Coping Process:

Falling in love with the new him

The caregiver is bound to her family member emotionally, mentally, and often physically. This may be out of love, out of duty, out of respect, or out of a belief in some moral code. With or without help from others, caring for this person occupies much of her time, thought, and energy. The primary caregiver believes she holds qualities that cannot be replaced by another caregiver, which may include information, skills, experience, relationship power, or even love. Even if tasks may be outsourced to others, she believes her role is nontransferable. She is forced to watch her loved one disappear inch by inch and is helpless to the effects of the disease. [She may reach the point when she wants to give up or walk away, but due to financial and legal restraints, she may not have any options other than to continue in her role.] Her only escape is the death of the person that she loves.

[ROLE ENTRAPMENT]

As the demands of caregiving increase and the caregiver says goodbye to this person one piece at a time, she misses the person she once knew and loved. [She also misses her own life before caregiving, which often includes her family, her job, her friends, her home, her privacy, her down-time, her vacations – essentially her life.] Losing her family member steadily and watching him suffer, she wonders how long this will go on, and is scared to think this may last many years. She may find herself wishing her family member would die just to end the pain for both of them. This leads to an overwhelming sense of guilt.

[MISSING THE OLD HIM]

[WISHING FOR DEATH]

When the family member begins to require total care, total time, and total thought, the caregiver often reaches a “breaking point.” The role of “loved one” fades as the role of “caregiver” takes over. She is at wits end and needs help. Some caregivers reach a point where they believe they would welcome their own serious injury or even death as a way out of this role. Something has to give. Family members at this point often seek hospice, assisted living, nursing home care, hired in home help, or at least increased help from other family members. The caregiver yearns for respite, but even if she is able to coordinate time away, she is not often able to take a break from the ongoing worry and devastation. [As much needed as this help is, the caregiver may find herself feeling jealous or hurt if she believes she has been “replaced” in the mind of her family member. In time, though, she may be relieved to know that her family member is comforted and loved by those providing care to him. She may also realize that her role of “family member” is irreplaceable even if her role of “caregiver” has been replaced.]

[REACHING BREAKING POINT]

[SEEKING HELP]

[YEARNING FOR RESPITE]

When help arrives, the caregiver is able to reclaim some of her role of family member. She is able to step back and refocus time spent with her loved one. She may be able to appreciate time spent holding hands, listening to music, and enjoying his company again. She realizes that he must “enter into his world” – in other words, not to argue with him or re-center his reality in hers, but to instead accept his reality and be there with him. She also learns to “live in the moment.” Looking back at what is lost is too painful. Looking ahead at what is to come causes anxiety and the realization that his function will only continue to diminish until he is gone. By living in the moment, she can love him in the moment for who he is, not who he was.

[ENTERING INTO HIS WORLD]

[LIVING IN THE MOMENT]

[DISCOVERING THE NEW HIM]

Through this process, the caregiver ultimately discovers and falls in love with the new him. She finds ways to bring him joy, and that brings her joy.

Stages of Process:

- 1) MISSING THE “OLD HIM” SO TERRIBLY
- 2) WISHING THE NEW HIM WOULD DIE
- 3) REACHING WITS END/BREAKING POINT, MAKING A DECISION FOR PLACEMENT OR HOSPICE OR GETTING EXTRA HELP... SOMETHING HAS TO GIVE
--GETTING HELP OR RESPITE
- 4) ENTERING INTO HIS WORLD/LIVING IN THE MOMENT
- 5) DISCOVERING AND LOVING THE NEW HIM

Appendix G

Books and Blogs Included in Sample

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