Finding Meaning in the Dementia Caregiving Relationship

by

Bomin Shim

Department of Nursing
Duke University

Date:_____

Approved:

_____
Linda L. Davis, Supervisor

_____
Julie Barroso

_____
Owen Flanagan

_____
Catherine L. Gilliss

Dissertation submitted in partial fulfillment
of the requirements for the degree
of Doctor of Philosophy in the Department of
Nursing in the Graduate School of
Duke University

2011

ABSTRACT

Finding Meaning in the Dementia Caregiving Relationship

by

Bomin Shim

Department of Nursing
Duke University

Date:_____
Approved:

_____
Linda L. Davis, Supervisor

_____
Julie Barroso

_____
Owen Flanagan

_____
Catherine L. Gilliss

An abstract of a dissertation submitted in partial fulfillment
of the requirements for the degree
of Doctor of Philosophy in the Department of
Nursing in the Graduate School of
Duke University

2011

Abstract

Caregivers of individuals with dementia describe a wide spectrum of caregiving experiences, ranging from very negative to very positive. Previous literature acknowledges these differing experiences, but how and why they differ has rarely been investigated. Dementia caregiving can be burdensome with many psychological, physical, social and financial challenges. However, it can also be an opportunity for growth and transcendence as caregivers find meaning in caregiving. High levels of mutuality (the perception that the quality of the care relationship is positive), reportedly ameliorates negative caregiver outcomes. Thus, this dissertation consists of three studies that explore aspects of the caregiver-care recipient relationship that may enhance positive caregiving experiences.

The first study was a secondary analysis of factors related to caregivers' perceptions of care relationship mutuality over a 12 month period. Caregivers who reported high mutuality were less likely to be depressed and more likely to provide care for longer periods before deciding to institutionalize the care recipient. The second study was a secondary analysis of caregiver interviews. It revealed that caregivers who reported a positive caregiving experience described both their past and present relationship in loving terms and reported that they understood their care recipient could not reciprocate. These caregivers focused on aspects of the relationship that still existed, rather than on what they had lost. They expressed satisfaction with caregiving, were other-focused, and reported little caregiving burden. The third study was a qualitative descriptive study.

Caregivers who reported finding meaning in caregiving were interviewed to explore how they were able to do so. These caregivers used strategies such as accepting the situation, deciding to care, choosing a positive attitude, focusing on the blessings of caregiving, and actively seeking care resources. They demonstrated altruistic values and the determination and discipline to live those values. They also possessed strong faith, love, and social support, and said they had derived strength from past challenges.

Clinicians and researchers should explore the quality of the caregiving relationship as a critical factor in caregiver and care recipient outcomes. Caregiver interventions should include relationship-building skills and empathy building techniques to offset adverse caregiver outcomes and enhance understanding and acceptance of changes that occur in the care recipient over time.

Dedication

This dissertation is dedicated to everyone around the world who is caring for a loved one with dementia.

Table of Contents

List of Tables

Acknowledgements

Thank you, Lord, for the trials and blessings during my doctoral studies, and the companions provided along the way.

I could not have completed this without my dissertation committee; Drs. Linda L. Davis, Julie Barroso, Catherine L. Gilliss and Owen Flanagan. Thank you Dr. Davis, my mentor and advisor, for taking me under your wing, for your patience and guidance, and pulling me through good and bad. Dr. Barroso, thank you for embracing my tears and frustration and revising so many editions! Thank you, Dr. Gilliss for your words of wisdom and warm but firm encouragement. And Owen, thank you for accepting a stranger's idea and helping blossom it. Thank you all!

Thank you, Dr. Richard Landerman for your help with statistical analyses and your words of counsel, Dr. Ruth Anderson, and Dr. Holditch-Davis, my wonderful faculty who helped with many revisions and hugs of encouragement. Thank you Revonda, Yvonne, Becky, Jada, Heather, Mark, Annie, Tiffany, Kim, Ryan, Kyong, Kate, Jenni, Judy, Ken, my PhD classmates for your love and support.

Thank you, Professor Lisa L. Gwyther and Dr. Deborah T. Gold for your steadfast trust in me. I thank the Alzheimer's Association Eastern Chapter Support group leaders and everyone who helped in recruiting caregivers for my study; Ms. Crystal Sterling Simmons, Charlene Riedel-Leo, DeeDee Harris, Kate Barrett, Lisa Goldstein, Dr. James R. Burke, Sandra, Michelle, Deb Chestnut, Candace L. Boyette, Nancy Ferree-Clark, and Melanie Bunn.

Duke University, School of Nursing and the Graduate School sponsored my graduate studies and financial aid from the Duke Aging Center (Leadership in an Aging Society Program Fellowship) and Duke University Graduate School (Travel Award) enabled me to conduct and complete this dissertation and travel to report findings from it.

Hugs to my lovely friends, Boknam, Sonia, Jeongok unni (both of you!), Jenn, Dr. Wynkoop & Duke Chapel Choir, Members of The Lord's Korean Church, Jinhei, Sr. Marivincent, Dr. Jennie DeGagne, LaJean, Jahyun unni, Kristie, Kathryn, Margie, Jennifer Dungan, Esther, you supported me when I was down. Thank you for your prayers, your company, and your love.

I cannot express all my thanks in words to my family; Mom, Dad, Abunim, Seunghi unni, Komobu, Suhan, my husband & our beautiful daughter Joy. I love you all so much. I could not have done this without your support.

And a special thank you to my lovely caregivers who so graciously shared their life stories with me, and are so beautifully amazing! Once again I was reminded that depending on how we approach our life challenges, our pain can sometimes become a fertilizer to blossom a miracle.

God bless you all.

1. Dementia Caregiving

1.1 Purpose of the Dissertation

Dementia is a progressive decline in memory and other cognitive functions that also leads to increasing dependence in activities of daily living. Because of this non-reversible decline, researchers began to recognize and study the burden and challenge that informal caregivers of individuals with dementia face in caregiving for extended periods of time. Hence, research has tended to focus on the negative outcomes of caregiving for the caregiver as well as the care recipient. More recently researchers acknowledge that not all caregivers have negative outcomes. In fact, some even report growth or thriving in their caregiving experience (Park, 1998; Siegel, Schrimshaw, & Pretter, 2005).

An increasing number of researchers have suggested that these variances in caregiving outcomes can be explained by the way caregivers appraise and find meaning in their caregiving situations (Ayres, 2000a, 2000b; Baumeister, 1991; Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991; Kim, Schulz, & Carver, 2007; Park & Folkman, 1997). The reciprocal relationship between the caregiver and care recipient has been recognized to be a critical source for finding positive meaning in caregiving (Cartwright, Archbold, Stewart, & Limandri, 1994; Hirschfeld, 1983; Nolan, Grant & Keady, 1996). However, how some caregivers are able to find meaning has not been well investigated.

With an understanding of the need to find meaning in challenging life events, such as dementia caregiving, nurse clinicians and researchers can play a pivotal role in promoting growth and thriving among caregivers. They can do this by providing interventions that include self-reflective activities (journaling, meditation) and formal or informal support (support groups, telephone or computer-based support, nurse visits) (Acton & Wright, 2000; Skaggs, & Barron, 2005). Further study of how spousal caregivers of individuals with dementia have positive caregiving experiences and investigation into the strategies used by these caregivers could be used to develop data-based interventions that foster positive experiences among other caregivers. Thus, in this dissertation, three studies were conducted that explored different aspects of the caregiver-care recipient relationship and its relation to positive dementia caregiving experiences.

. The first study investigated caregiver or care recipient factors that affect caregivers' perceptions of the dynamic quality of their relationship with the care recipient as the illness progresses. A better understanding of changes in the perceived quality of the relationship may clarify factors that promote positive dementia caregiving experiences. To accomplish the purpose of the first study, a secondary analysis was conducted on three waves of questionnaire data that was collected over a 12 month period from caregivers of people with Alzheimer's disease (AD) or Parkinson's disease (PD). Caregivers caring for people with PD, a disease involving degenerative physical decline, was included in the study as a comparison group to caregivers dealing with AD, a

cognitively deteriorating disease. AD and PD are the two most prevalent neurodegenerative diseases in the United States (Nussbaum & Ellis, 2003).

The second study was a secondary analysis of 3 waves of interview data from spousal caregivers about the challenges and gratifications experienced in dementia caregiving. Spousal caregivers were the focus for this study because spouses often report more caregiving challenges as they are themselves older adults who typically face more health challenges and limited resources than other family members (George & Gwyther, 1986). The personal, demographic, and situational characteristics of dementia caregivers who reported positive experiences were compared with caregivers who did not report such experiences.

The third study was a descriptive qualitative study, and interviews were conducted with spousal caregivers of individuals with dementia, who self-identified as having found positive personal meaning in caregiving. This study focused on the meaning caregivers found in dementia caregiving, how they perceived they were able to find meaning and how meaning changed their caregiving experience. Exploring how some spousal caregivers of people with dementia can find meaning in this difficult task may lead to development of interventions that enhance and promote positive caregiving experiences and outcomes for caregivers.

The following literature review will provide a brief summary of previous research on the negative and positive experiences of dementia caregiving and on how and why some caregivers may have more positive experiences.

1.2 Background

An abundance of research indicates that informal dementia caregivers experience considerable physical, psychological, social and economic decline over time as many continue care for extended periods (Acton, 2002; Chenoweth & Spencer, 1986; Donaldson & Burns, 1999; Wuest, Ericson, & Stern, 1994). Because of the nonreversible, deteriorating characteristics of dementia over time, research in dementia caregiving has tended to focus on the negative rather than the positive experiences of caregiving. The dominant theory in dementia caregiving research has been the stress-coping theory developed by Lazarus and Folkman (1984). The stress coping theory views the care recipient with dementia, internal caregiver characteristics, and external situational characteristics of caregiving as stressors that deplete resources of the caregiver. This theory contributed to identifying the complex stressors of dementia caregiving, and investigating different coping methods to these stressors, but was not adequate in portraying the positive experiences of caregivers. Qualitative research methods based on theories such as existentialism have been suggested as an alternative theory for investigating the positive experiences of caregivers of people with dementia (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991).

The number of dementia caregivers (who are typically spouses and adult children) is reported to be almost 11 million (Alzheimer's Association [AA], 2010). Alzheimer's disease [AD] is the most common type of dementia in older adults, and the seventh leading cause of death in the United States (AA, 2010). More than 5 million people in the United States (AA, 2010), and 35.6 million people worldwide (Alzheimer's Disease

International, 2010) are estimated to have dementia, and the incidence is rapidly increasing.

Dementia impacts families as well as health care systems (Plassman, Langa, Fisher, Heeringa, Weir, Ofstedal, et al., 2007). Families provide 80% of community-based care for these increasingly impaired and dependent older adults (National Alliance for Caregiving & AARP, 2004). The average time from AD diagnosis to death is 7 years (Rait, Walters, Bottomley, Petersen, Iliffe, & Nazareth, 2010), but caregivers are usually already providing some form of care before the actual diagnosis. Clearly, the challenges that caregivers of individuals with dementia face are long-term. The annual unpaid health care contributions of these informal caregivers are 306 billion dollars, almost twice as much as the estimated 158 billion dollars spent on formal homecare in the United States (Arno, 2006).

1.2.1 The Negative Experiences of Dementia Caregiving

Caregivers of individuals with dementia are reported to perceive higher levels of burden and suffer more negative health outcomes than those caring for depressed elders (Leinonen, Korpisammal, Pulkkinen, & Pukuri, 2001), cancer patients (Clipp & George, 1993) and noncaregivers (Pinquart & Sorensen, 2003). Furthermore these negative experiences are not only harmful to the caregiver, but they also negatively impact the quality of care provided to the care recipient (Gainey & Payne, 2006).

Many caregivers' physical and mental health decline after initiation of care, and those caring for the cognitively impaired are at a significantly greater risk of both

psychiatric and physical morbidity (Acton, 2002). This is thought to be due to the stressors of caregiving, commonly referred to as *caregiver burden*. Moreover, high caregiver burden can lead to higher mortality rates for caregivers than for non-caregivers (Schulz & Beach, 1999), lower quality of care provided (Gainey & Payne, 2006), or early termination of the caregiving situation due to caregiving "burnout" (Bedard, Molloy, Squire, Dubois, Lever, & O'Donnel, 1997; Chenier, 1997). Caregiver burden has also been related to decreased caregiver employment rates (AA, 2010), and increased poverty risks in women (Wakabayashi, & Donato, 2006). Negative experiences of caregiving may lead to increased health care costs and other resources being devoted to the deteriorating caregivers and may exacerbate family destabilization and impoverishment (Arno & Memmott, 1999).

In addition to the progressive cognitive and physical decline in the care recipient, some caregivers must also manage problem behaviors of the care recipient, paranoid and delusional ideation, hallucinations, aggressiveness, affective disorders, and wandering (Farran, Gilley, McCann, Bienias, Lindeman & Evans, 2007; Robinson, Adkisson & Weinrich, 2001). As the care recipient's cognitive loss worsens and their personality changes, dementia caregivers have been reported to experience "emotional loss" of the care recipient, followed by social isolation (Hirschfeld, 1983; Rodriguez, DeLeo, Girtler, Vitali, Grossi, & Nobili, 2003).

Health decline in the caregiver naturally affects the health of the care recipient. Highly stressed caregivers may provide lower quality of care and some may even abuse care recipients (Gainey & Payne, 2006). Furthermore, a longitudinal study found that

dementia care recipients living with highly distressed caregivers had a more rapid disease progression and more problem behaviors and agitation (Vitaliano, Young, Russo, Romano, & Magana-Amato, 1993).

Spousal caregivers may have more negative experiences around dementia care than other informal caregivers because the caregivers themselves are elderly and may have multiple chronic diseases of their own (George & Gwyther, 1986). In one study, spousal dementia caregivers showed significant decrements in cellular immunity, and significantly more days of infectious illness - primarily upper respiratory infections - when compared to non-caregivers (Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991). They also reported higher levels of loneliness and depression (Beeson, 2003; Bergman-Evans, 1994). The communication difficulties and problem behaviors of dementia care recipients were also reported to elevate care burden for the caregiver (Fried, Bradley, O'Leary, & Byers, 2005; Savundranayagam, Hummert, & Montgomery, 2005).

Clyburn and colleagues (2000) identified three dominant factors in dementia caregiving burden: care recipient characteristics, caregiver characteristics, and caregiving context. In dementia caregiving, examples of care recipient factors include physical and cognitive decline, personality change and neuropsychiatric symptoms such as behavioral and psychotic disturbances (Donaldson & Burns, 1999). According to Bergman-Evans (1994), when the care recipient has dementia, the caregiver eventually comes to perceive the care recipient as a stranger, which leads to lack of companionship. Because of the care recipient's need for constant supervision, the caregiver is confined to the house and isolated from social contacts and supports.

Examples of caregiver factors contributing to caregiver burden are caregiver's personality, cultural beliefs, perceived resources, feelings of situational overload, resentment, fatigue and relational deprivation (Pearlin, Mullan, Semple, & Skaff, 1990). Some caregivers feel trapped in their role of caregiving, (a phenomenon defined as 'role captivity' by Pearlin et al., 1990). Female caregivers of certain cultures expressed greater feelings of anger, anxiety, guilt and sadness associated with wanting to relinquish care (Rudd, Viney, & Preston, 1999; Spitzer, Neufeld, Harrison, Hughes & Stewart, 2003). Examples of caregiving contextual factors contributing to caregiver burden include the lack of social or community resources and family or support networks (Pearlin, Mullan, Semple, & Skaff, 1990).

In spite of the recognition of caregiver burden and its consequences, findings about the predictors of negative outcomes have been somewhat inconsistent. Several predictors of greater caregiver burden and early institutionalization have been identified as higher frequency of problem behaviors of the care recipient (Burns & Rabins, 2000; Clyburn, 2000; Rymer et al., 2002), decreased care recipient functional ability (Chenier, 1997), cognitive loss and disorientation (Chenoweth & Spencer, 1986), caregivers' perceived or actual inability to handle troubling behaviors (Montgomery & Kosloski, 1994), and limited income (Andren & Elmstahl, 2007). On the contrary to these studies, other studies have suggested that caregiver burden levels are not related to the frequency of memory and behavior problems, extent of cognitive impairment, level of functional impairment, or duration of illness (Kasper, Steinbach, & Andrews, 1994). Rather, caregivers who report more informal support from other family members report less

burden (Zarit, Reever & Bach-Peterson, 1980). In terms of gender, though females report higher levels of burden (Bedard et al, 1997; Burns & Rabins, 2000; Torti, Gwyther, Reed, Friedman, & Schulman, 2004), they have also been shown to be more reluctant to relinquish care than have male caregivers (Kramer, 2005).

No single factor explains caregivers' feelings of burden. Rather, it is the combinated assessment of the caregiver, care recipient characteristics, and caregiving context that seem to synergistically affect the caregiver's perception of burden. The wide variety of caregiver perceptions leads to a correspondingly wide variety of caregiver experiences. It is also important to note that the characteristics of the care recipient, the caregiver and the caregiving context continue to change as the dementia progresses. Clinicians should be aware, and make an assessment of these changes in caregiver needs and resources.

1.2.2 The Positive Experiences of Dementia Caregiving

A growing number of dementia studies report that many caregivers are able to identify personal uplifts (Kinney & Stephens, 1989), rewards (Picot, 1995a; 1995b), gratifications (Motenko, 1989), or gains (Kramer, 1997) even in the midst of burden. For example, Farran and colleagues (1991) reported that 90% of the caregivers interviewed in their study reported the value of positive aspects of caregiving. In fact, some caregivers even reported significant gratification or positive gains from caregiving (Cohen, Gold, Shulman, & Zucchero, 1994; Folkman, 1997; Kinney & Stephens, 1989; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991; Motenko, 1989; Picot, 1995a; 1995b; Pinquart and

Sorensen, 2003). This phenomenon has been identified in other non-dementia populations as well. For example, Folkman (1997) found that positive psychological states can coexist with the pain of caring for a dying care recipient who has AIDS. Cancer caregivers too, were able to find psychological benefits such as acceptance, empathy, appreciation of family, positive self view and reprioritization through caregiving (Kim, Schulz, & Carver, 2007).

Kinney and Stephens (1989) called these positive experiences, uplifts and defined them as events that made the caregiver feel good, joyful, glad or satisfied. Examples are "He or she smiled at me today", "He or she said thank you to me." Picot (1995a, 1995b) called them rewards and defined it as "positive subjective feelings or objective changes in the caregiver's life (e.g., personal and social relationships, financial status, mental outlook) resulting from caregiver responsibilities" (Picot, 1995a, p. 31). Kramer (1997) called them caregiver gains and defined it as "…to which the caregiving role is appraised to enhance an individual's life space and be enriching, including any positive affective or practical return experienced as the direct result of becoming a caregiver such as the satisfactions, rewards, gratifications, or benefits that are perceived " (p. 240). There is no unified or commonly accepted definition for these positive caregiving experiences, but they commonly include feelings of pride in the ability to meet challenges; an improved sense of self-worth; a sense of growing closer to the care recipient; and the experience of warmth, comfort and pleasure in caregiving (Motenko, 1989).

Whereas some positive experiences are instantaneous positive affective responses, there are also more long-term positive experiences to caregiving. For example, Klein

(1989) explored burden in caregiving as being an essential component to moral development. Klein compared caregiving burden to apostolic suffering where the merit to suffering comes in a sacrifice for a greater goal; faith, love and glory. Lawton and colleagues (1989) called long-term positive experiences, caregiver satisfaction. They defined it as an accumulation of daily uplifts, a more stable concept than uplifts, that involves periodic confirmation that what the caregiver does is a source of personal satisfaction. Other long-term positive experiences of caregiving include growth or thriving, a higher level of functioning following stressful situations (Frankl, 2006; Park, 1998; Park & Folkman, 1997).

A sense of personal growth occurs when individuals perceive expansion in their attitude toward the self, in their relationship to others, or in their philosophy of life;. Individuals who experience growth find value and meaning in life beyond the individual self (cf. Siegel, Schrimshaw & Pretter, 2005). Also called self-transcendence, the growth phenomenon allows individuals to move toward more meaningful and fulfilling lives, reaching beyond themselves to find a larger sense of meaning, in spite of difficulties (Acton & Wright, 2000). The specific meaning caregivers derive from giving care also affects their expectations and future decisions regarding care (Ayres, 2000b).

The distinction between short-term and long-term positive experiences is important because an occasional uplift does not necessarily mean the caregiver has achieved satisfaction or growth. Furthermore, because the burden of dementia is chronic, due to the disease's irreversible and unpredictable degeneration, short-term uplifts cannot be secured. Rather the short-term positive experiences of caregiving can be

conceptualized as part of the process towards long-term positive outcomes (Siegel & Schrimshaw, 2007).

A pathway to moving from short-term positive experiences (such as uplifts) to long-term positive experiences (such as growth), lies in finding meaning in difficult situations (Davis & Morgan, 2008). A critical source for caregivers to find meaning in caregiving and have positive caregiving experiences is through the relationship with the care recipient (Archbold, Stewart, Greenlick & Harvath, 1990; Frankl, 2006; Hirschfeld, 1983). In a longitudinal study exploring spouses' strategies for living positively with dementia, Hellstrom and colleagues (2007) found that sustaining a sense of couplehood (that is, the partnership between caregiver and care recipient), maintaining involvement, and moving on (the caregiver taking on the care recipient's previous roles in the partnership as the dementia progresses) are three main processes of achieving a positive long-term caregiving experience through a nurturing relational context. It can be surmised from this and many studies that the positive or negative relational context between the caregiver and care recipient is a key element to the quality of the caregiving experience.

1.2.2.1 Finding meaning as a source of positive caregiving experiences

Finding meaning is considered a critical aspect of achieving long-term positive experiences such as growth from experiences of stressful events (Davis & Morgan, 2008; Frankl, 2006; Park, 1998). The ability to find meaning is suggested to play a significant role in caregivers' affective responses to caregiving as well (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilkin, 1991; Motenko, 1989).

Finding meaning after a short-term trauma or crisis, has been investigated in concepts such as post-traumatic growth (Tedeschi, Park, & Calhoun, 1998). However, finding meaning during chronically challenging situations such as during dementia caregiving is a different phenomenon. Certainly it is important that caregivers find meaning in past challenges, but it is also important to find their current and ongoing experiences meaningful in order to experience peace and pleasure over the long term.

The outcome of the search for meaning is affected by many elements of the individual, including: personality, world view, social support, socioeconomic status, preexisting physical and psychological adjustment, and previous experience (Park, 1998). For instance, in one study, individuals with chronic illness, described their disease as being a part of who they are, but also felt that they were more than just the disease (Corbin & Strauss, 1988). To understand the unique reality, expectations, and decisions of each caregiver, the act of caregiving as well must be approached and understood as merely one component of the caregivers' existential meaning of life (Ayres, 2000b; Baumeister, 1991). In fact, Ayres (2000a) suggested that the reason there is so much individual variance in caregiver experiences is because each caregiver makes different meanings from caregiving even under apparently similar circumstances.

Another distinctive aspect of the search for meaning in dementia caregiving is that the burden is dynamic and chronic rather than acute. The search for meaning by individuals who have chronic diseases has been described as "recapturing the past, examining the present, and projecting into the future – all interpreted in the light of the present" (Corbin & Strauss, 1988, p. 70). Likewise for those caring for individuals with

dementia, the search for meaning incorporates past, present and anticipated future care situations. Ayres (2000a) reported that dementia caregivers made decisions to act based on their future expectations and searched for explanations to account for the discrepancies between the predicted and actual experiences. These expectations, explanations, and decisions for action were all a part of the search for meaning (Ayres, 2000a).

Meaning can be found through a wide variety of sources, including love, creative work or even unavoidable suffering (Frankl, 2006). When applied to caregiving, meaning can be found through the loving relationship between the caregiver and care recipient (reflected in statements like "I am glad I am here for him/her"), through caregiving, as meaningful work ("I am thankful to be able to do something for someone else"), and even through unavoidable suffering ("I am losing my wife as I knew her, but I cherish our memories and the time we have left"). In other words, meaning in caregiving can be found from many different sources, such as from the relationship, from the care situation, from caregiving itself, and even from within the self. However, all these sources are related to the specific care recipient; therefore, the current dissertation focuses on different aspects of the caregiver-care recipient relationship as a critical source for finding meaning in caregivng.

1.2.2.2 The caregiver-care recipient relationship as a source of finding meaning

Dementia is a cognitive deteriorating disease that involves personality change, problem behaviors, decreased communication skill, disorganized thought and decreased shared memory; thus the reciprocity, intimacy and connection between caregiver and care

recipient are slowly lost with time (Fried, Bradley, O'Leary, & Byers, 2005). As a results, the caregiver–care recipient relationship must be continuously redefined. Ultimately, dementia caregivers are faced not only with the challenges of caring for an impaired older adult, but also with losing the close relationship they once had with another person.

Notwithstanding these challenges, some dementia caregivers are still able to find meaning in a continued sense of mutuality with the care recipient. Hirschfeld (1983) defined mutuality in dementia caregivers as the ability to find gratification from the relationship by perceiving the demented care recipient to reciprocate by virtue of his or her continued existence. This sense of mutuality and reciprocation is useful in understanding the caregiver's feelings of lasting affection toward the care recipient, even after the dementia has become very advanced.

In caregiving research, the term mutuality has been used to describe the caregiver's perceived quality of the relationship with the care recipient (Archbold, Stewart, Greenlick & Harvath, 1990). While most factors that affect the experiences of caregivers show inconsistent effects, the caregivers' perceived mutuality with the care recipients has shown consistent significant positive effects of caregiver experiences (Archbold, Stewart, Greenlick & Harvath, 1990; Carter et al., 1998; Kneeshaw, Considine & Jennings, 1999; Lyons, Sayer, Archbold, Hornbrook & Stewart, 2007; Schumacher, Stewart & Archbold, 2007; Schumacher, Stewart, Archbold, Caparro, Mutale & Agrawal, 2008). Mutuality has also been found to be the most important factor in the decision to continue care (Archbold, Stewart, Greenlick & Harvath, 1990; Hirschfeld, 1983). Caron & Bowers (2003) reported that the decision to continue care can

only be understood in the context of the relationship between the caregiver and care recipient as well. According to their study, it was only when the caregiver could no longer maintain a meaningful relationship with the care recipient that the caregiver would consider receiving help or institutionalizing their loved one.

Mutuality has also been defined as a communal feeling (that is, a feeling of having mutual concern for, and being responsive to one another's needs) (Williamson, Shaffer, & Schulz, 1998); having a high degree of communication and openness, a greater ability to resolve interpersonal conflicts, a greater degree of caring and affection, intimacy and closeness, more satisfaction with relationship roles, and more overall relationship satisfaction (Steadman, Tremon, & Davis, 2007); and enjoying feelings of general closeness, communication, a similarity of life views, and a higher degree of getting along together (Lawrence, Tennstedt, & Assmann, 1998). Lawton and colleagues (1991) found the positive experiences of caregiving include enjoying the spouse's (who has dementia) company, being happy when their spouse was happy or showed appreciation, or just being happy knowing that their spouse was getting good care.

Unlike informal caregivers, such as nurses, informal caregivers usually have an existing relationship history with the care recipient. Research findings indicate that a positive caregiver-care recipient relationship prior to onset of dementia, is critical in fostering positive caregiver experiences (Archbold, Stewart, Greenlick & Harvath, 1990; Kramer, 1993b; Lawrence, Tennstedt, & Assmann, 1998; Williamson, Shaffer, & The Family Relationships in Late Life Project, 2001). Kramer (1993b) reported interpersonal variables such as marital history and quality of the relationship prior to onset of dementia

to be the most important predictors of positive experiences. Other researchers reported the relationship quality with the care recipient (Kramer, 1993a), more time spent with the care receiver (Kinney & Stephens, 1989), and social support that caregivers received (Talkington-Boyer & Snyder, 1994) were associated with perceived positive caregiver experiences.

In a study of dementia caregivers, those with high relationship satisfaction prior to onset of dementia, had significantly less burden, less reactivity to memory or problem behaviors, better problem solving skills, and more effective communication skills (Steadman, Tremont, & Davis, 2007). Conversely, low mutuality in the relationship before the onset of illness predicted depression, lower quality of life (Kramer, 1993a), resentment (Williamson, Shaffer, & Schulz, 1998), potentially harmful behaviors, greater likelihood of abuse (Williamson, Shaffer, & The Family Relationships in Late Life Project, 2001), negative mood disturbances, more perceived burden (Archbold, Stewart, Greenlick, & Harvath, 1990; Schumacher, Stewart, & Archbold, 2007), and angry feelings (Schumacher, Stewart, Archbold, Caparro, Mutale, & Agrawal, 2008).

1.2.3 Overall Purpose of Dissertation and Specific Aims

The overall purpose of this dissertation is to explore how some caregivers of care recipients with dementia are able to have positive caregiving experiences despite the difficulties of non-reversible cognitive and physical decline in the care recipient. Existing research suggests that finding meaning in caregiving, especially through a positively perceived relationship with the care recipient, is a critical component to positive

caregiving experiences. Thus the papers of the present dissertation focused on how the relationship between the caregiver and care recipient changes over time, and how this relationship differs between dementia caregivers who report positive caregiving experiences and those who do not. Finally, the caregivers who found positive personal meaning in caregiving were interviewed to learn how they were able to do so.

2. Correlates of Care Relationship Mutuality among Caregivers of People with Alzheimer's and Parkinson's Disease

Mutuality, the perceived quality of a caregiver[1] - care recipient relationship, is reported to ameliorate the stress of informal caregiving and motivate family members and other informal caregivers to continue providing home care (Archbold, Stewart, Greenlick, & Harvath, 1990; Kesselring et al., 2001). However, few published studies describe factors affecting caregiver mutuality over time. Alzheimer's and Parkinson's disease, two common progressive neurodegenerative diseases, result in non-reversible physical and cognitive loss and increased functional dependencies (Nussbaum & Ellis, 2003) which may have a negative influence on caregiver mutuality. This paper describes factors correlated with caregivers of people with Alzheimer's and Parkinson's disease perceptions of care relationship mutuality over a 12 month period.

2.1 Background

2.1.1 Alzheimer's Disease and Parkinson's Disease Caregiving

Alzheimer's disease (AD), a type of dementia, involves loss or decline in memory and other cognitive abilities, as well as physical abilities over time (Alzheimer's Association [AA], 2010). Parkinson's disease (PD) is a group of motor system disorders, involving tremor, rigidity, bradykinesia and postural instability due to a loss of dopamine producing brain cells (National Institute of Neurological Disorders and Stroke, 2008).

---

[1] 'Caregiver', the more common term in American English, is used in the current dissertation for consistency between chapters. 'Carer', was used in the original journal article written in British English (Shim, Landerman & Davis, 2011; refer to reference list).

Twenty four to 31% of those with PD also have dementia in the later stages of the disease (Aarsland, Zaccai, & Brayne, 2005). In 2010, AD was the 7th leading cause of death in the United States (US) and there were more than 5 million people over 65 years old with the disease (AA, 2010). More than 1.5 million were reported to have PD in the US (National Institute of Neurological Disorders and Stroke, 2008). The worldwide prevalence of AD was 26.6 million in 2006 (Brookmeyer, Johnson, Ziegler-Graham, & Arrighi, 2007), but not well documented for PD. The National Parkinson Foundation (2010) estimates approximately 4 to 6 million people with PD across the world. Both being age-related diseases, the incidence of both diseases, is anticipated to further increase with the aging population.

Most individuals around the world with chronic degenerative disease are still cared for in the home by informal caregivers such as family, friends or neighbors (cf. AA, 2010; Lee, Friedmann, Picot, Thomas, & Kim, 2007; O'Rourke & Tuokko, 2003). Long-term chronic illness caregiving in progressive diseases such as Alzheimer's and Parkinson's disease has been correlated with a number of negative physical, psychological, emotional, social or financial problems for families and other informal caregivers (Gainey & Payne, 2006; George & Gwyther, 1986). Studies from different countries document higher burden among AD and PD caregivers when compared to other chronic disease groups (Acton, 2002; O'Reilly, Finnan, Allwright, Smith, & Ben-Shlomo, 1996,). Dementia caregivers have been reported to have more depressive symptoms (Pinquart & Sorensen, 2004), and higher morbidity and mortality than non-dementia caregivers (Schulz & Beach, 1999). Both AD and PD caregivers are reported to involve

similar length of time providing care, similar levels of distress and both more depressed than caregivers of other diseases (Dura, Haywood-Nile, & Kiecolt-Glaser, 1990).

2.1.2 Mutuality

Mutuality is concerned with the degree of caring, affection, intimacy, mutual concern and overall relationship satisfaction experienced by those involved (Steadman, Tremont, & Davis, 2007). Caregiving has a high interpersonal stress component, so the manner of interaction and use of interpersonal relationship strategies that build and sustain mutuality are suggested to be very important (Kramer, 1993a). Kramer describes positive caregiver relationship strategies as negotiation, compromise, considering the other person's limitations, empathy, and compassion. Negative relationship strategies involve criticizing, ignoring, confronting, or minimizing communication.

A sense of positive mutuality reportedly ameliorates the negative effects of caregiving (Archbold et al., 1990). In the existence of cognitive decline, mutuality has been noted to be the ability of the caregiver to find gratification from the relationship by perceiving the demented family member to reciprocate by virtue of their existence (Hirschfeld, 1983). For instance, high mutuality before dementia onset was found to be related to less caregiver depression (Kramer, 1993b), less potentially abusive behaviors towards the care recipient (Williamson, Shaffer, & The Family Relationships in Late Life Project, 2001), significantly less stress, less reactivity to problem behaviors, better problem solving skills and more effective communication skills with care recipient (Steadman et al., 2007). In PD as well, increased mutuality was associated with less PD severity, less caregiver burden and less depression of both the spouse and PD care

recipient (Tanji et al., 2008). Previous studies suggest that both care recipient and caregiver factors influence caregiver mutuality and thus impact caregiver outcomes.

2.1.3 Care Recipient Factors that Influence Mutuality

Care recipient factors reported to influence mutuality are the care recipient's level of cognitive or physical functional ability. Cognitive impairment has been reported to negatively impact caregiver mutuality in several studies (Lawrence, Tennstedt, & Assmann, 1998; Williamson et al., 2001). This may be due to the loss of shared common memories and interactions or changes in personality and troubling problem behaviors such as paranoia and delusional ideation, hallucinations, aggressiveness, affective disorders, and wandering associated with AD (AA, 2010). Increasing cognitive impairment associated with AD also makes it more difficult to maintain high levels of mutuality as the disease progresses. While the correlation of cognitive loss with caregiver mutuality has received little attention, the reported 6-10% loss of cognitive function in AD each year (Doraiswamy & Kaiser, 2000) justifies exploring this linkage.

In PD, mutuality has been reported to decline as the disease progresses and begins to involve both sides of the body i.e. a score of 2 or higher on the 5-point Hoehn and Yahr PD screening measure (Carter et al., 1998). Mutuality has also been reported to decline over time in caregivers of the frail elderly (Lyons *et al.* 2007) and post bypass surgery adults (Kneeshaw, Considine, & Jennings, 1999). In frail older adults, physical disability has also been reported to have significant negative effects on caregiver mutuality (Lyons, Sayer, Archbold, Hornbrook, & Stewart, 2007). These researchers

found that worsening care recipient health was related to declines in caregivers' perceptions of mutuality over a 20 month period.

2.1.4 Caregiver Factors that Influence Mutuality

Perceived relationship mutuality reportedly differs between men and women. In a study comparing AD and PD spousal caregivers, only AD female caregivers showed worse mental health outcomes, possibly due to loss of reciprocity and mutuality compared to males (Hooker, Manoogian-O'Dell, Monahan, Frazier, & Shifren, 2000). There were no differences between PD wives and husbands. On the other hand, among 118 caregiving couples, Wallsten (2000) found husband caregivers to consistently report higher mutuality towards their wives although wives had more social support from others around caregiving. Although literature identifies differences among caregiver characteristics by age and race (Connell & Gibson, 1997), mutuality between caregiver and care recipient has not yet been revealed to differ by these factors. Because the association of these factors to mutuality is unknown they were included in initial analyses.

The caregiver-care recipient kin relationship influences mutuality as well. Husband-wife, child-parent, friend-friend dyads are reported to result in different expectations from the care recipient and different interactions with the care recipient, thus resulting in different care situations and interactions (Gerdner, Tripp-Reimer, & Simpson, 2007; Raschick & Ingersoll-Dayton, 2004). Spouses may report different levels of mutuality than non-spouse caregivers. Published reports indicate spouses experience greater emotional, physical and financial stress from caregiving than adult children (George & Gwyther, 1986), which may have a more negative impact on mutuality.

Various investigators have reported lower mutuality predicts higher number of depressive symptoms for caregivers (Lawrence et al., 1998, Williamson et al., 2001). Depressive symptoms can lead to deterioration in couples' interpersonal behavior and interactions (Williamson et al., 2001). Lyons and colleagues (2007) reported that not only was higher mean depression related to lower mean mutuality, but increasing depressive symptoms predicted declining mutuality. Although the temporal sequence of depressive affect and relationship mutuality is unclear, that is, whether depressive symptoms results in lowered mutuality or lower mutuality causes an increase in depressive symptoms, the two have been closely related for informal caregivers.

2.2 Project ASSIST (The Parent Study)

Data for this secondary analysis were from Project ASSIST (*Assistance, Support and Self-health Initiated through Skill Training*), a 5-year, prospective, longitudinal, 2-group randomized trial (NINR RO1 008285) designed to increase caregiving preparedness, reduce depressive symptoms and care burden for informal caregivers of older adults with Alzheimer's or Parkinson's disease.

ASSIST participants were recruited from memory clinics, general geriatric clinics, private medical practices and home care agencies and support groups in two regions of the United States.. After informed consent was obtained, baseline data was collected and caregivers were randomly assigned to either the intervention group (ASSIST training) or the control (social call) group. The intervention group received intensive skills training and information, while the control group received 3 monthly short social phone calls to talk about neutral or casual topics. Participants of the control

group were given the option to receive the intervention, after the 1 year study period. Key caregiver and care recipient measures were repeated during home visits at 6 and 12 months after baseline in both groups.

2.3 The Study

2.3.1 Aim

The aim of the secondary analysis was to explore whether selected caregiver or care recipient factors that are related to change in mutuality over time. This information can provide researchers with information on the critical time points and factors of change in caregiver mutuality. Specifically, we examined whether mutuality differed by care recipient factors (level of physical and cognitive ability) or caregiver factors (age, gender, race, kin relation to care recipient, depressive symptoms, years of caregiving).

2.3.2 Sample

A total of 187 dyads (102 AD and 85 PD dyads), of whom 80% were women, 79% White, and 71% were spousal caregivers, participated in Project ASSIST, the parent study. Project ASSIST's AD caregivers had been caregiving for a duration mean of 4.5 years, and the PD caregivers 8.8 years. One hundred and fifty two caregivers (81%) completed the 12 month participation protocol and final assessment. Among these caregivers, data on the 91 caregiver-care recipient dyads in the control (social call) group who completed the study were used for the current secondary analysis.

2.3.3 Instruments

The dependent variable of interest for this secondary analysis was caregiver mutuality and the independent variables were care recipient functional ability, caregiver age, gender, race, kin relation to care recipient, years of caregiving, and depressive symptoms. Variables that do not change over time were collected at baseline with a demographic questionnaire. Variables that change over time, such as caregiver mutuality, care recipient physical and cognitive dependence and level of depressive symptoms were collected by the following measures at all three time points.

2.3.4 Dependent Variable

Mutuality was measured by 'The Mutuality Scale of the Family Care Inventory' (Archbold et al., 1990). This tool includes 15 items. Sample items are "How close do you feel to him or her?", "To what extent do the two of you see eye-to-eye?", and are measured on a 5-point Likert scale from 0 "*not at all*" to 4 "*a great deal*". The individual score is calculated by the mean across all item scores, ranging between 0 and 4. The tool has been shown to have good stability over time (Archbold et al., 1990) and internal consistency as reflected in Cronbach' alphas at .90 to .95 in caregiver populations (Archbold et al., 1990; Carter et al., 1998; Kneeshaw et al., 1999). In the parent study, internal consistency for the mutuality scale at baseline was .93.

2.3.5 Independent Variables

2.3.5.1 Care Recipient Functional Ability

The Lawton Instrumental Activities of Daily Living Scale (IADL) is often used to measure physical and cognitive dependence in dementia individuals. The IADL scale

measures the care recipient's level of cognitive, motor and decision making ability (Lawton & Brody, 1969). Research has reported IADL scores to be highly associated to physical ability (Judge, Schechtman, & Cress, 1996) and cognitive impairment (Cromwell, Eager, & Poulos, 2003). Item scores range from 0 "*unable to do at all*" to 2 "*needs no help*". Total scores range from 0 to 16, with lower scores indicating higher level of disability or dependence. Sample items include "using the telephone", "taking medications" or "managing money". The IADL scale is commonly used in caregiver studies in different countries with Cronbach's alphas ranging from .85 to .93 (Gitlin et al., 2003; Izal, Montorio, Marquez, & Losada, 2005) and also demonstrating good stability over time at .73 (Lawton, 1988). In the parent study, internal consistency at baseline was .86.

2.3.5.2 Caregiver Depressive Symptoms

The Center for Epidemiologic Studies Depression Scale (CESD; Radloff, 1977) measures depressive symptoms by 20 items on a 4-point Likert scale or 0 "*rarely or none of the time*" to 3 "*most or all of the time*". Total scores range from 0 to 60 with higher scores indicating more depressive symptoms. The CES-D scale has been widely used in caregiver research and Cronbach's alphas ranged from .85 to .89 (Beeson, 2003). This scale also demonstrated good stability over time at .74 (Lewinsohn, Seeley, Roberts, & Allen, 1997). In the parent study, internal consistency was .86 at baseline.

2.3.6 Ethical Considerations

Human subjects' procedures for Project ASSIST were reviewed and approved by University Institutional Review Boards (IRB) in the two states that data were collected.

All consent procedures were conducted as approved, participant confidentiality was protected and data were kept secure.

2.3.7 Procedures

For the secondary analyses, data from the AD and PD control group dyads of project ASSIST, for baseline, 6 months, and 12 month assessments were stripped of identifiers and merged into one dataset.

2.3.8 Data Analysis

Pearson correlations were estimated for all caregiver and care recipient variables of interest to identify variables significantly related to mutuality. Multilevel (mixed) regression models were then used to estimate the relationships between potential predictors and mutuality at baseline and over time (Singer & Willett, 2003). With a multilevel model for change, a level 1 model of each subject's individual growth trajectory on the repeated measures of the dependent variable is obtained. The level 2 model further describes how these trajectories differ across people by each independent variable of interest. Mixed models have the advantage of allowing for missing values, correlated error terms, and measurements taken at unequal intervals (Singer & Willett, 2003). All models were estimated using SAS PROC MIXED (SAS, version 9.2; SAS Institute; Cary, NC).

Given the small number of cases (91) and the large number of potential predictors (17 including product terms), we decided to screen predictors using initial bivariate models to maintain at least 10 cases per predictor (Harrell, Lee, Califf, Pryor, & Rosati, 1984), and avoid potential collinearity and overfitting of the sample data. Potential

predictors entered into these bivariate models included gender, age, ethnicity, education, spouse/non-spouse relationship, logged years of caregiving, time-varying caregiver CESD, and time-varying care recipient IADL. Each bivariate model tested the main effect of a predictor and its interaction with time. Based on initial diagnostic tests for normality and linearity, years of caregiving was skewed toward fewer years, and the log value was used in the analyses. The final regression model took the form: $Y_{ij}=\gamma_{00}+\gamma_{01}$(Logged years of caregiving)$+\gamma_{02}$(CESD)$+\gamma_{03}$(IADL)$+\gamma_{10}$(time)$+\gamma_{11}$(Logged years of caregiving*time)$+\zeta_{0i}+\zeta_{1i}$(time)$+\varepsilon_{ij}$. For the final model, variance inflation factor (VIF) scores for all variables were below 10, with the highest value being 2.695. (High VIF scores indicate high multicollinearity and instability of coefficients).

Analyses included an analysis of 'missingness' to ensure that missing data were missing at random. The analysis of missingness assessed for a relationship between independent variables of caregivers lost to attrition. Any measures in which missingness was a potential confounder were to be included in the final model as a covariate.

2.4 Results

Fifteen caregivers from the control group (16%) dropped out by T3. They did not significantly differ from those who remained in caregiver gender, race, education, depressive symptoms, years of caregiving, kin relation to care recipient or care recipient functional ability. They did however have a trend (p=0.09) of being younger in age.

The characteristics of the 91 caregivers in the control group and their care recipients are shown in Table 1. Approximately half of the participants were caring for those with Alzheimer's disease, and the other half Parkinson's disease. Additional mixed

models revealed there were no significant changes over time in caregiver mutuality, depressive symptoms (CESD scores), or care recipient functional ability (IADL scores).

Table 1: Caregiver and Care Recipient Characteristics (n=91)

Characteristics		Mean (SE)	Range	N (%)
Caregiver	Age	65 (12.3)	23-98	
	Years of caregiving	6.3 (6.2)	0 - 25	
	Race			
	White			74 (81)
	African American			15 (16)
	Other			2 (2)
	Female			73 (80)
	Kin Relation			
	Spouse			59 (65)
	Adult Child			24 (26)
	Other			8 (9)
Care Recipient	Alzheimer's Disease			49 (54)
Characteristics		Baseline	6 months	12 months
		Mean(SD)	Mean(SD)	Mean(SD)
Caregiver	Mutuality scores	2.61 (0.8)	2.61 (0.9)	2.51 (0.8)
	CESD scores	13.6 (10.0)	14 (10.3)	12.5 (9.5)
Care Recipient	IADL scores	4.2 (3.6)	4.4 (4.0)	4.0 (3.9)

CESD, Center for Epidemiologic Studies Depression Scale; IADL, Instrumental Activities of Daily Living.

Pearson correlations for variables of interest at baseline were estimated for all 187 caregivers of the parent study to identify variables related to mutuality (Table 2).

Table 2: Pearson Correlations at Baseline (n=187)

	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)
Mutuality (1)	1	0.37***	-0.30***	-0.23**	0.26***	0.002	-0.03	0.001	0.10
CR-IADL (2)		1	-0.03	-0.14	0.02	0.15*	-0.04	0.11	0.14
C-CESD (3)			1	0.19**	-0.12	-0.04	-0.10	0.14	-0.14
Female (4)				1	-0.11	-0.07	-0.06	-0.08	-0.23**
Years of care (5)					1	0.23**	0.08	0.12	0.06
Spouse (6)						1	0.57***	0.35***	-0.24**
C-Age (7)							1	0.34***	-0.09
White (8)								1	-0.06
CG-Education (9)									1

C, Caregiver; CR, Care Recipient; CESD, Center for Epidemiologic Studies Depression Scale; IADL, Instrumental Activities of Daily Living.
* p<.05, ** p<.01, *** p<.001

Mutuality was significantly related to care recipient functional ability, caregiver depressive symptoms, being female, and the length of caregiving. In order to determine which variables to include in the final model, bivariate mixed models analyses were performed between each variable and mutuality. Table 3 presents the results of bivariate and multivariate mixed models for the effects of each predictor on mutuality. Two types of coefficients are presented in column 1 for each bivariate predictor. The coefficients in the upper panel give its effect on baseline mutuality while the (coefficient by time) product terms in the lower panel indicate whether the effect of time (trajectory of change over time) varied across levels of that predictor. For example, logged years of caregiving was associated with an increased mutuality (.309**). However its interaction with time in the lower panel (-.002) was not significant, indicating that change in mutuality over time did not vary with logged years of caregiving. Caregiver depressive symptoms and care recipient functional ability also had significant effects on baseline mutuality, but not on change in mutuality over time. Given our limited sample size, only significant bivariate effects were included in the multivariate model (column 2), where the effects of each predictor are estimated controlling for one another. For time logged years of caregiving, including its (non-significant) interaction with time in our multivariate model enabled us to estimate its effect on baseline mutuality. For caregiver depressive symptoms (CESD) and care recipient functional ability (IADL), non-significant product terms were dropped in order to estimate their time-changing effects on mutuality, averaged over time. This differential handling of time-invariant and time-changing predictors is consistent with recommended practice (Singer & Willett, 2003).

Table 3: Mixed Models Results: Bivariate and Multivariate Effects of Predictors on Mutuality (n=91)

Predictor	Bivariate models		Multivariate model	
	Estimate	SE	Estimate	SE
Intercept	--[a]		2.166**	
Female[b]	-.260	.208		
Spouse[b]	-.011	.175		
Log(years of caregiving) [b]	.309**	.110	.278*	.106
C-CESD[c]	-.011*	.005	-.010*	.004
CR-IADL[c]	.035*	.014	.026*	.012
Age[b]	.001	.007		
White[b]	.163	.214		
Education[b]	.295	.172		
Time	-.045	.025	-.068	.067
Female*time	-.035	.067		
Spouse*time	-.031	.054		
Log(years of caregiving)*time	-.002	.036	.016	.035
C-CESD*time	-.000	.003		
CR-IADL*time	-.006	.007		
Age*time	.002	.002		
White*time	.002	.062		
Education*time	.052	.054		

C, Caregiver; CR, Care Recipient; CESD, Center for Epidemiologic Studies Depression Scale; IADL, Instrumental Activities of Daily Living.

* p<.05, ** p<.01

[a] Because each bivariate model has a different intercept, we do not report intercepts for the bivariate models in this table.

[b] Time-invariant predictor.

[c] Time-changing predictor.

Results from the multivariate model show that logged years of caregiving was associated with a mean increase of .278 in mutuality at baseline. Higher average recipient IADL score was associated with higher mutuality (.026) at each time point, while higher average caregiver CESD score was associated with lower mutuality (-.010).

2.5 Discussion

2.5.1 Study Limitations

Findings from this study should be interpreted within the context of study limitations. As in any secondary analysis, variables or measures that can be analyzed are limited to those of parent study. Also, in order to prevent potential effects of the intervention on mutuality, the parent study intervention group was excluded from analysis. The control group received monthly social calls for the first three months after recruitment during the one year data collection period. This retention strategy was considered unlikely to affect caregiver mutuality.

A longer study period may have captured significant changes in mutuality. However even the 12 month follow-up period provides longitudinal data variables reported to influence mutuality. Future studies should include data collection with larger samples over longer periods of time to provide a better understanding of factors that influence changes in mutuality among caregivers of degenerative diseases.

2.5.2 Discussion of Findings

Longitudinal studies provide information on trajectories of change over time on variables of interest, and enable a closer look into causal relationships between variables (Taris, 2000). Using longitudinal analysis methods, we were able to investigate individual trajectories of mutuality over time, and then whether these trajectories differed based on care recipient functional ability, caregiver gender, kin relation to care recipient and years of caregiving. These analyses focused on factors reported to influence caregivers' perceived mutuality among these 91 AD and PD caregivers. Findings indicated factors

related to lower mutuality for these caregivers were, lower functional ability in the care recipient, shorter length of caregiving, and higher levels of depressive symptoms for caregivers.

In this secondary analysis, mutuality did not significantly decline over time. This may be because one year was not sufficient enough to capture change, or care recipients did not experience significant degeneration during the 12 month period. Previous research show conflicting results. Using a retrospective method, PD spousal caregivers' mutuality declined in Stage 2 of the disease (Carter et al., 1998) and Kneeshaw and colleagues (1999) reported that mutuality declined over a 6 month period of time in caregivers of patients discharged from bypass surgery. However Lyons and colleagues (2007) found that caregivers of frail older adults' mutuality did not significantly decline over a 20 month period. More research with longer periods of data collection is needed to determine whether mutuality actually changes over time in degenerative diseases and why.

Study findings identified differences among caregivers by length of caregiving. Caregivers who had been caregiving for longer periods of time had significantly higher mutuality. The Alzheimer's Association (2010) reports that about one third of dementia caregivers care for more than 5 years. The present study shows that these caregivers had significantly higher mutuality than those with short lengths of caregiving, supporting earlier reports that high mutuality is an important motivator for continuation of care (Archbold et al., 1990; Caron & Bowers, 2003). Another explanation may be that high mutuality lessens the likelihood that caregivers will institutionalize the care recipient

(Kesselring et al., 2001). Caron and Bowers (2003) suggest the relationship between the caregiver and care recipient is a critical factor for the decision to continue care. Feelings of gratitude, love, trust or responsibility towards the care recipient may motivate caregivers to initiate and continue care. On the other hand, caregivers with lower mutuality may relinquish care earlier in the experience.

Caregivers of individuals with low functional ability perceived significantly lower mutuality towards their care recipient. These results are consistent with previous literature. Low functional ability indicates that the care recipients have more difficulty independently executing tasks that require normal cognitive and physical function. In both AD and PD, unpredictable, non-reversible decline in cognitive and physical ability occurs with disease progression. Individuals with AD have personality changes, or loss of memory and communication skills which may decrease the caregivers' perceived mutuality. Severe physical dependence has also been reported to decrease mutuality in frail older adults (Lyons et al., 2007).

Our findings are consistent with previous studies reporting a significant relationship between caregivers' depressive symptoms and mutuality (Lawrence *et al.* 1998, Williamson et al., 2001). While Lyons and colleagues (2007) reported that more caregiver depressive symptoms increased declines in mutuality, we did not see these results in this analysis. This may be because the caregivers in the parent study were not highly depressed (mean CESD scores range from 12.5 to 14).

In summary, this study suggests that high mutuality between caregivers and their care recipients increases the likelihood of caregivers to continue care. Longer length of

caregiving was correlated with greater mutuality in this study. Furthermore, mutuality was negatively affected by low care recipient functional ability and more caregiver depressive symptoms. These study results have important research and clinical implications. Although we may not be able to change perceived mutuality itself, as suggested by Kramer (1993a) positive relationship strategies (negotiation, compromise, considering the other person's limitations, empathy, and compassion) can promote better health outcomes among caregivers of degenerative diseases. By providing accurate information and understanding about the disease progression, clinicians can enable the caregiver to set realistic expectations and be more empathetic towards their care recipient. On the other hand, negative relationship strategies such as confronting, criticizing, ignoring or minimizing can damage relationships further. Herbek and Yammarino (1990) found that empathy building and interaction improvement training on formal caregivers (nurses), was not only effective in building empathy towards patients, but also seemed to improve the nurses' job satisfaction. Interventions that teach informal caregivers empathy-building skills and positive relationship focused coping strategies can provide caregivers with tools for a more positive caregiving experience. Also, mutuality being a concept between at least two people should probably be surveyed from all parties involved. The mutuality scale from the parent study was developed to measure the caregiver's perception of the relationship quality with the care recipient. As relationship quality may be perceived differently by each party, future studies should also include the care recipient's perception of the relationship whenever possible.

2.6 Conclusions

Findings from these secondary analyses indicate that the caregiver's relationship mutuality is an important factor in long-term caregiving for an individual with a progressive chronic disease such as AD or PD. Given that caregivers can perceive the care relationship to continue having a positive quality, despite the functional losses of the care recipient and the increasing challenges of caregiving, there is strong support for developing and testing nursing interventions that promote or enhance care relationship quality. Not only can this potentially prevent premature institutionalization, but it also may enhance the caregiving experience for both caregiver and care recipient over time.

3. A Qualitative Analysis of Caregiver Stories on Caring for Spouses with Dementia

3.1 Introduction

Caregivers of individuals with dementia describe a wide spectrum of reactions to caregiving experiences, from resentment, depression, helplessness and isolation (Beeson, 2003; Rodriguez, De Leo, Girtler, Vitali, Grossi, & Nobil, 2003), to feeling value, love, gratitude, satisfaction, or finding personal meaning (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991; Lawton, Moss, Kleban, Glicksman, & Rovine, 1991). Why do the experiences of these spousal caregivers of individuals with dementia seem to be so different? Is it because of the prior marital relationship qualities, the caregiver's personality or worldview, or is it the care recipient's disease characteristics? Or some combination of all of these? The aim of this study was to explore how caregiving experiences of spousal Alzheimer's disease (AD) caregivers differed. The results of this study are intended to provide a better understanding of dementia caregivers who have a more positive caregiving experience in generally overwhelmingly negative situations. This information may provide researchers and clinicians with better ways to aid caregivers who are struggling for a more positive caregiving experience.

3.2 Background

3.2.1 Alzheimer's Disease Caregiving

Alzheimer's disease (AD), the most common type of dementia in the United States (Alzheimer's Disease International [ADI], 2009), involves loss or decline in memory and other cognitive abilities, as well as loss of motor abilities over time

(Alzheimer's Association [AA], 2010). In 2008, there were more than 5 million people over 65 years old with AD in the US (AA, 2010). The worldwide prevalence of dementia in 2010 is 35.6 million (ADI, 2010), and the global incidence and economic burden is anticipated to further increase with the global aging population (Brookmeyer, Johnson, Ziegler-Graham, & Arrighim, 2007). The worldwide estimated cost of informal and formal dementia care is 604 billion US dollars in 2010, of which 70% occur in Western Europe and Northern America (ADI, 2010). Most individuals with AD are cared for in the home by informal caregivers, estimated to be almost 11 million US dollars of unpaid family members or friends doing dementia caregiving in 2009 (AA, 2010). Approximately one third of dementia caregivers provide care for more than 5 years, and 12% provide care for more than 10 years (AA, 2010).

Based on the degenerative disease characteristics, research in dementia caregiving has largely been based on the social stress/burden model, which views the individual with dementia as a stressor that drains the caregiver's resources to cope with the burden of caregiving (Montgomery, Gonyea, & Hooyman, 1985; Pearlin, Mullan, Semple, & Skaff, 1990; Zarit & Bach-Peterson, 1980). Now research suggests the importance of studying the lived experience of caregivers for a more holistic understanding of what caregivers are going through, because their experiences can be vastly different even in externally similar situations, depending on how the caregiver interprets or constructs meaning in caregiving (Ayres, 2000a, b; Chesla; 1994; Farran, 1997; Nolan, Ryan, Enderby, & Reid, 2002). In many cases this stems from the relational context between caregivers and their

care recipients (Cartwright, Archbold, Stewart, & Limandri, 1994; Chesla, Martinson, & Muwaswes, 1994; Hellstrom, Nolan, & Lundh, 2005a; Kramer, 1993b).

The disease characteristics of dementia usually change the relational context between the caregiver and care recipient. Caregivers face a fundamental change in the person they are caring for. Due to the characteristics of the disease, the care recipient progressively goes through loss or changes in memory, cognitive function, recognition, and personality, leaving the caregivers caring for someone who is not the person that they once knew. Spousal caregivers in later life have been found to express an additional loss of meaning in life itself, and a sense of disconnection with the sick spouse in diseases with cognitive impairment (Zuckerberg, 2006). Especially if the care recipient becomes violent or shows other problem behaviors, it is not hard to imagine the cognitive shifts the caregiver must go through and the patience needed to effectively cope. Dementia caregivers have an additional emotional turmoil that makes their caregiver burden different from that of caregivers of other diseases.

3.2.2 Negative Caregiving Experiences

As a consequence, much of previous caregiving research documents many stressful or problematic negative caregiving experiences. Long-term chronic illness caregiving in progressive diseases such as Alzheimer's disease has been correlated with a number of negative physical, psychological, emotional, social or financial problems for families and other informal caregivers (Gainey & Payne, 2006; George & Gwyther, 1986). For instance, caregivers showed 63% higher mortality risk in a 4 year longitudinal study than non-caregivers (Schulz & Beach, 1999), as well as more depression (Pinquart

& Sorensen, 2003; Schulz & Sherwood, 2008), decreased employment rates (AA, 2010), and increased future poverty risks in women (Wakabayashi & Donato, 2006). This may potentially lead to more elder abuse, or lower quality of provided care (Gainey & Payne, 2006), or early termination of the caregiving situation due to caregiver burnout (Bedard, Molloy, Squire, Dubois, Lever, & O'Donnel, 1997; Chenier, 1997).

Spousal caregivers may have more negative experiences than other informal caregivers around dementia care because the caregivers themselves are older adults and have multiple chronic diseases of their own (George & Gwyther, 1986). They also report higher levels of loneliness and depression (Beeson, 2003; Bergman-Evans, 1994). As the care recipient's cognitive loss worsens and personality changes, dementia caregivers experience the emotional loss of the care recipient and social isolation (Rodriguez et al., 2003).

Specifically in dementia caregiving, Clyburn and colleagues (2000) identified three dominant factors that contributed to negative experiences: care recipient factors, caregiver factors, and caregiving context factors. Care recipient factors include physical and cognitive decline, personality changes or neuropsychiatric symptoms such as behavioral and psychotic disturbances (Donaldson & Burns, 1999). According to Bergman-Evans (1994), dementia caregivers feel like their care recipient is becoming a stranger, which leads to loss of the previous relationship and lack of companionship. This is worsened by the fact that because of the need for constant supervision, the caregiver is usually confined to the house and isolated from other social contacts and supports. Unmet communication needs or communication problems also elevated perceived burden in the

caregiver and problem behaviors in care recipients (Fried, Bradley, O'Leary, & Byers, 2005; Savundranayagam, Hummert, & Montgomery, 2005). Other challenges for the dementia caregiver include managing difficult problem behaviors such as paranoia and delusional ideation, hallucinations, aggressiveness, affective disorders, and wandering (Farran, Gilley, McCann, Bienias, Lindeman, & Evans, 2007; Robinson, Adkisson, & Weinrich, 2001). Caregiver factors contributing to negative experiences include the caregiver's personality, cultural beliefs, perceived resources, feelings of situational overload, resentment, fatigue and relational deprivation (Pearlin et al., 1990). For example, some caregivers feel trapped in their role of caregiving (defined as 'role captivity' by Pearlin et al., 1990). Women and caregivers of certain cultures express more feelings of anger, anxiety during care, and guilt and sadness associated with wanting to relinquish care (Rudd, Viney, & Preston, 1999; Spitzer, Neufeld, Harrison, Hughes, & Stewart, 2003). Caregiving contextual factors contributing to care burden include the lack of social or community resources and family or support networks (Pearlin et al., 1990).

3.2.3 Positive Caregiving Experiences

Despite the many difficulties, not all caregivers have negative experiences (Pinquart & Sorensen, 2003). We may be able to learn valuable strategies from caregivers who are thriving in their caregiving. Yet research on positive caregiving experiences has not received much attention. More and more researchers reveal important findings on the positive aspects of caregiving and how some caregivers were able to achieve them. Some caregivers report significant gratification or positives from caregiving (Cohen, Gold, Shulman, & Zucchero, 1994; Park & Folkman, 2007; Kinney & Stephens, 1989; Lawton

et al., 1991; Motenko, 1989; Picot, 1995a, b), while Klein (1989) viewed the burden of caregiving as a foundation for moral development, individual dignity or social influence. Kramer (1997) defined positive caregiving experiences as situations where the caregiver appraises caregiving as enhancing or enriching their life. Lawton and colleagues (1989) distinguished uplifts from caregiving satisfactions. Uplifts are small events that evoke some response of pleasure, affirmation, or joy in the caregiver, and the cumulation of daily uplifts are thought to compose caregiving satisfaction, a more stable expectation, with periodic confirmation. Of course the goal as a researcher or provider would be enhancing long-term positive experiences for dementia caregivers.

3.2.4 How Some Caregivers have Positive Caregiving Experiences

There are several theoretical suggestions or research trends on how some caregivers may achieve positive caregiving experiences. Farran (1997) suggested existentialism, which views caregiving as a source of finding meaning in life. In other words, seeking meaning in times during which an individual is experiencing helplessness, anxiety, meaninglessness or isolation, which are common in dementia caregiving, is a choice that the caregiver can make out of his/her situation. Furthermore, the existential domain has been found to play an important role in the perception of an individual's quality of life (Cohen et al., 1996). An increasing number of researchers report findings that support the importance of finding meaning in caregiving for a positive experience (Ayres, 2000a, b; Baumeister, 1991; Norman, Redfern, Briggs, & Askham, 2004; Park & Folkman, 1997). This process of finding meaning or pleasure for both caregiver and care recipient has been described as 'enrichment' and it is achieved by acquiring symbolic

meaning through activities or objects, performing activities that keep their lives as much the way as it was, fine tuning to accommodate changes, creating customary routines for the day and innovative routine breakers that add a bit of stimulation to each day (Cartwright et al., 1994).

Frankl (2006) suggested three ways through which individuals can find meaning in life: 1) through a work or deed, 2) by experiencing beauty, goodness, truth, nature, culture; or encountering another human being in his/her very uniqueness by loving him/her; or 3) choosing an attitude toward unavoidable suffering and being challenged to change oneself. Research reveals all three in caregivers who report positive caregiving experiences. Because caregiving is a dynamic interaction between the caregiver and care recipient, caregivers find meaning in caring for that person, in experiencing a different, perhaps deeper love for them as they become increasingly dependent, and in challenging the self to accept and rise above the difficulties of caregiving to make it a worthwhile experience. For instance, Hirschfeld (1983) found that dementia caregivers who had better health outcomes were those who could find gratification from the relationship by perceiving the individual with dementia to reciprocate by virtue of his or her existence. Results from a study by Motenko (1989) suggest that spouses who give care out of reciprocity and love perceived many uplifts, whereas spouses who provided care primarily out of responsibility did not.

Recently, more attention has been focused on preserving the personhood/self of the individual with dementia (Hellstrom et al., 2005a; Perry & O'Connor, 2002). Maintaining the dignity, autonomy and sense of self (personhood) in the individual with

dementia is not only beneficial to that person, but also for the integrity of the relationship and caregiver him/herself in doing so for them (Hellstrom et al., 2005a). Caregivers achieve this by maintaining continuity, sustaining existing competencies, protecting the care recipient from incompetence, and strategizing public encounters (Perry & O'Connor, 2002). Hellstrom and colleagues (2007) expand this to exploring strategies of maintaining the 'couplehood' between the caregiver and spouse, recognizing that sustaining the personhood of the individual with dementia cannot be achieved alone. Strategies spouses used for a positive caregiving experience were talking things through, being affectionate and appreciative, making the best of things, keeping the peace, maintaining involvement and moving on (Hellstrom, Nolan, & Lundh, 2007).

Whether the focus is finding meaning or preserving the personhood of the individual with dementia, research suggests that positive caregiving experiences stem mainly from the dynamic between the caregiver and care recipient. Therefore, based on previous research, this analysis focused on answering the following research questions: 1) What was/is the caregiver-care recipient relationship like?, 2) How were caregivers who reported positive experiences in caregiving different from those who could not?, and 3) What meaning did caregivers find in the experience of caregiving? Interviews from an existing study were analyzed across three points in time over a one year period.

3.3 Methods

3.3.1 Design

This study was a secondary analysis of interviews collected during a longitudinal caregiver skill training intervention of Alzheimer's disease (AD) and Parkinson's disease

(PD) caregivers (NINR RO1 008285, PI L.L. Davis). The purpose of this study was to delineate the characteristics of spousal AD caregivers who reported positive experiences versus those who did not. Interviews of spousal caregivers of individuals with AD were included to target a potentially more vulnerable population because these caregivers are older adults, caring for life partners with a cognitively deteriorating disease. Caregivers in the intervention group were excluded to prevent treatment effects on the caregivers' responses. Interview data were collected at baseline (enrollment), 6 months, and 12 months post-enrollment.

3.3.2 Sample

The parent study had a total of 187 caregivers (102 AD and 85 PD caregivers), of which 80% were women, 79% White, and 71% were spousal caregivers. The control group originally had a total of 25 AD spouse caregivers, but three caregivers dropped out after the death of the individual with dementia. From the 22 remaining AD caregivers one caregiver was further excluded as there was missing or insufficient interview data for analyses.

Thus the analysis included a total of 57 interviews from 21 spousal caregivers of individuals with AD. There were 16 wives and 5 husbands. Seventeen were White, two Black and two reported as other. Mean caregiver age was 71 years old and mean AD care recipient age was 75.5 years old. The mean length of time of caregiving was 6 years. At the baseline interview all caregivers and care recipients were living at home in the community. However, during the course of the parent study, six care recipients were institutionalized or in a rehabilitation unit at the time of the second or third interview.

Caregiver characteristics are depicted in Table 1. Caregivers are numbered to provide demographic context for their quotations in the results.

3.3.3 Data Collection Procedures

3.3.3.1 Project ASSIST (The Parent Study)

The parent study was a prospective, longitudinal, 2-group experimental study design. The aim of the study was to test the effects of a caregiver intervention designed to increase caregiver preparedness, and reduce depressive symptoms and care burden in caregivers of Alzheimer's and Parkinson's disease. Caregiver-care recipient dyads were recruited from memory clinics, general geriatric clinics, private medical practices, home care agencies and support groups in two regions of the United States. After informed consent was obtained, baseline data were collected and caregivers were randomly assigned to either an intervention group or a friendly phone call control group.

Interviews were conducted at three time points at the caregiver's home, baseline, 6 months and 12 months for each caregiver. Interviewers were female social workers or nurses trained to use the research project interview guide. Training processes included simulated interviews among peers (other study personnel) and the principal investigator (PI), observing others conducting the interviews and doing interviews with the PI for feedback. Interviewers kept field notes for interviews. Finally, interviewer consistency in conducting interviews was checked by the PI or project manager on an on-going basis. Interviews with caregivers were recorded simultaneously by two tape recorders to ensure data capture. Caregivers were interviewed about the three most challenging or difficult situations and three most satisfying caregiving situations during the past month before the

interview. Interview questions were: 1) describe three aspects (or areas of things) of caregiving that you find most difficult or stressful that has occurred in the past month, and 2) describe three aspects of caregiving that stand out as being positive or having gone well in the last month. All interviews were transcribed verbatim, and both tapes and transcriptions were stored in secure cabinets accessible only by project team members.

De-indentified interviews (those stripped of identifiable variables) were obtained for the secondary analyses by permission of the PI. All data relevant to the three research questions of this study were extracted to separate sheets on word documents. Data tables for each individual's time 1 (baseline), time 2 (6 months after baseline) and time 3 (12 months after baseline) interviews were created and extracted data were entered into corresponding columns. All of the interviews for each caregiver were read several times to include all relevant data in the tables.

3.3.3.2 Ethical Considerations

Human subjects procedures for Project ASSIST were reviewed and approved by University Institutional Review Boards (IRB) in the two states in which data were collected. All consent procedures were conducted as approved, participant confidentiality was protected, and data were kept secure. Only unidentifiable data were obtained for this secondary analysis.

3.3.4 Data Analyses

Interview data were analyzed by manifest and latent content analysis techniques (Boyatzis, 1998). Manifest content analysis is the analysis of the visible or apparent content, while latent content analysis is the analysis of the underlying aspects of the

phenomenon of interest, and thematic analysis enables the researcher to use both techniques at the same time (Boyatzis). These methods were used because the study questions differed from those of the parent study.

Interview data were analyzed across three time points, baseline, 6 months and 12 months, then analyzed longitudinally by individual caregiver. Data in these tables were entered for individual caregivers over time. Caregivers were first grouped depending on whether they reported positive or negative caregiving experiences. Sub-groups were then identified based on common characteristics in their answers to the three research questions.

Comparisons between the characteristics of the three groups of caregivers were made. Common themes were found across these caregiver groups based on the answers to the three research questions, such as how they described their past or current relationship with the care recipient, what types of positive caregiving experiences they reported, and if they suggested they had found meaning in their experiences. A data grid was created to compare caregiver characteristics such as caregiver education, age, race, gender, employment status, perceived social support, domestic abuse, institutionalization during the study, the care recipient's physical and cognitive ability and mutuality scores (the caregivers' perceived positive quality of the relationship with the care recipient), and care duration between the groups. Then another data grid was created by compiling all major themes and relevant quotes into tables to ensure group cohesiveness and group distinction. Independent reviews of the transcripts were conducted by an experienced qualitative

researcher to verify the trustworthiness of results and conclusions drawn from these analyses.

3.4 Results

Based on the three research questions, three groups of caregivers, a negative group, an ambivalent group and a positive group, were identified. Demographic details of these caregivers are presented in Table 4 to provide context of the narratives.

Table 4: Demographic Profile of Caregivers (n=21)

CG Group	ID	Age	Sex	Race	Total Edu (yrs)	Year Dx	Institution
Negative	CG1	74	Female	White	12	2002	N
	CG2	56	Female	White	20	2002	N
	CG3	71	Female	White	12	2003	N
Ambiguous	CG4	73	Female	White	14	1996	Y
	CG5	59	Female	Other	12	2001	N
	CG6	67	Female	White	12	.	N
	CG7	73	Female	White	12	1992	N
	CG8	76	Female	White	13	1995	Y
	CG9	73	Female	Black	12	1998	N
	CG10	79	Male	White	11	1994	N
	CG11	68	Female	Other	18	2005	N
	CG12	75	Female	White	12	2002	N
	CG13	47	Female	Black	11	2000	Y
	CG14	72	Female	White	12	1993	N
	CG15	77	Male	White	12	1999	Y
Positive	CG16	61	Female	White	11	2000	N
	CG17	91	Male	White	14	1995	Y
	CG18	72	Female	White	17	2001	N
	CG19	74	Male	White	15	1997	Y
	CG20	77	Female	White	18	2001	Y
	CG21	77	Male	White	17	1998	N

CG, Caregiver; Total Edu, Total years of education; Year Dx, Year of spouse's dementia diagnosis; Institution, Care recipient Institutionalized by 1 year after baseline; N, No; Y, Yes.

Caregivers showed descriptive differences in the narrative of their caregiving experiences on the level of positivity or negativity they perceived. The negative group caregivers perceived their caregiving experience negatively and could not report positives about it. The ambiguous

group caregivers reported mostly negative experiences and minimal positivity, while the positive group reported a pervasively positive experience, and minimal negativity.

3.4.1 The Negative Group

There were three caregivers in the negative group with similar, distinctive characteristics when compared to the other groups. First they described both their past and present relationship with their spouses in negative terms. Because of the abuse, hurt or mistrust from the existing relationship, it affected how they viewed their spouse's behavior in the present. Instead of attributing behavior or words to the disease as those in other groups did, they thought the negative behavior was a continuation of previous behavior.

> *"He always put me down and I haven't felt like I was capable of doing anything…He still wants to be the head. He insults me…. I've never had any sympathy from him so to speak" (CG3)*

> *"He does that (compliments) to other people, but he doesn't to me…. He also sees and hears better than he says. I think sometimes just to irritate me. I really think so. I really do." (CG1)*

In relation to their view of a current negative relationship, these caregivers were unable to describe positive or satisfying caregiving experiences in caregiving. They were unable to describe other-focused comments; their focus was on their own (unmet) needs and they described extreme burden from caregiving. Caregivers in the negative group did not mention any discomfort, pain, or confusion of the spouse with dementia. Any behavior or symptoms of the spouse with dementia was mentioned to describe how it

negatively affected them. The caregivers did not express empathy towards their spouse, which was different from the ambiguous group or positive group.

> *"I can't… cannot… you know it's real hard for me to say.. joy or pleasure in this. No, it's something I have to do and I try to do with as much care and ethics… integrity as I can, but… joy (sighs) I don't have a sense of joy about it. I've read enough to know that people talk about how sweet… unfortunately for me… that's not what I bring into it. And when he is hurtful… he is just so very, very hurtful that it does not… positives do not emerge because of all the hurt. … " (CG2)*

> *"It makes me angry because I don't think it's fair for me to do this, and I tell him that… but it doesn't do any good…." (CG1)*

These caregivers reported they had been mistreated during the entire marriage and were resentful that this carried on into later life: *"He still treats me the same way he's always treated me. And I don't know why it bothers me now more than it used to."* Thus, they seemed unable to find any meaning in caregiving:

> *"It has been a tense, difficult marriage all the way through…….. Then being told that he had Alzheimer's when he was 57, at the point that we should have been finally getting through the tense times, was just like a final blow. It was like, of course, what else? There just would be no goodness in the marriage." (CG2)*

3.4.2 The Ambivalent Group

This group was labeled the ambivalent group because the caregivers described very sad or frustrating caregiving experiences, but reported satisfaction with continuing caregiving because of a positive past relationship. They still cared for their spouse, even though the relationship was lost. Although negative emotions such as grief or frustration permeated the interviews, they reported that they were satisfied that they were caring for their spouse. Twelve caregivers were in the ambivalent group and they described their

past relationship with the care recipient as mostly positive but the current relationship as being conflicted.

> "*constant repetition, forgetfulness, and ah, I'll be honest, I sometimes lose it. And then I feel guilty… I honestly sometimes feel as if he doesn't trust me… I scream. Yeah, I yell… .. sure because when you really get down to it, it's not his fault… you feel guilty because you made it his fault and it's really not his fault, so you feel guilty and frustrated.*" *(CG11)*

> "*because if the shoe was on the other foot, I believe he would give me his all and all… I just feel like he would do the same thing for me… I see him in a way now that he's not him. And I look at his body and I say I know my husband… it's not him… To me, he's already gone.*" *(CG13)*

> "*We had always talked… that we had something special… (voice breaks).. God has blessed us in very.. a lot of ways, but when I sense that he is hurting… uh, I try to get in there with him and let him know that um.. we're a team… and that we'll always be there for each other (crying) and he just… he has… always been my strength and uh (sobs)… he can .. tell me I'm beautiful… and still there's a sense of …. Even though there's still love flowing between us… it's in a different way… (sobs)*" *(CG6)*

They could not find a coherent pattern in their spouse's current behavior and reported mixed emotions about caregiving. They tried to be focused on the needs of their spouse, but found this difficult because they could not accept the changes in their spouse, therefore, uncertainty permeated their caregiving. They were also overwhelmed by the tasks of caregiving, struggling to continue each day, because they felt they had no power over the situation.

> *"He wants to do his thing. Well… they ain't nobody don't want to do their thing. I'd rather do my thing, but I don't get to." (CG4)*

"I had trouble realizing that it's not his fault. And um… I have trouble with him talking to the TV… waves at em and says 'I know them'… that bothers me. And then I have trouble with him always wanting to get a job. He wants to go back to work." (CG5).

"I don't know what it will look like next week or next month, I just know what we're doing today and what we'll do tomorrow and whatever comes, it just comes and we have to deal with it." (CG12)

They had difficulty accepting the changes in their care recipients and understanding that their care recipient could no longer reciprocate as before. These caregivers struggled to find meaning in caregiving.

"*I'm thrown back to the very core of my being about who I am as a human being in relationship to another human being who is not really a human being any more" (CG10)*

3.4.3 The Positive Group

The positive group included six caregivers. The most prominent character of this group was that they described not only their past relationship but also their present relationship with their spouse in positive terms. It was not that they did not grieve the loss of the individual or relationship that was once there, but their focus was on the moments or the relationship that was left. For example,

"One of the most wonderful things that I have with her is there is something that happens when she suddenly seems not to have Alzheimer's. She might be sitting where she is sitting now and she will talk and speak lucidly and all that one day and it brought the tears to my eyes, she was sitting over there and she said to me 'do you know something? I love you, I really do!' and she said that to me and it brought tears to my eyes." (CG17)

"*She came alive. She stole the show. It's like she was herself all over. It's amazing like there's nothing wrong with her. … you don't focus on what they can't do, focus on what they can do because you don't know they don't hear you." (CG21)*

These caregivers described satisfaction and joy in caregiving and were able to be other-focused. They were not focused on their own needs, and did not seem burdened by this. They expressed some frustration or sadness in the loss, but were able to focus on what they still had. Women showed more emotion during interviews about the loss, and sadness that the end was coming. Men seemed to find meaning in 'giving back' the love that they received during the marriage.

> *"It's like… two deaths, he's died a slow death and I know that there's gonna be another one." (crying) "I think any time you're doing something for someone else and you see that you've done something that's good for them, it's rewarding. If you can make someone else more comfortable, then that's a job well done." (CG20).*

> *"Every time we hug and kiss. I mean every moment is a special moment. It's like every day's an anniversary. Just thankful to be alive and I'm thankful to be together. And just I love you. I love you. Comes from both of us. That's the best part. Marriage… it's ninety-ten. Sometime you gotta give ninety, sometimes you get ninety. She gave me ninety several times in our lifetime. Now it's my turn." (CG19)*

They accepted that their care recipient could not reciprocate, were understanding of this, and expected nothing in return. They accepted the situation as it was, had a sense of peace with themselves, and were able to find caregiving meaningful. Expressions such as 'I am blessed' or 'I am so thankful' colored their interviews.

> "*Caregiving is a soul-searching thing because you never know from one day to the next what you're going to be asked to do. You just hope you're going to do the right thing at the right time. I don't have any guilts about the time that I have spent with my husband and taking care of him and I don't have any regrets… I feel like that, I seized the moment as it came and did the best I could." (CG20)*

"I've learned to live with that…. You have to learn to accept this is the way it is. It's not the way you wished it was…. I don't see a lot of big problems now, because you just adjust to whatever you have to do and in a way this is easier and harder. … and there's a good part of anything and a bad part. But it's also just life. And I've learned to live with this. … I like being the one doing the caring to see that he's fed like I think he ought to be and that he's bathed and he's clean and his bed's clean and he's treated the way I want him to be treated. And I think that's wonderful. And at times, we still share when he's happy. Kind of like if I walk in the room and he smiles. Hey if he's happy, I'm happy." (CG16)

"Well, I still got her to hug and kiss on, you know. I got a lot of friends who lost their wives to cancer and watched them suffer and the die. You know, I'm very blessed that I have what I have. That's what I enjoy." (CG19)

3.5 Discussion

3.5.1 Discussion of Findings

The current secondary qualitative analyses revealed many hidden nuances among dementia caregivers' experiences. Despite the fact that the parent study's interview questions were not posed to discover meaning in caregiving, the data revealed multiple perspectives and unique stories about spousal caregivers of individuals with dementia finding meaning in their experiences. We found roughly three groups of caregivers, and labeled them negative, ambiguous and positive, based on the perceived level of positivity or negativity of their experiences. Most importantly we were able to delineate distinct characteristics among caregivers that could somewhat explain how certain caregivers are better able to achieve positive experiences and find meaning in dementia caregiving, while others are unable. Qualitative methods seem to be critical in capturing these unique differences in the experiences of dementia caregivers.

Upon finding three groups of caregivers in our analyses, we focused on the positive group caregivers in order to explore how they were different from the other groups to find useful strategies that other caregivers could adapt. The positive group caregivers in our sample expressed a high level of empathy and compassion towards their spouse, and were more focused on the needs or integrity of their spouse rather than their own unmet needs. They accepted the changes in their spouses, and the changes it brought in their own lives without resentment, and expressed caregiving as something meaningful to them. In fact they were thankful for whatever they had left of the relationship. This emotional connection seemed to be the key to their success. The love, empathy and compassion described by these caregivers enabled them to be attentive to the care recipient's dignity and preservation of self. As other studies on strategies for maintaining the care recipient's personhood and having a positive caregiving experience (Hellstrom et al., 2007; Perry & O'Connor, 2002), they went out of their way to continue activities or rituals the couple previously enjoyed or the care recipient enjoyed; they were affectionate, appreciative and sensitive to the mood and feelings of their spouse being attentive to their body language; and they tried to sustain existing competencies in their spouses and made the best of the things that they had.

The relationship between caregiver and care recipient in the three groups can be explained by that of Chesla (1994) who described three types of relationships with an individual with dementia;: one that is continuous to the relationship prior to the disease, one that is continuous but transformed by the disease, and one that is radically discontinuous from the prior relationship. The positive group and negative group

caregiver-care recipient relationships were continuous in that they were either positive or negative throughout the marriage into caregiving. The difference was that the positive group focused on any similar behavior of their spouse that linked to familiar past behavior, in order to sustain whatever relationship they had left for comfort and maintaining intimacy. Whereas the negative group interpreted certain behavior of the spouse as a continuity of past negative behavior in the marriage, even though it may just be from the disease.

The ambiguous group caregivers described the continuous but transformed relationship and the radically discontinuous relationship. The caregivers who expressed a continuous but transformed relationship showed frustration because they mourned the change and were still struggling to accept the losses in the relationship. Caregivers who expressed a radically discontinuous relationship showed deep sadness, as if they had given up all hope on the relationship. However for some reason, as Chesla (1994) found, these caregivers were still motivated to care for their spouses: "*I love my wife. But it's difficult for me to muster up the desire to go see her, in the shape she's in. (But I still go) to make sure she's cared for… Yeah, I'm proud that I'm able to take care of her.*" These caregivers seemed to find meaning in the deed, caregiving itself, even though they no longer had a relationship to hold on to. Caregivers who had previous positive relationships tend to have more positive caregiving experiences. However, the ambivalent group reveals that previously positive relationships may not always be enough for positive caregiving experiences. Even though these caregivers had previous positive

relationships, because they perceived negative emotions about their current relationships, they reported ambivalent caregiving experiences.

There were some other interesting differences between the ambiguous caregivers and positive caregivers. For instance, although the ambiguous group was able to express joy in caregiving, they were not the same as those of the positive group. The joy that the ambivalent group described were mostly uplifts, a short-term joy, such as going to church with the spouse, having a relative visit them, or just an uneventful day without a lot of stress. The positive group, however, identified a more stable kind of satisfaction in caregiving, which was more prominent in male caregivers. As one husband caregiver reported after institutionalizing his wife, "*Looking back, I don't think I looked on it as a challenge really. I looked on it as part of my husbandly responsibilities. I took care of her all my life, provided for her and the children and I think I did a pretty good job*." The wife caregivers also described a satisfaction in caregiving, in the support they received and were thankful for the remaining pleasant moments with their spouses. In contrast, the negative group did not find any kind of joy in caregiving. They reported a negative past and current relationship with their spouse. This agrees with prior research suggesting that subjective relational deprivation increases caregivers stress (Pearlin, et al., 1990).

Another difference between the ambiguous group and positive group's joy was the focus. When asked what the joys of caregiving were, the ambiguous group members reported things such as when the grandchildren visited, when they go for walks, or when the spouse with dementia does not get angry. Their joy was from things other than the relationship, and they verbally described a loss of the relationship. For the positive group,

their joy was about their spouse or their relationship and not about themselves. They mentioned such things as moments of shared intimacy, such as dancing, singing, or praying together, hugging and kissing and sharing words of love, or just holding and comforting their spouse: *"I dance with her… She'll sing in my ear. That's very pleasurable…. Dancing close…"*

Farran and colleagues (1991) described two types of meaning in caregiving: provisional meaning which refers to the meaning caregivers derive from day to day, and ultimate meaning referring to philosophical, religious or spiritual meaning. Interestingly, not only the positive group but also a few caregivers in the ambiguous group expressed provisional meaning or ultimate meaning in caregiving. Examples of provisional meaning that were expressed were: "*I am glad to be here to care for my relative,*' '*caregiving has made me a stronger and better person,*' or '*the hugs and the 'I love you' from my relative make it worth it all.*" Examples of ultimate meaning that were expressed are: "*I believe in the power of prayer; without it I couldn't do this,*' or '*the Lord won't give you more than you can handle.*" Some caregivers from the ambiguous group did report certain types of meaning from caregiving, but hardly any joys. They were struggling with the challenges of caregiving, and were not able to see beyond those difficulties. They were also confused and struggling to understand what everything meant. When compared to the positive group, the ambiguous caregivers felt they could not discern patterns in the changes in their spouse, and thus felt a loss of prediction or control in their lives. They were unable to accept their changing situation.

The most poignant caregiver stories were about the loved one connecting with the caregiver for a few moments as they used to, but then fading away again. These stories were from the positive group caregivers. To them finding meaning was about a sense of acceptance with the changes in their spouse, with the care situation, and with themselves. This acceptance seemed to enable positive caregivers to focus on and cherish the joys that they have, instead of the losses. In contrast, ambivalent caregivers felt that their spouses were no longer there. As one caregiver said: "*I see him in a way now that he's not him. And I look at his body and I say I know my husband… it's not him. To me, he's already gone.*" For negative caregivers both past and present relationships were expressed negatively.

There were relatively few caregivers in the negative group in the current analysis. The participants of the parent study were caregivers who voluntarily enrolled and stayed in a year-long intervention study, which may explain why there were many caregivers in the ambivalent group, and few in the negative group. Caregivers in more negative situations may be too overwhelmed or resentful to participate, while ambivalent caregivers may eagerly seek interventional help in their struggle to reach a more homeostatic state. According to Cohen and colleagues (2002), out of 289 dementia caregivers, 73% could find at least one positive aspect of caregiving, while 7% could identify more than one. The ambiguous caregivers of our analyses who were able to express at least one positive aspect are probably representative of the majority of caregivers' experiences, and the group needing interventions, to help them along their journey to a more positive caregiving experience.

As can be seen in Table 4 there is no difference between the groups in length of caregiving. Because quantitative measures from the parent study were not the focus of this article, they are not included, but care recipient's physical ability, cognitive ability or the caregiver's perception of the level of positive relationship (mutuality) were compared in the data grid to explore if the groups differed based on these characteristics. Along with the other characteristics compared in the data grid (caregiver education, age, race, gender, employment status, perceived social support, domestic abuse, institutionalization by time three), these did not differentiate the groups. There were 3 caregivers younger than 65, but their experiences did not differ from the rest of the caregivers.

3.5.2 Study Limitations

Because this study was a secondary analysis, our data were limited to caregivers' responses to the parent study's original interview questions. The original interview questions were; 'What are the three most challenging things in caregiving?,' and 'What were the three positive or satisfying things about caregiving?' These same questions were asked over each of the three data collection points. As the original research questions asked about the joys and challenges of caregiving, most of the interview data was applicable to positive and negative experiences. Caregivers shared multiple stories of the relationship, their everyday life, and ever-changing life in their two to three interviews over a one year period. The original interviews averaged between 10 to 50 pages, generally over 20 pages of transcription. Caregivers' values and attitudes towards their spouse and caregiving, and the level of acceptance of the changes in their lives had a strong influence on whether they were able to express joy in caregiving.

3.5.3 Implications

Our study results suggests that caregivers perceive the positivity or negativity of their experience based on their current relational dynamic with their spouse, on the level of empathy or compassion towards their spouse to be able to accept and understand the changes associated with disease progression and decrease in reciprocity, and furthermore, the ability to find caregiving meaningful. These results provide a basis for clinicians and researchers to possibly incorporate empathy-building training, and educating dementia caregivers to focus on the aspects of the relationship that is left and enjoy the simple joys of life.

As research focused on the lived experience and changing relationship between caregiver and care recipient expands, more study of the enrichment process longitudinally can reveal the relational dynamics and facilitators of enrichment over time. Furthermore, in order to fully understand the dynamic, the care recipient should be included in research by interviewing the care recipient when possible, and using observational methods when interviews are no longer possible. In studies where care recipients are included we can see a discrepancy between the caregiver and care recipient in their understanding of the other's role or acceptance of the situation (Cartwright et al., 1994; Hellstrom et al., 2005b, 2007.)

Meaning for caregivers seems to come from searching for meaningful reasons to continue care, and trying to accept the changes in their spouses' and their own lives. Finding meaning in extremely challenging situations has been suggested to be a choice, not a fixed trait of the individual such as personality, suggesting ground for future studies

to apply meaning-seeking skills in nursing interventions (Farran, 1997). Foundations of successful methods that encourage individuals to find meaning in difficult life issues in psychiatry, such as logotherapy (Frankl, 1988), may also be incorporated into nursing research.

Furthermore, we did not observe any change over time in the caregivers' reports of positive experiences. This may be because the one year data collection period was not long enough to capture change, or data was not collected at a time that could capture a change. This provides a basis for studies of longer durations. Of course it may be that caregivers need many years after terminating caregiving before they are able to see any positives in caregiving. If in fact caregivers' perceptions of positive experiences do not change over time, this indicates that ambiguous or negative caregivers continue to be unable to have positive experiences. As can be seen in Table 4, while 6 caregivers (28%) described positive caregiving experiences, the remaining 15 (72%) reported negative or ambiguous experiences. Thus research of how positive caregivers continue to perceive positive caregiving experiences, and why ambiguous or negative caregivers are unable should be further investigated. Future research should also address the process of achieving positive caregiving experiences. Do positive caregivers start out with positive attitudes? Or do they go through a process starting from negative or ambivalent and eventually become positive? If so, how were they able to develop a positive stance, and what factors, resources or caregiving context enabled them to do so? These answers can help clinicians guide ambivalent or negative caregivers who are seeking meaning and peace to eventually have a more positive caregiving experience.

3.6 Conclusion

Caregiving experiences of spousal caregivers of individuals with dementia seem to differ by their view of the past or present relationship, whether they can accept that change, whether they can focus on their spouse's needs, and whether they can find meaning in their caregiving. Those who describe a positive caregiving experience are focused on their spouse's needs rather than their own; show a high level of empathy, compassion and understanding towards their spouse; accept the many changes in their spouse and also in their lives due to caregiving; and find some sort of personal meaning in caregiving. Future studies should address how these positive caregivers achieved their high level of understanding, acceptance, and meaning in dementia caregiving.

4. Spousal Caregivers Finding Meaning in Dementia Caregiving

"What man is, he has become through that cause which he has made his own."

– Karl Jaspers

Dementia is characterized by non-reversible cognitive decline. A recent study showed that 14% of older adults over 70 years old in the United States have dementia (Plassman et al., 2007) and the number is rapidly increasing with the aging population (Alzheimer's Association, 2010). Caregivers of individuals with dementia must endure continuous cycles of physical, psychological, financial and emotional challenges related to dementia care for a long period of time. However, variances in caregiver experiences exist from negative to positive, and can be somewhat explained by the ways in which caregivers derive meaning from their particular caregiving situations (Ayres, 2000b; Kim, Schulz, & Carver, 2007; Park & Folkman, 1997).

Finding meaning is considered a critical aspect of being able to grow as a result of stressful events (Davis & Morgan, 2008; Frankl, 2006; Park, 1998) and the meaning caregivers derive from caring for the care recipient plays a significant role in their affective responses to caregiving (Farran, et al., 1991). The purpose of this article is to describe the experience of spousal caregivers of individuals with dementia, and explore how these spouses found meaning from their roles as caregivers. We interviewed spousal caregivers of individuals with dementia who reported to having found personal meaning in caregiving. Understanding how these caregivers found meaning in their role may

reveal strategies that can be helpful to other caregivers who may be struggling to find meaning of their own.

4.1 The Experience of Spousal Dementia Caregivers

Caregivers of individuals with dementia are reported to suffer more negative health experiences than those caring for frail elders (Acton, 2002), depressed elders (Leinonen, Korpisammal, Pulkkinen, & Pukuri, 2001), cancer patients (Clipp & George, 1993) and same age non-caregivers (Pinquirt & Sorensen, 2003). Further, spousal caregivers of individuals with dementia report higher levels of stress than other family caregivers because they are more likely to elderly themselves with chronic diseases of their own and limited resources compared to other age groups (George & Gwyther, 1986; Zarit, Reever, & Bach-Peterson, 1980).

Despite the abundance of research that portrays dementia caregiving as a primarily negative experience, not all caregivers have negative experiences (Pinquart & Sorensen, 2003). In fact some caregivers report significant long-term positive caregiving experiences such as personal growth or transcendence (Frankl, 2006; Park & Folkman, 1997). Growth is a phenomenon in which individuals perceive themselves as being better off than before and perceive an expansion in their attitudes towards self, in their relationships with others, or in their philosophy of life (Siegel, Schrimshaw & Pretter, 2005). Transcendence is a deeper personal knowledge of one's strengths and limitations; a feeling of positive solitude, contentment and acceptance; and a deeper connection with others or a higher power (Acton & Wright, 2000).

Research identifies finding existential meaning to be a critical source of this growth or transcendence (Acton & Wright, 2000; Cartwright, Archbold, Stewart, & Limandri, 1994), or well-being (Ryff, 1989), better quality of life (Cohen, Mount, Tomas, & Mount, 1996), or adaptation (Park & Folkman, 1997). Cartwright and colleagues (1994) described the process by which families create meaning or pleasure for both the caregiver and care recipient as "enrichment." The antecedents of enrichment are the unique personal histories of the caregiver and care recipient, the interaction between their personalities and life experiences, and the quality of the dyadic relationship they create. Enrichment maintains or strengthens the dyadic relationship, increases feelings of comfort and self-esteem for the care recipient, meaning for the caregiver, and identity sustenance for both.

4.2 Meaning in Caregiving

Frankl (1988) said that true meaning of life is discovered in the world rather than the psyche, by forgetting the self and serving a cause or loving another person. Caregivers can construct meaning based on their perception of social contexts, such as their relationship with a spouse, their expectations in life at a given time, their family or social support system, or their inner strengths. Meaning can be discovered by: a) creating a work or doing a deed; 2) experiencing beauty, goodness, truth, nature or encountering another human being in his/her very uniqueness by loving him/her; and c) choosing an attitude toward unavoidable suffering and being challenged to change oneself (Frankl, 2006). Within the context of caregiving, meaning can be discovered in the very act of caregiving, in loving the spouse they are caring for, and in being challenged to change or

grow from the caregiving experience. In other words, individuals facing dementia caregiving can choose to make the experience meaningful.

4.2.1 Meaning from Caregiving

Existential meaning is at the core of one's purpose in life and provides a lens onto how one makes sense of the self and one's existence in the world. Research indicates that elders derive a sense of meaning by engaging in activities that are different, helpful to another, or positive in nature (Trice, 1990). Perhaps caregivers in particular are able to derive meaning from the act of caregiving, in that they are caring for, helping and assisting another being who is totally dependent upon them. Paid caregivers caring for seriously mentally ill individuals have reported that caregiving gave their lives meaning, self-fulfillment or self-actualization (Rhoads & McFarland, 2000). In that study, caregivers tended to be highly other-oriented (altruistic). This suggests that even without a previous positive relationship or any existing relationship with the care recipient, meaning can still be found in caregiving.

4.2.2 Meaning from the Caregiving Relationship

According to Caron & Bowers (2003), caregivers try to find recognizable behaviors or expressions that are characteristic of the care recipient as they remember them, and only when they are no longer able to do so, do they consider discontinuation of care. This suggests that the purpose of caregiving lies in the caregiver's perceived relationship with the care recipient. Hirschfeld (1983) also reported that the caregiver's ability to find gratification in the relationship with the care recipient with dementia, and

their perception of the care recipient as reciprocating by virtue of his or her existence, as the most important factor in continuing care. Many caregivers reported being able to retain feelings of closeness to a spouse with dementia for as long as the spouse was alive (Hayes, Boylstein, & Zimmerman, 2009).

A longitudinal study exploring spouses' strategies for living positively with dementia identified three processes at work in a nurturing relational context: sustaining the relationship between caregiver and care recipient, maintaining the recipient's involvement, and moving on (caregiver taking on more of the recipient's roles) (Hellstrom, Nolan, & Lundh, 2007). Schulz and colleagues (2007) suggest that caregiver compassion, defined as a sense of shared suffering, combined with a motivation or desire to alleviate the suffering of the care recipient, is a critical component of caregiving. Alleviating or sharing suffering may be what makes caregiving meaningful to caregivers who feel compassion towards their care recipient. Thus the relational context between caregiver and care recipient seem to be key to positive caregiving experiences.

4.2.3 Meaning from Suffering

Many caregivers refuse to relinquish care for extended periods of time and disregard the hardships of caregiving (Caron & Bowers, 2003). Research has shown that higher caregiver burden correlates with more positives for the caregiver (Lawton, Moss, Kleban, Glicksman, & Rovine, 1991), more benefit finding (Kim, Schulz & Carver, 2007), or growth (Siegel, Schrimshaw, & Pretter, 2005). By choosing a meaningful attitude towards their unavoidable suffering, caregivers may be able to achieve more positives in their caregiving experience overall. This phenomenon can be seen in other

diseases or situations as well. For instance, finding meaning was a key factor in the growth of bereaved parents (Miles & Crandall, 1983), and was a critical step towards obtaining a new outlook on life, better psychological adjustment and a sense of coherence among chronic heart disease patients (Skaggs, Yates, Hertzog, Barron, Norman, & Pozehl, 2007).

Trauma and suffering have been recognized as opportunities for growth or personal development by many existential psychologists (Reker & Chamberlain, 2000; Tedeschi, Park & Calhoun, 1998). Traumatic events challenge fundamental assumptions or philosophy of life, and thus inspire a search for meaning (Baumeister, 1991; Tedeschi et al., 1998). Posttraumatic growth has been studied in the aftermath of acute stress situations, such as bereavement, but there is relatively little research on growth in long-term stressful situations such as caregiving, where the stress changes continuously and there is no guarantee as to when it will end. Finding meaning in caregiving with long-term or continuous suffering may be more difficult than finding meaning after an acute trauma because caregivers are in the midst of ever-changing and ongoing suffering.

In order to describe how spousal caregivers of individuals with dementia found meaning, caregivers who reported finding personal meaning in dementia caregiving were recruited and interviewed. They were asked to describe the meaning they derived from caregiving and how they were able to find this meaning. Then they were asked how finding meaning had changed their caregiving experience.

4.3 Methods

This qualitative study involved semi-structured interviews to explore how caregivers of individuals with dementia found personal meaning in their caregiving experiences. Because "meaning" is a subjective concept of the individual in relation to the world (Mason, 2006), the interview method was selected to stay faithful to the caregiver's own reality. This method allowed us to collect rich information on each caregiver's unique and evolving experience of caring for their progressively ill spouse (Creswell & Miller, 2000). The interview guide is included in Appendix A.

4.3.1 Setting

The settings for this study were rural counties in a southeastern state in the United States where Alzheimer's disease prevalence had increased 31% over the past 10 years (Alzheimer's Association, 2010). Caregivers living in the community with their spouses with dementia were recruited for the study; our purposive sample was chosen to allow us to interview individuals with dementia whose primary caregiver was their spouse and who could illuminate the phenomenon of finding meaning in caregiving.

4.3.2 Participants

Participants in this study were self-selected individuals who responded to the study flyer or were referred by other participants. Caregiver eligibility was assessed by phone, based on participant inclusion criteria, which were: a) being a caregiver living with a spouse with dementia (the spouse must have been diagnosed with dementia or be taking cognition-enhancing drugs); b) being the primary caregiver providing at least 3

hours of daily care; c) having at least one year of caregiving experience; d) being cognitively able to participate in interviews; and e) able to effectively communicate in English. Criteria of providing at least 3 hours of daily care, being the primary caregiver and having a minimum of 1 year caregiving experience enabled us to recruit caregivers who have had sufficient time to experience caregiving and reflect on finding meaning prior to data collection. Participants (n=12) were recruited until data saturation was obtained. Institutional review board approval from the researchers' affiliated university was obtained for participant protection.

During phone screening one caregiver said he had recently institutionalized his wife but still provided her direct care each day. However, at the interview, the caregiver reported spending less than 3 hours a day with his wife, so his interview was excluded from analysis. Of the 11 remaining participants, 5 were husband caregivers and 6 wife caregivers with ages ranging from 63 to 81. All caregivers had more than a high school education, and they had been caregiving from one to 14 years. Caregiver characteristics are depicted in Table 5 to provide context for narratives.

Table 5: Caregiver Characteristics (n=11)

ID	Gender	Age	Race	Education	Diagnosis	Religion
CG1	Male	74	White	More than college	2005	Catholic
CG2	Female	80	White	College	2006	Christian
CG3	Female	64	White	High school	2000	Christian
CG4	Female	69	White	College	2000	Mormon
CG5	Female	66	White	More than college	1995	Christian
CG6	Male	81	Black	College	2008	Christian
CG7	Female	63	White	More than college	2007	Catholic
CG8	Male	78	White	More than college	1999	Christian
CG9	Female	77	White	High school	2007	Christian
CG10	Female	69	White	College	2001	Quaker
CG11	Male	80	White	More than college	1997	Christian

4.3.3 Procedures

Flyers were distributed at support groups for caregivers of individuals with dementia, neurology clinics, adult day care centers, senior centers, churches, events in the community that caregivers of individuals with dementia might attend, and email announcements distributed through various Listservs. Flyers were worded to target spousal caregivers who self-identify as having found personal meaning in their caregiving. Flyers directed caregivers who were interested in participating in the study to call the principal investigator (first author). When applicable, snowball sampling (screening individuals referred by previous participants) was also used.

When caregivers contacted the investigator, the general study purpose, aims, and requirements were explained, and caregiver eligibility was determined. The printipal investigator assessed the caregivers' cognitive ability to consent during this initial phone screening. The investigator looked for signs of confusion through inappropriate responses to questions or incoherent, or illogical communication. If the cognitive status had been questionable during the phone screen, the *Evaluation to Sign Consent* measure (DeRenzo, Conley, & Love, 2001) would have been administered before obtaining written consent. However, none of the participants showed signs of confusion. If the caregiver verbally agreed to participate in the study, the consent form was mailed or e-mailed to the caregiver. The investigator contacted the caregiver again a week later, to confirm interest in study participation and schedule the interview. A one-week time frame allowed the caregiver sufficient time to review the consent form and carefully decide whether or not they wished to participate in the study. Interviews were conducted at a time and place of

the caregiver's choosing. All interviews except one were conducted in the caregivers' homes.

Written consent was obtained before conducting the interview. All caregivers were cognitively able to understand the consent process. The interviewer explained the purpose of recording the interview and explained the caregiver's right to discontinue the interview at any time for any reason. Interview data were collected by two digital audio recorders to ensure minimal data loss. To protect both the caregiver and care recipient's privacy the interviews were conducted when the care recipient could be with another temporary caregiver or at adult day care. Interviews were also scheduled when and where caregivers felt that they could talk privately. Care recipients were only present at the interview when caregivers indicated that they wished to be with their spouse and that their spouse was comfortable around strangers. Participants were compensated $15 for completing the interview.

4.3.4 Data Analysis

Digital audio recordings were transcribed verbatim. Transcripts were read multiple times and analyzed using thematic qualitative content analysis methods. Data were then grouped by common themes (Boyatzis, 1998). Themes emerged based on the three research questions: 1) What meaning do spousal caregivers of individuals with dementia find in caregiving? 2) How are they able to find meaning? and 3) How has that meaning changed/affected their caregiving experience? During the interview caregiver comments were summarized and debriefed with the caregivers after each interview question in order to ensure that the comments were captured accurately. If the

investigator later had questions about certain comments, the caregivers were contacted by phone or e-mail to clarify, with prior permission from the caregivers.

Data were analyzed during the data collection period and used to inform subsequent interviews. This method focuses and shapes the subsequent interviews to help the researcher obtain data that best answers the research questions (Speziale & Carpenter, 2007). First-level coding identified quotes and themes in each caregiver's story, with a minimum level of abstraction, and stayed as close as possible to the caregiver's original words. Individual stories were reviewed and developed into individual caregiver matrices that included the caregivers' answers to each research question. In second level coding, quotes and themes from the first level coding were extracted according to caregivers' answers to each research question. Findings were compared within the individual's responses to determine how the answers to each research questions were related to each other. At the third level of coding, common themes across individual caregivers were reviewed cross-sectionally, to explore similarities or differences among participants (Bloomberg & Volpe, 2008).

An experienced qualitative researcher guided and periodically evaluated the emerging analysis to ensure trustworthiness. Because interviews are an interaction between the interviewer and interviewee, qualitative researchers must be aware of the influence of their own values, norms, and institutional pressures when conducting interviews and interpreting findings (Bloomberg & Volpe, 2008). To address this issue the experienced researcher independently analyzed several interviews and results were

compared to ensure that findings were consistent and true to the data and not the outcome of the researcher's biases or subjective interpretations (Bloomberg & Volpe).

4.4 Results

The results of this study are arranged according to the three research questions: the meaning caregivers found in caregiving, the process of how they found meaning, and the changes they experienced as a result of finding meaning.

4.4.1 Meaning in Caregiving

The first research question captured the personal meaning caregivers found in caring for their spouses with dementia. The sources of meaning caregivers described stemmed either from their spouse or from caregiving itself. When the source of meaning was the spouse, it developed from a) being able to keep the spouse at home; b) a commitment to the marriage vows or a deeper, changing relationship with the spouse; and/or c) for men, returning the love and care they had received from their wives. Caregivers who found meaning from keeping their spouses at home felt that being there for their spouses or having their spouses at home rather than in an institution was meaningful. For these caregivers the source of meaning was in doing what was important or meaningful for their spouses. In this sense, keeping the spouse at home seemed to be an act of determination:

> I don't want to have to put him anywhere. We had to do my mother that way and we died a thousand deaths when we did that. (CG3)

> We're still wanting to keep her here, not at a nursing home. One reason it's so expensive. […] and I, even if it was free, I wouldn't let her go to a nursing home if at all possible, if we can take care of her here. This is home [cries]. (CG8)

> There's still a body here and whether he knows, [turning head to spouse] whether you know what I'm thinking or what's going on, I can imagine that you do, um, you're still [spouse's name] to me and that's just, his presence is still here. (CG4)

The caregivers who described their marriage vows as a sacrament or promise that was meant to be kept found it meaningful that they were keeping that promise. Caregivers focused on the changing relationships with their spouses expressed how much their relationship still meant to them:

> Meaning for me, I would say, ah, mostly change, the change in relationships. Meaning of, what is love, what is care, what is acceptance. I have to accept what it is I have. How has my love changed, love, unconditional love. Just giving and not expecting anything in return. Care is just doing, just doing and being. To me, in terms of relationships, she was the only relationship. She's the only person I was always happy with. The only person that I really wanted to be with all the time. And that hasn't changed. (CG11)

> Well, you know, you say you love somebody and, you can walk through all these years and until you really are giving completely, totally of yourself, I don't think you really understand that total meaning of love. But I love him greater now than I've ever loved him and it's just, um, it's two-way [crying throughout]. I bet he tells me a dozen times or more a day, I love you. He'll say, "I don't know what I'd do without you. I couldn't do this without you" you know. It's just, my heart overflows with gratitude. [crying] (CG3)

Husbands, distinctly, reported finding a source of meaning in being able to return the love that they had received during their married lives. They told stories of how their spouses had been wonderful wives, mothers, and women who not only took care of them and their families, but also significantly impacted their lives. While they would not have asked for this situation (that is, the spouse's dementia) to befall them in their later years, they were still thankful to have an opportunity to give back to their spouse:

> And it just seems that this is an opportunity. Most days I look at it that way. To uh, I shouldn't say pay her back, but I guess you know it's an opportunity, to return the love, and the care that I, I've been on the receiving end from this wonderful woman. (CG1)

> Now she looked after me when I was, ah, needed help. I, as I said, crashed and burned in Vietnam and had 44% burns or 33% third degree and, ah, until I could get back into shape, she took care of me. She brought me back into the way of life that we had had. (CG8)

When meaning stemmed from caregiving, it was related to personal growth the caregiver had experienced in the act of caring for somebody else, putting that person before themselves. They embraced the changes in their lives that had occurred as a result of caregiving and perceived it to be meaningful. They felt good about what they were doing. Some caregivers experienced simultaneous changes in their general philosophy of life or what they found meaningful in everyday life. These caregivers demonstrated transcendence: a deeper understanding of the self and a deeper connection with others or a higher power as a result of caregiving:

> At least some of the meaning I find in caregiving is the opportunity to recognize my strengths and to identify those areas in which I am growing in this time of our lives. That seems a little me-focused and it certainly is not all about me. But at the depth of my being that is what I am thankful for in this process. (CG4)

> Well, I think we have a purpose in our heart. We want to grow, you know. We want to learn. I don't, I don't want to be what I was ten years ago or five years ago or a year ago. You know, I want to grow in my faith and it takes the things around us, the trials and the tests to, you know, make that growth work and bear fruit, you know. (CG3)

> It's a growing experience, you know, a changing experience, makes you really care for somebody and [in] a lot of ways you might not if you were both on your own tracks, you know, you learn to try to understand what, what, where they're coming from and that's very broadening really. (CG2)

4.4.2 How Caregivers Found Meaning in Caregiving

The second research question, of how caregivers found meaning was more challenging for the caregivers, because most were not consciously seeking meaning but rather found that it emerged as part of their journey. As one caregiver expressed about

finding meaning, “It’s just my existence, I haven’t really looked for meaning.” Finding meaning in caregiving evolved over time. Some caregivers described it as a process, while others did not consider it a process at all because they did not consciously think about it. They described it as something that comes and goes, but then gradually becomes more stable. Eventually they would find peace and accept their new reality. Some described finding meaning as a series of challenges or decisions. Through these processes they had to redefine themselves to adjust to each change:

> It’s been a gradual process of reading up, on Alzheimer’s, becoming aware of it, talking to people that have been caregivers and are caregivers and all and just, you know, just seeing my wife’s good side come through. It’s all […] so it’s been a gradual process. (CG1)

> Okay, well, from the very beginning, it's been a series of changing challenges. And it started before I knew what was happening. (CG10)

> Well, it's just really right lately coming to me more evenly. Before it was just little stabs here and there just when you least expect it, you know. […] I went through a period where I said. He can remember better than this, you know. I need to realize it's not just memory loss. Of course, that exacerbates everything but he's losing mature thinking, too. Which is exacerbated by memory loss…it's every day a change. It's not even a process, it's a, you know, I guess it could be a process if I would be more total thinking. (CG5)

Caregivers’ strategies for how finding meaning included accepting the situation, deciding to care, choosing a positive attitude, focusing on the blessings, and actively seeking resources.

4.4.2.1 Accepting the situation

Whatever meanings they found, these caregivers were able to accept their situations and work from there. This meant accepting the disease, changes in their futures, and their own or their spouse’s limitations. It also meant accepting that there would be continuous unpredictable changes to these many facets of life:

> But basically, it has, it has shifted from, fighting a disease to accepting a disease and accepting what goes on. That has helped somewhat by having a, the 12-step program of accepting first, Alcoholics Anonymous, you know? First step is you have to admit you're powerless to alcohol, but it's, in other words, it's the same, it's basically, you've got to admit that you're defenseless against the dementia. And then you say, Okay, now how am I going to get around this? Well, obviously she is not the cause, so what it is, is my resistance to just accepting what's going on. You can't, there's, there's no way you win against the disease. So the sooner you surrender, the sooner you accept that, the easier it is to do the rest of it. […] have no expectations, it'll be what it is […] If you think, well, now, because there's these plateaus and you think, oh man, I've got it. All I've got to do is lay out the clothes, get this, and everything will be cool. It's just no. It doesn't happen that way. (CG11)

> You know, you just may as well accept it. At first, I have a book that thick [gesturing with hand]. Every time I'd go to the doctor, I'd take [it], and write all this down and try to keep up with [the doctor] and come home at night and study. Almost like homework because I was trying to figure it all out. Finally, it dawned on me, if the doctors can't figure all this out [laugh], I didn't know how I was going to figure it all out. It was almost like I thought there was some way I could stop this, that I could change it, that I could make it not happen. I think acceptance is very important. (CG9)

4.4.2.2 Deciding to care

As a part of accepting their realities, caregivers made deliberate decisions to care for their spouses, despite the expected hardship of dementia care. It was something they wanted to do, and by believing that their decision was a choice rather than an obligation, they were able to take the initial step of adopting a positive attitude towards that decision:

> First it was a question of do I want to do it or not. I solved that one. So that gave me the meaning. Second one is Okay, I'm going to be a good husband and not a caregiver. (CG11)

> My feeling is, it's something that I want to do. And in that the life we've lived together for over 50 years, it's a relief to know that I can still take care of her. (CG8)

4.4.2.3 Choosing a positive attitude

Having made the choice to care for their spouse, these caregivers realized they had a choice in how to view their situations and that they could reframe it if they wanted to. They realized they did not have control over their spouse's dementia, so they focused

on what they did have control over, which was their attitudes. In this way, they learned to be at peace with what they did not have control over:

> Because bitterness does grow and I could be very resentful, I could be very bitter. But I can't, I'm not going to be, you know. I have a choice, I have a choice. How is my attitude going to be, you know, what is my motive for the day? I do, everything I do is unto the Lord, you know. I could choose to be bitter or I could choose to get better and I want to get better, you know. We're a vessel being made in the process. (CG3)

> For one reason, you have to [find meaning]. That's one reason. You can't just throw him out with the bath water. Another way, you've got to just admit this is what's going to happen to you for the foreseeable future for me, you know. (CG9)

> I'm going to assume the road, our road, will be comfortable until proven otherwise. Why should I worry about the worst? So I'm gonna assume that it'll be comfortable. And then I hope if it isn't, if that's not right, I just hope that I face that properly. (CG1)

> You know, we're on one little itty bitty planet and what is it, there's 200 billion stars in this galaxy and there's 200 billion galaxies? So, you know how are you going to worry but so much? That's a whole nother subject. Don't, yeah, don't get too caught up in who am I and what am I doing here. It helped, that helped mentally to say, hey man, things aren't terrible. (CG2)

4.4.2.4 Focusing on the blessings

By accepting their situation and choosing a positive attitude, these caregivers were able to see beyond their losses and focus on their blessings. These attitudes were expressed as being thankful, being optimistic, feeling blessed, focusing on the positive, taking joy in the moment and finding humor in things. This was also related to downward comparison, comparing themselves to others who were worse off than themselves. Some caregivers explained that although people often complain about their problems, when asked if they would switch and take on another person's challenges, they would not. In this way, they would be able to see that they were better off with their own problems:

> I learned that life does go on and you don't even think about it after a while because you, you find good things. I think anything that makes you stronger and gives you experience lets you know that this isn't the end of the world sort of thing, you know. And that you might as well enjoy each day while you can. You can appreciate the more simple things of life, you know, the less complicated things. It's like stop to smell the roses. (CG4)

> I think, um, gratitude, joy, things like that kind of get me through, you know, enjoying, even if I see a rainbow or, like I said, have a good day. What it really is, is living in the moment. You know, that's what it is. It's, it's taking joy in the moment, and people forget [to do that], you know. (CG5)

> And then every now and then, he'll say to me, "And where is your husband now?" [chuckle] Which is sad, particularly the first time that happens, but you get over that, you know. I, I don't, I try not to take that personally. Um, he can't help it and it doesn't do any good to be upset about it. I used to try to make a little joke about it. So you learn to laugh about some of the things. Ah, that, the first time it happens, I think you, you, it kind of shocks you. But you have to take a lot of that, you know, and laugh about it. Otherwise, you know, you'd be crying and wringing your hands all the time. (CG9)

4.4.2.5 Actively seeking resources

Caregivers actively sought strength, resources, and support to continue giving care. Examples included participating in support groups or research studies; learning to accept and actively seek help or respite; reading about dementia to learn what to expect; and trying to maintain other interests such as gardening, religious meditation or singing in the choir. These were deliberate activities caregivers remained engaged in to maintain some balance in their lives. They also advised other caregivers to take advantage of everything in their environment that was positive for them. Learning to accept help was not easy for most caregivers, because they were not used to being dependent on others:

> First of all, joining a support group is very, very helpful. I don't know what I would've done without mine. We have, I made friends with one couple and we used to meet at the mall at first and we would walk, have lunch at the food court. You don't have to worry about if maybe he uses the wrong fork or takes his knife and, ah, puts jelly on chicken, or whatever, you know, just what they do, or say, they say things sometimes that are maybe not appropriate, but you don't worry about it because these people [other caregivers] know what you are going through.

> […] and then she [friend from caregiver support group] and I get on the phone sometimes late night and we may talk for an hour, hour and a half, because she tells me how he's doing, I tell her how he's, my husband's doing, ah, we commiserate, but we also laugh about the things that are happening to us and we share those things. (CG9)

In addition to adopting these strategies, these caregivers had several other common characteristics: altruistic values, the determination and discipline to live one's values, faith, love, social support, and past challenges.

4.4.2.6 Altruistic values

Caregivers were altruistic, and this often stemmed from their religious faith or upbringing. Because these values were embedded in their way of life, caring for a person with whom they had spent most of their lives was important to their existential meaning:

> Putting somebody else ahead of myself. Yeah. To lay my all on the altar of sacrificing myself, you know. I mean, that's just what is required of us. And to say, 'Not my will, but Thine be done.' And every day, you know, 'Lord, not my will, but Thine be done.' Because it doesn't take but a moment to get an attitude, right? (CG3)

> But I've always visited sick people in the church. […] When my college coach moved back to New Jersey, he got sick. We took care of him. So we did, we did a lot of these things, so being a caregiver is not too difficult […] I was that kind of person, I guess. I always had time for people […] And so now why would I change now because she got sick, like some people would do? Put her in an institution or something? No, no, no. And I told her, "Oh no. As long as I can take care of you, you're going to be here." (CG6)

> What do you have at the end of your life except how you're remembered? That's really all you have. Did you do any good? Did you help anybody? Did somebody remember you well? (CG7)

> Well, I thought it (doing this interview) might help other people too. I know my life is going to be different from many others, but what I have learned and, and the way I have, ah, carried things out that I felt needed to be carried out, I was hoping it would help the world a little bit. (CG8)

4.4.2.7 Determination and discipline to live one's values

Having the determination and discipline to live according to their altruistic values was also a distinct common characteristic of these caregivers who had found personal meaning. This was expressed by caregivers as the determination to do something about life's difficulties rather than worrying or simply doing nothing, meeting challenges rather than avoiding them, pushing on in the midst of difficulties, and taking life one day at a time rather than becoming overwhelmed by worries of an uncertain future:

> I understand that I can't beat myself up daily over this, because I'm not going to be perfect at it. People try to be perfect at this and you can't be. I just take each day, do the best I can. If I don't have a good day, I hope for a better one the next day…. so you just do what you have to do and whatever works, if it's prayer, if it's faith, if it's some spiritual connection, if it's getting out and doing things with friends or going to a movie or whatever it is to keep yourself going. Um, as I said, I don't see myself just running away. I, I've not done that. (CG7)

> Just dive in. Dive in. Just meet every challenge with as much gusto as you can. (CG10)

> So, I had a very, ah, career that kept me on the move and on the go and I didn't have time to really sit down and let too many things worry me. I kept things in order and she helped me keep things in order and so it went, ah, a good life for both of us for that reason. […] Do something. If you see something that needs to be done, do it. Don't wait til a week from now to go back and try to, ah, straighten up what messed up while you were not taking care of things. Do it now. (CG8)

4.4.2.8 Faith

Considering that the participants were recruited from a neurology clinic and community support groups, it was interesting that faith was also a common factor that caregivers felt led to meaning. Having faith enabled them not only to see their choices to provide care as meaningful, but also to find the strength to carry it through. Through their

faith, they were able to trust that things were in the control of a higher power, so they were able to have hope, lean on the higher power for strength, and view caregiving as an opportunity to grow. Prayer or prayer support from others was also important in their lives.

> It, ah, you've got to have something. If you didn't it would be terrible just to not have any faith in, on anything. You've got to have a little faith out there to pull you through this. It's, ah, a necessity to have that. (CG8)

> Of course, it's, you know, been frustrating times all these years. But, um, as a Christian. I'm always to ask, Lord, what am I to learn through this experience? What are we to do, you know? How, how do I function in this situation? (CG3)

> But, um, if you really live your faith, God never leaves you. He's with you and He's with you while you're caretaking or not caretaking. And you might even have an opportunity to see Christ in the person that you're caring for, whether that be a friend, a spouse, my mother. And these are the most significant relationships in my life […] There was no way to predict all these brain tumors and auto accidents, right? I'm not in charge of this, God is. And I'm just one of God's children trying to, whether I'm sitting in the prayer garden or tending to my husband or myself or whatever. That's the point I'm making. It's that some, that people have something to believe in. (CG7)

4.4.2.9 Love

In relation to altruistic values or faith, caregivers commonly said love for their spouse was the reason they were able to find caregiving meaningful. To these caregivers, love was not only a motivation but a decision to make each day. Except for one caregiver, all described a strong, happy and trusting marriage. However, even the one who expressed a negative past relationship reported positive *current* feelings for her spouse: "I call it love. It's a warmth that just fills me. I obviously loved him all along, it was just hard for me to express it because of the communication difficulties we had." Love for one's spouse or finding meaning in the marriage was related to having compassion or

empathy for the spouse. This led caregivers to treat their spouses with dignity, and be considerate of their spouses' feelings. This was true even though the spouse was no longer as aware of things as they had been before the dementia, and even when the caregiver could no longer be sure of what the spouse was feeling.

> Love is about a decision and people forget this. They think, oh, my heart beats for such and such and every day. It's not, it's not just a feeling. Every day, you have to wake up and make a decision that you're going to love somebody and some days, it's harder than others, right? (CG7)

> It's the compassion, the empathy, the just, you know, just such feeling, I can't describe it. . . . and I want to make my husband as comfortable as possible and to make him, his life as easy as possible, you know, because I know that it's so frustrating for him not to be able to express what's on the inside of him, you know. …I just understand that he needs me. And I want to be there, I want to be here. Can I say any more? (CG3)

4.4.2.10 Social support

Social support was also an important factor that caregivers found helpful in finding caregiving meaningful, whether it was from family, friends, or more organized support such as hospice or church organizations. The support or comforting they got from their spouses, however rare or spontaneous, was especially important to them:

> Use your support, whatever support you can find, um, that's available to you. Um, and make sure everybody knows how much you appreciate them. You have to give back to the givers that give to you. That's very important. Um, oh, be a part of every community. Be outgoing. If you're not outgoing, become outgoing. Um, maintain, maintain as many, maintain all positive relationships that you have, as difficult as it may be at times. (CG10)

> Ah, because it does help, it helps sometimes when, mostly when my sisters call me. Sometimes now, I think, oh, I don't have time to talk on the phone [chuckle], but it, it helps to know that people care about you. Ah, and that, you know, they're concerned about him [my spouse] also. And give me support, tell[ing] me, 'Oh, you're doing a fantastic job.' I say, 'Well, I don't know about that, but.' [chuckle] But that, that helps. (CG9)

> I need lots of hugs. And that's one thing, we always hug each other, you know. I said, "I need a hug, I need a hug. Help me, I need a hug." And he hugs me, you know….But he'll, he just

says, you know, “We'll, we'll work through it, we'll get through it, you know, we'll get through it” (CG3)

4.4.2.11 Life experiences and challenges

Each caregiver seemed to derive strength from their experiences, education, careers, or upbringing. They actively searched for inner strength from their past with a confidence that they had met challenges before, and were able to get through them. With this in mind, the difficulties of caregiving for a spouse with dementia could be faced as a new challenge rather than as a burden:

> I try to remember all the things that happened to me and maybe there was a time when I dealt with some terrible tragedy and people forget how strong they are, they really do. So I try to look back on all those other things that may have happened and how I handled it and did I learn anything from it and can I now apply it to this very tough job of being a caretaker, an exhausted caretaker […] There were other times, I know, for everybody. Ah, and you wonder. How am I going to do this? But, but somehow you get through it. (CG5)

> I don't want to get too soft, you know, take the easy way out […] that's another thing, we moved out here and most of our people lived out there and I think this helps a lot really, because you're on your own. I really feel like that made us more independent and self-sufficient. […] we had to take care of our own things and I think that makes you stronger. (CG4)

> Well, I was raised in a family that way. There was 10 of us children. And our mom and dad took care of us. And then [there was] my time in the military, you know. We looked after each other in the military. We did. When I say we, the military people, not speaking, strictly man and wife, we all in our tours in the combat and all this, we took care of each other. So it's a way of life for me that, ah. I've always been like that. And I'm not about to give up on it now. (CG8)

4.4.3 Changes from Finding Meaning

In response to the third research question about any changes in the caregiving experience due to finding meaning, caregivers expressed the notion that finding meaning helped them feel more peaceful. They had gradually come to accept the continuous

changes in their lives due to the progression of their spouse's dementia, and realized that they must continuously adapt to those changes:

> I'm more relaxed. I don't worry. I guess I'll always be a worrier, but I don't worry as much about what's going to happen to us. I, I know that we're doing the best we can, and, and we still have good moments. (CG1)

> Well, there's just such peace, there's such peace in our lives […] God's given us peace and I'm thankful. (CG3)

Many caregivers also expressed a sense of growth or broadening in their relationships with their spouses, in their life views or life focuses, or in the existential meaning of life. Because of the peace and growth caregivers had found, they also seemed to find their caregiving experiences richer and more fruitful:

> If you took a snapshot of our marriage at different times, sometimes you'd see flowers blooming, and things were good. And other times you'd see weeds, things weren't so good. But you know it's not just a seasonal thing. It's over the long run. Some things that are weeds can end up being flowers. I think that's happened with us. We didn't always have the best of marriages, I mean we had differences, and. But you know uh, sometimes you have to let stuff lay in the ground for a while, before it blossoms. Even stir it up a little bit and I'm, I'm just. It's not just a sense of obligation that I. It is a love that has, has grown, that I may not have had earlier. (CG1)

> Um, but, um, yeah, look at everything, ah, in a new light. I mean, you have a new life. […] I'm in a good place right now so I can tell you that there are benefits and that you can find them and that you, you know them when you aren't anxious and can enjoy a lot of things that go on in life. You know you have succeeded at something. Some things. Quite a few things. [chuckles] (CG10)

4.5 Discussion

4.5.1 Discussion of Findings

The German philosopher Nietzsche (1998) said, "He who has a why, can live with almost any how." The 11 caregivers of individuals with dementia interviewed for this study who found personal meaning in caring for their spouse found their why, and

experienced acceptance, peace, changes in their focus of everyday living, and a richer view of life as a result. It was a struggle, but they made an initial choice to care for their loved ones, and to take on an attitude that would make that experience meaningful. Caregivers of people with dementia found meaning while undergoing chronic distress and accommodating to continuously changing challenges. Analyses revealed common characteristics among these caregivers as to how they thought they were able to find their why.

Several factors seemed to motivate these caregivers to make the initial choice to care for and to continue to care for their spouses despite the expected difficulties. The decision was based on their ethical or moral values, which sprang from the caregiver's upbringing, career or religion, or personal history with the spouse. Cartwright and colleagues (1994) also identified personality and life experiences as antecedents to find meaning in the dyadic relationship. Whether the caregivers' found meaning were related to themselves (what they got out of caregiving), the relationship (marriage history or marriage vow), or the spouse (what they thought was meaningful to the spouse), they had all made a conscious choice to initiate and continue care.

No matter how difficult caregiving sometimes was, caregivers were determined to live the values they believed in, with regard to how others should be treated or how they wished to honor their marriage. These caregivers found meaning in valuing the marriage relationship, which is consistent with previous literature (Frankl, 2006; Hirschfeld, 1983). Perry and O'Connor (2002) also found that caregivers reported their wedding vows as a purpose and rationale for caregiving, referring to their care recipient as not just "a

spouse" but as "my spouse," valuing their spouse as a unique individual. In that study, caregivers tried to establish a valued presence for their spouse by ensuring that whoever was meeting the spouse connected with who the spouse used to be and who they still are. We were able to see this in our interviews as well. Each caregiver talked about what kind of person the spouse was before the disease: their accomplishments, their positive personality traits, their contributions to the family, how much they still loved the spouse, and how proud of the spouse they still were.

Caregivers in our study showed great empathy by trying to maintain the spouse's dignity, focusing on the needs of the spouse, and focusing on the spouse's abilities and strengths rather than their deficits or weaknesses. In a case study, Hellstrom and colleagues (2007) reported how a caregiver repeatedly emphasized how much his wife with dementia gave him in terms of companionship and love. We also found that even when care recipients were advanced in their dementia, caregivers still tried to sustain their spouse's dignity. Showing compassion, sharing suffering with the spouse, or trying to alleviate it (Schulz et al., 2007), were all strong motivations to continue care.

In order to enhance their positive caregiving experiences, caregivers expressed helpful attitudes as "taking one day at a time", "making the most of the situation", "focusing on the positives", "being thankful for what I have", and "meeting the challenge". They seemed to make a purposeful effort to take charge of their attitude towards the situation, from moment to moment as well as from day to day. Hellstrom and colleagues (2005a, 2007) suggested the use of strategies such as living for today instead of worrying about the future; they also note that caregivers' efforts to make the best of

things does not constitute denial or a minimizing of unavoidable hardship, but rather is a conscious decision to make life as meaningful as possible. The participants in our study as well consciously made the most of the life they had.

Finding peace and experiencing growth or transcendence were common indications of having found meaning. Previous literature supports these results and demonstrates that finding meaning is a critical aspect of growth or self-transcendence (Davis & Morgan, 2008; Frankl, 2006; Park, 1998). It is also a consequence of enrichment in caregiving (Cartwright, Archbold, Stewart, & Limandri, 1994). Finding peace may be an aspect of growth as well, since individuals with their newly expanded worldview or sense of value and meaning (cf. Siegel, Schrimshaw & Pretter, 2005), are able to accept the unexpected, changing situations of life more easily than before. Hellstrom and colleagues (2005a) reported that a mutual acceptance of a dementia diagnosis with a focus on maintaining a meaningful life helped to create a nurturing relational context between the caregiver and care recipient.

Frankl (2006) suggests that a person is responsible for what he or she makes out of life by trying to rise above their challenging situations. To help with this process, he developed a method called logotherapy that helps individuals realize they have the freedom to take a stand on whatever conditions they might confront, and find meaning in difficult life circumstances. Similarly, in the current study, one of the caregivers expressed that she had never thought caregiving could be meaningful or positive until she heard another caregiver share his story about participating in this current study at a caregiver support group meeting. She called the researcher a month later to share her

story. She commented that it made her rethink her experience and realized that there *were* positives in the experience and that it was meaningful to her. This suggests that introducing positive stories and outlooks to caregivers who are struggling to find meaning or understanding in their experience may trigger them to perceive their experiences in a more positive light. Further intervention research using this approach should be tested with struggling caregivers.

4.5.2 Limitations

This study focused on data collected at a single time point, asking caregivers to reflect on the personal meaning they found in their experience, the process through which they found that meaning and the changes they encountered along the way. As perception and meaning can change with time, longitudinal interviews across the course of caregiving are recommended to capture the trajectories of the process of change. Dementia is a progressive degenerative disease, so the issues that caregivers must deal with over time and the relational dynamic between the caregiver and care recipient changes as the disease progresses. Moreover, dementia progresses at different speeds and in different patterns depending on the individual, making it difficult to compare the experiences of caregivers of individuals with dementia at different stages in their caregiving experience. Nevertheless, the study results suggest that there are strategies and attitudes caregivers can use that could enhance their ability to make their care experiences more meaningful or positive. The lack of racial/ethnic diversity in the sample may be a limitation as well; while there appeared to be similarities across interviews in

this study that transcended race, future research should include a broader range of participant ethnic backgrounds.

4.6 Conclusions

To quote one of the caregivers: “Not [to] overlook the negative aspect but all you hear is caregiver stress and this and that. If that’s all you hear, that’s what you’ll expect. But there are humorous times. There are positive things, and an opportunity to give back. So people should know that.” As suggested by this quote, sharing the positive stories of the caregivers in this study with struggling caregivers can inspire hope or help them reframe caregiving as a positive experience. The results of this study can be a basis for developing interventions for caregivers who struggle to seek understanding or meaning in their experiences. The strategies and attitudes of the caregivers in this study could help struggling caregivers feel that they have the power to shape their experiences and adopt a more positive attitude towards caregiving.

5. Conclusions

"*Remember then: there is only one time that is important--Now! It is the most important time because it is the only time when we have any power*." -- Leo Tolstoy

5.1 Discussion of Findings

This dissertation consists of three studies on the caregiver-care recipient relationship, and meaning caregivers find in this relationship. The majority of previous research in dementia caregiving focused on the negative experiences and consequences for the caregiver. Recently more studies have recognized and explored the positive aspects of dementia caregiving. In those studies, the positive aspect of caregiving was related to the relational dynamic between the caregiver and the care recipient. However there is little research on the changes that occur in relationships as dementia progresses, and on the question of how some caregivers can maintain their positive experience in the face of a deteriorating relationship. Some research suggests that finding meaning is the key to positive outcomes for caregivers. Therefore this dissertation investigated the changing relationship between the caregiver and care recipient. The main findings of this dissertation accentuate the importance of an on-going positive relationship between caregiver and care recipient during caregiving, rather than on a positive relationship history alone, and on caregivers being able to find meaning in caregiving for their recipients.

This dissertation consists of three papers, each of which used different approaches to investigate the relationship between the caregiver and care recipient. The first paper (Shim, Landerman & Davis, 2011), a secondary analysis, focused on different factors that

may affect caregivers' perception of the positive relationship with the care recipient (mutuality). Results of that paper suggest that high mutuality increased the likelihood of caregivers deciding to continue care, while low mutuality was associated with low care recipient functional ability and more caregiver depressive symptoms.

The second paper was a secondary analysis of interviews from dementia caregivers of the same parent study as the first paper, and it further explored factors that affected the caregiver-care recipient relationship,. Specifically it explored: a) what the caregiver-care recipient relationship was like, b) how caregivers who reported positive experiences in caregiving were different from those who did not, and c) what meanings caregivers found in caregiving. Three groups of caregivers were identified: negative, ambivalent and positive. The caregiving experiences of the spousal caregivers of individuals with dementia in this analysis differed according to four factors; a) the caregivers' views of the past or present relationship, b) whether caregivers thought they could accept the changes that had occurred within the relationship, c) whether caregivers could emphasize with their spouse's needs, and d) whether they could find meaning in their caregiving. Those who described a positive caregiving experience tended to focused on their spouse's needs rather than their own; these individuals showed a high level of empathy, compassion, and understanding toward their spouse, accepted the many changes in their spouses and in their lives due to caregiving, and found personal meaning in caregiving. Only those caregivers who described a positive caregiving experience found meaning in caregiving. For women meaning was related to their sense of duty for

caring for their spouse. For men meaning was related to returning the love they had received from their wives over the course of their lives together.

The third paper advanced these results about the positive caregivers experience to explore how some caregivers were able to perceive their experience as positive or meaningful, even in the face of great difficulties. Specifically, caregivers were asked to reflect on the personal meanings they found in their experience, the process through which they found meaning and the changes they encountered through that process. Caregivers reported that finding meaning was a gradual process, evolving over time. They reported several common factors that contributed to finding meaning: a) making a conscious decision to care for their spouse, b) choosing a positive attitude towards caregiving, c) learning to accept help from others, d) accepting their situation, and e) focusing on their blessings. They also expressed strong altruistic values, and the determination and discipline to live those values. Many caregivers talked about having a high level of faith and love, and said that they had found social support and past life challenges helpful to making their experience positive. These caregivers described how their experiences had been made more peaceful and richer as a result of finding meaning. Some expressed that they had experienced growth. In spite of increasing relational difficulties with the care recipient (due to progression of dementia), these caregivers were still able to maintain a positive attitude toward the spouse or caregiving through a conscious act of will.

The present dissertation raises four discussion points. The first discussion point raises the question about the importance of the on-going relationship between caregiver

and care recipient, versus the prior relationship before dementia onset. Previous research emphasizes the centrality of the existing relationship between caregiver and care recipient prior to onset of dementia (Frankl, 2006; Hirschfeld, 1983; Perry and O'Connor, 2002). However the current dissertation suggests that the quality of the on-going relationship dynamic during caregiving is more important in determining the caregivers' perception of the positivity or negativity of their experiences. In other words, even if the relationship quality between caregiver and care recipient was positive prior to dementia onset, if the relationship dynamic is negative during caregiving, caregivers will perceive their experience to be negative. This is because the loss of a positive prior relationship may actually frustrate, anger, or sadden a caregiver even more than if the prior relationship was negative to begin with, since what they had before was so good, their expectations are higher, and their loss seems all the greater. Third study revealed that mutuality is not merely a positive perception of the relationship; rather, it is a conscious decision to understand, empathize with, and care for the care recipient in the present, no matter what the care recipient is able to give in return. This emotional connection was key to these caregivers' success. Consistent with existing literature, this connection enabled caregivers to continue enjoying activities or rituals the couple had previously enjoyed together; to be affectionate, appreciative and sensitive to the mood and feelings of their spouse; to sustain existing competencies in their spouse; and make the best of the things they had left (Hellstrom, Nolan, Lundh, 2007; Perry & O'Connor, 2002). Because of the care recipient's dementia, reciprocity in the relationship may seem unidirectional with the caregiver doing almost all of the giving. However for caregivers who perceived their

caregiving experiences as positive or meaningful, the lack of reciprocity was not only accepted but considered valuable, in that it was something that built their character or faith. As these caregivers viewed it, there was great value in helping someone who was totally dependent on them. All three studies suggest that there are many different nuances to the caregiver-care recipient relationship. Further investigation into these nuances may reveal areas that interventions should focus on.

The second discussion point is that existing literature indicates that the relationship between the caregiver and care recipient is key to the caregiver's decisions about institutionalization (Caron & Bowers, 2003; Kesselring, Krulik, Bichsel, Minder, Bech,& Stuck, 2001). Caregivers were more likely to consider institutionalization after they had begun to perceive the prior relationship as lost or saw the current relationship as negative. At the same time however, all three studies demonstrated that the decision to institutionalize a care recipients, does not necessarily mean that the relationship with their recipients has been lost or has become negative. In the first study, caregivers reporting high mutuality were in fact caregiving for significantly longer periods of time. While in the second study, a number of caregivers reported a positive current relational dynamic, and had still decided to institutionalize their spouses. In the third study as well, several caregivers who found caregiving meaningful investigated institutionalization long before they actually made the decision, so that they could prepare arrangements in advance, and give the care recipient more time to accept the possibility of institutionalization. Indeed, in cases where the caregiver can no longer handle the caregiving situation, temporary or permanent institutionalization may benefit both the caregiver and care recipient. Length

of caregiving did not determine the quality of the relationship, but caregivers perceiving a positive relationship had a tendency to continue caregiving longer than those who did not.

The third discussion point is that an essential component of a positive caregiving experience was acceptance. This includes acceptance of the disease, acceptance of the couple's changed future, of the spouse's limitations, of the lack of reciprocity in the relationship, and of the unpredictable changes to all these entities. By accepting the situation in its totality, caregivers in this dissertation were able to adopt a positive attitude, focus on their blessings, and actively seek resources or help. As a result, they had a sense of peace with themselves, and were able to find caregiving meaningful. Finding peace may be an aspect of growth, a phenomenon where individuals experience an expansion in their attitudes of the self, in their relationships or their philosophy of life, to find a larger sense of meaning. Individuals who have found peace have an expanded worldview or sense of value and meaning, and were able to accept their unexpected and changing situations more easily. Hence, in contrast to acute stress situations where acceptance is found in the aftermath of the event (Tedeschi, Park, & Calhoun, 1998), caregiver who said have found peace were able to thrive in the midst of their experiences, by humbly accepting each change associated with the continuous decline in the care recipient.

Furthermore, Park (1998) suggested that although some people thrive in difficult situations, it does not mean that they have not suffered, nor that they are thriving in every aspect of their lives. In fact, caregivers who experience the most growth may be those who also perceive the most suffering. Their suffering may be so great that they must find meaning and grow in order to accept and live through what they perceive as devastating.

This may be why caregivers who reported positive caregiving experiences in the second study, and caregivers reporting to have found personal meaning in the third study of this dissertation, all expressed a deep sense of pain, loss and sadness in their lost relationship with their care recipient, despite their continued positive attitudes towards the care recipient. In a study of people with tinnitus (Davis & Morgan, 2008), some experienced growth through seeking meaning. However there was also a group of people who never sought meaning (that is, they never asked the question of 'Why me?' which is how finding meaning was measured in this study) but accepted their disease as a given and coped with it. For those caregivers who cannot accept their situation as a given, finding meaning may be the route they must take to grow. In other words, they need to expand their views, values, and existential understanding of the meaning of life, in order to achieve acceptance and peace.

The fourth discussion point is that, for caregivers who reported meaningful caregiving experiences, finding meaning was not an active search, but rather something that emerged from living their lives. Caregivers interviewed in the third study reported that they were doing their best to accept their life, live their values, and live in the now, and they had come to realize that their act of caregiving was meaningful. For them, caregiving was not an active process of soul-searching, but a decision to live by their values, and by making this decision they had come to more clearly understand their existential meaning, that is, the meaning of their existence in this world. In fact, previous research (Davis & Morgan, 2008) suggests that an active search for meaning, in this study, asking the why me question, actually increased "if only" thoughts, which in turn

led to self-blame and depressive symptoms. Raising unanswerable questions tended to paralyze the caregivers, preventing them from accepting their new reality. Conversely, caregivers needed to stop asking these questions and decide to accept and live their lives, in order for meaning to come to them. Frankl (1988) called this fulfillment of meaning in life, self-actualization. The extent of self-actualization was determined by the extent one fulfills a meaning in the world. Thus, it was not obtained by seeking, but by living. Recognizing that self-actualization was an effect, like happiness, Frankl expressed self-actualization as "the unintentional effect of life's intentionality" (Frankl, 1988, p. 38)

5.2 Limitations

Although previous literature reports discrepancies between the caregiver and care recipient in their understanding of each other's role or acceptance of the situation (Cartwright et al., 1994; Hellstrom et al., 2005b, 2007), the current dissertation was only able to include the caregivers' perceptions of the relationships. The first and second papers were secondary analyses with only caregiver data on the relationship available, and the in the third study the care recipients' dementia was very advanced, so they could not be interviewed. Furthermore, caregiving is often a family experience, so while there is a primary caregiver (usually the spouse or adult child), other family members may provide different views of the caregiving experience. This dissertation only includes the perceptions of the primary caregivers: future research should try to include perspectives from other family members or secondary caregivers.

5.3 Implications

Given that caregivers' perceptions of the positive caregiving relationship can continue despite the functional losses of the care recipient and the increasing challenges of caregiving, there is strong support for developing and testing nursing interventions that promote or enhance care relationship quality. Clinicians and researchers should include the current relational dynamic between the caregiver and care recipient in their assessment of the caregiving situation and target caregivers reporting low mutuality for intervention. Various caregiver support tools can be provided through means such as empathy building and interaction improvement training (Herbek & Yammarino, 1990), positive relationship strategies training (Kramer, 1993a), education about disease progression, self-reflective activities, and formal or informal caregiver support (Acton & Wright, 2000; Skaggs, & Barron, 2005). Positive relationship strategies include negotiation, compromise, considering the other person's limitations, empathy, and compassion. Providing accurate information about disease progression can help caregivers prepare for the future, and understand the care recipient's limitations. Further understanding of how spousal dementia caregivers maintain a positive caregiving experience and investigation of strategies suggested by these caregivers could be used to develop data-based interventions that foster positive caregiving experiences for future caregivers.

It was important to caregivers that their caregiving was meaningful. Nursing interventions that help caregivers to view their caregiving as meaningful may benefit struggling caregivers, because a positive attitude can be a choice, not a fixed trait of the

individual (Farran, 1997; Frankl, 2006; Skaggs, 2006). One method that helps individuals realize they have a choice in their attitude towards whatever conditions they are in, and encourages individuals to find meaning in their difficult situations can be found in psychology. This method called logotherapy (Frankl, 2006) can be incorporated into nursing research. Hellstrom and colleagues (2005a, 2007) suggest that the use of strategies such as, living for today instead of worrying about the future and making the best of a situation, is not denial or minimizing the inevitable future by caregivers, but rather a conscious decision to make life as meaningful as possible while they can. Introducing positive stories and outlooks to caregivers struggling to find meaning or understanding in their experience may trigger a positive perception of their experience by inspiring hope. This way we can help caregivers feel that they have the power to shape their experience and adopt a more positive attitude towards caregiving.

It is important for caregivers to have a space in which they can be heard. Within this space, caregivers' frustrations, losses and grief can be shared with other people who understand, and can help them realize that they are not alone in their struggle. In this sense, having a support group, or being able to talk to someone with someone who understands what they are going through, seems essential to caregivers, as can be seen in this dissertation as well. However, as one caregiver mentioned in this dissertation study, if one hears only about the negative side of something (like dementia caregiving), that is what they will come to expect. But by hearing about the positive side of caregiving, caregivers can expect positives as well. Clinicians and support groups leaders can assist

caregivers to reflect on the positive aspects of caregiving, and encourage them to focus on those small things that can make their days meaningful.

5.4 Conclusions

The results of this dissertation emphasize the importance of the current or ongoing attitude of the caregiver towards their care recipient. By finding caregiving meaningful, caregivers can obtain peace and pleasure in the currently lived experience. For the caregivers in this study, their current attitude toward the relationship dynamic with the care recipient (rather than the past relationship or anticipated future relationship) is what seemed to bring the most meaning.

As this dissertation shows, caregiver attitudes toward the relationship with care recipients and the recipients' degenerative decline, color the quality of the caregiving experience. Therefore, the relational dynamic between the caregiver and care recipient may be more affected by an internal choice and way of life, rather than external circumstances. These findings support the creation of nursing interventions that empower, inspirec and motivate caregivers to challenge their limitations, to accept and rise above the difficulties, and to learn and grow from their experiences.

Appendix A

Interviewer Guide

Call caregiver the day before the interview to confirm they will be home. Call again just before leaving to be sure this is still a good time to visit. Be pro-active when introducing yourself on initial visit. (Wear Duke Badge)

"Hi, my name is Bomin Shim. I'm from Duke University School of Nursing. We spoke on the phone. Thank you for inviting me to your home."

Review study purpose and explain audio-tape recording. Obtain written consent. Fill out demographic sheet. Test taping equipment before beginning interview.

Can you hear me ok? Ok.

All of us seek to find some meaning out of our life experiences. Caregivers often tell us that they have found meaning in caregiving despite the challenges associated with memory problems and dementia. I would like to begin by asking you to tell me about your caregiving situation. Then I will ask you to talk about the meanings you found in your care situation and how you came about finding those meanings. I am going to record our conversation and take some notes so I can be sure I have a complete picture of your thoughts.

First, tell me about your caregiving situation.

1. ***For example, tell me about the kind of things you do for your husband/wife. Paint me a picture of what it's been like caring for your husband/wife.***

   (Prompts: ***Tell me what kinds of things you helped with this morning***)

   (Summarize in their words) **"It sounds like…**(ex, you are doing a lot of physical care) pull out at least 3 things in their words " (ask questions to clarify if needed)

2. ***You've shared with me that you found meaning in your care experience. Tell me more about that.***

   "It sounds like you've had a very meaningful experience." *Then summarize in their words, ask for agreement, clarify.*

(BE SURE to IDENTIFY meaning)

3. How did that come about, finding meaning?

(***That may take a little time to think about.*** Prompts: ***When did it happen? Was there a specific event or moment? Who did you talk to? What did they say?)***

4. ***What happened then? Was anything different? How was it different? Tell me about that. What did it change?*** (Prompts: you, your husband/wife, your view of caregiving, purpose in life?)

5. Have you had other experiences in your life that were challenging? How did you find meaning in those situations?

6. Summarize whole interview in their words. Then ask "***It sounds like your meaning came from*** (ex. Your relationship.). ***Is there anything else you want to tell me about your experience?***

In responding to phrases such as……:

- "It's a horrible disease.", "It's been a terribly hard time." Respond with, "***I hear how difficult it is."***
- "Does that make sense?" respond with an immediate ***"yes it does***" and don't dwell on it..Try being silent and letting them talk.. Or "***yes, I hear what you're saying. Anything else you want to say about that?"***

In general:

- Be grounded in what they say. Have a good ear and understanding voice. Use their words to rephrase. (***What I hear you say…, what I'm hearing…, I'm hearing…)***.
- Show that you are really hearing them, not just trying to get at what you want. Always reflect back before moving on to the next question, unless it's a direct question on what they just said.
- Don't guess, always ask (don't provide your explanations: ex. Bad moments. ***Tell me about that,*** **or** ***what does that mean?***)
- If you screwed the question up, stop and start over. It's ok to say "*Let me rephrase that…"*
- Be careful with your own reactions. Don't react more than the speaker. Don't go beyond their responses (ex. Do not laugh unless they do…. You may pull their emotions away from where they are, or where they want to go.)

References

Aarsland, D., Zaccai, J., & Brayne, C.A. (2005). A systematic review of prevalence studies of dementia in Parkinson's disease. *Movement Disorders 20*, 1255-1263.

Acton, G.J. (2002) Health-promoting self care in family caregivers. *Western Journal of Nursing Research* 24(1) 73-86.

Alzheimer's Association (2010). *2010 Alzheimer's disease facts and figures*. Retrieved May 26, 2010 from http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf

Alzheimer's Disease International. (2009). *About Alzheimer's disease*. Retrieved December 4, 2010 from http://www.alz.co.uk/alzheimers/

Alzheimer's Disease International. (2010). *World Alzheimer Report 2010*. Retrieved December 4, 2010 from http://www.alz.co.uk/research/files/WorldAlzheimerReport2010ExecutiveSummary.pdf

Acton, G. J. (2002). Health-promoting self care in family caregivers. *Western Journal of Nursing Research, 24*(1), 73-86.

Acton, G. J., & Wright, K. B. (2000). Self-transcendence and family caregivers of adults with dementia. *Journal of Holistic Nursing, 18*(2), 143-158.

Andren, S. & Elmstahl, S. (2007). Relationships between income, subjective health and caregiver burden in caregivers of people with dementia in group living care: A cross-sectional community-based study. *International Journal of Nursing Studies, 44,* 435-446.

Archbold, P.G., Stewart, B.J., Greenlick, M.R. & Harvath, T. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing & Health* 13, 375-384.

Arno, P. S. (2006). *Economic value of informal caregiving*. Presented at the Care coordination and the caregiving forum, Dept. of Veterans Affairs, NIH, Bethesda, MD, January 25-27. Retrieved on January 25, 2007 from http://www.thefamilycaregiver.org/who/stats.cfm

Arno, P. S., & Memmott, M. M. (1999). The economic value of informal caregiving. *Health Affairs, 18*(2), 182-188.

Ayres, L. (2000a). Narratives of family caregiving: Four story types. *Research in Nursing & Health, 23*, 359-371.

Ayres, L. (2000b). Narratives of family caregiving: The process of making meaning. *Research in Nursing & Health, 23*, 424-434.

Baumeister, R.F. (1991). *Meanings of Life*. New York: The Guilford Press.

Bedard, M., Molloy, D.W., Squire, L., Dubois, S., Lever, J.A., & O'Donnel, M. (2001). The Zarit Burden Interview: A new short version and screening version. *The Gerontologist, 41*(5) , 652-657.

Beeson, R.A. (2003). Loneliness and depression in spousal caregivers of those with Alzheimer's disease versus non-caregiving spouses. *Archives of Psychiatric Nursing* 17(3), 135-143.

Bergman-Evans, B. (1994). A health profile of spousal Alzheimer's caregivers; depression and physical health characteristics. *Journal of Psychosocial Nursing, 32*(9) 25-30.

Bloomberg, L.D., & Volpe, M. (2008). *Completing your Qualitative Dissertation; A roadmap from beginning to end*. Los Angeles; Sage.

Boyatzis, R.E. (1998). *Transforming Qualitative Information: Thematic Analysis and Code Development.* Thousand Oaks: Sage.

Brookmeyer R., Johnson E., Ziegler-Graham K., & Arrighi H.M. (2007). Forecasting the Global Burden of Alzheimer's Disease. *Alzheimer's and Dementia 3*(3),186-191.

Burns, A. & Rabins, P. (2000). Carer burden in dementia. *International Journal of Geriatric Psychiatry, 15,* S9-S13.

Caron C.D., & Bowers B.J. (2003) Deciding whether to continue, share or relinquish caregiving: Caregiver views. *Qualitative Health Research 13,* 1252-1271.

Carter J.H., Stewart B.J. Archbold P.G., Inoue I., Jaglin J., Lannon M. et al. (1998). Living with a person who has Parkinson's disease: The spouse's perspective by stage of disease. *Movement Disorders 13*(1), 20-28.

Cartwright, J.C., Archbold, P.G., Stewart, B.J., & Limandri, B. (1994). Enrichment processes in family caregiving to frail elders. *Advanced Nursing Science, 17*(1), 31-43.

Chenier, M. (1997). Review and analysis of caregiver burden and nursing home placement. *Geriatric Nursing, 18*, 121-126.

Chenoweth, B. & Spencer, B. (1986). Dementia: The experience of family caregivers. *The Gerontological Society of America, 26*(3), 267-272.

Chesla, C., Martinson, I., & Muwaswes, M. (1994). Continuities and discontinuities in family members' relationships with alzheimer's patients. *Family Relations, 43*(1), 3-7.

Clipp, E.C. & George, L.K. (1993). Dementia and cancer: A comparison of spouse caregivers. *The Gerontologist, 33*(4), 534-541.

Clyburn, L.D., Stones, M.J., Hadjistavropoulos, T., & Tuokko, H. (2000). Predicting caregiver burden and depression in Alzheimer's disease. *Journal of Gerontology; Psychological Sciences and Social Sciences, 55*(1), S2-S13.

Cohen, C.A., Colantonio, A., & Vernich, L. (2002). Positive aspects of cargiving: rounding out the caregiver experience. *International Journal of Geriatric psychiatry, 17,* 184-188.

Cohen, C.A., Gold, D.P., Shulman, K.I., & Zucchero, C.A. (1994). Positive aspects in caregiving; An overlooked variable in research. *Canadian Journal on Aging, 13*(3), 378-391.

Cohen, R.S., Mount, B.M., Tomas, J.J.N., & Mount, L.F. (1996). Existential well-being is an important determinant of quality of life. *American Cancer Society, 77*(3), 576-586.

Connell, C.M., & Gibson, G.D. (1997). Racial, ethnic and cultural differences in dementia caregiving: Review and analysis. *The Gerontologist 37*(3), 355-364.

Corbin, J. M., & Strauss, A. (1988). *Unending work and care.* San Francisco: Jossey Bass.

Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory Into Practice, 39*(3), 124-130.

Cromwell, D.A., Eager, K., & Poulos, R.G. (2003). The performance of instrumental activities of daily living scale in screening for cognitive impairment in elderly community residents. *Journal of Clinical Epidemiology 56*, 131-137.

Davis, C. G., & Morgan, M. S. (2008). Finding meaning, perceiving growth, and acceptance of tinnitus, *Rehabilitation Psychology, 53*(2), 128-138.

DeRenzo, E. G., Conley, R. R., & Love, R. (1998). Assessment of capacity to give consent to research participation: state-of-the-art and beyond. *Journal of Health Care Law Policy, 1*(1), 66-87.

Donaldson, C., & Burns, A. (1999). Burden of Alzheimer's disease: helping the patient and caregiver. *Journal of Geriatric Psychiatry and Neurology, 12,* 21-28.

Doraiswamy M., & Kaiser L. (2000). Variability of the Mini-Mental State Examination in dementia. *Neurology* 57(7), 1538-1539.

Dura, J.R., Haywood-Niler, E., & Kiecolt-Glaser, J.K. (1990). Spousal caregivers of persons with Alzheimer's and Parkinson's disease dementia: a preliminary control. *The Gerontologist 30*(3), 332-336.

Farran, C.J. (1997). Theoretical perspectives concerning positive aspects of caring for elderly persons with dementia: Stress/adaptation and existentialism. *The Gerontologist, 37*(2), 250-256.

Farran, C.J., Gilley, D.W., McCann, J.J., Bienias, J.L., Lindeman, D.A., & Evans, D.A. (2007). Efficacy of behavioral interventions for dementia caregivers. *Western Journal of Nursing Research, 29*, 944-960.

Farran, C.J., Keane-Hagerty, E., Salloway, S., Kupferer, S., & Wilken, C.S. (1991). Finding meaning: An alternative paradigm for Alzheimer's disease family caregivers. *The Gerontologist, 31*(4), 483-489.

Folkman, S. (1997). Positive psychological states and coping with severe stress. *Social Science & Medicine, 458*, 1207-1221.

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

Frankl, V.E. (1988). *The will to meaning: Foundations and applications of logotherapy*. New York: Plume books.

Fried, T.R., Bradley, E.H., O'Leary, J.R., & Byers, A.L. (2005). Unmet desire for caregiver patient communication and increased caregiver burden. *Journal of the American Geriatrics Society, 53*(1), 59-65.

Gainey R.R. & Payne B.K. (2006). Caregiver burden, elder abuse, and Alzheimer's disease: testing the relationship. *Journal of Health & Human Services Administration* 29(2), 245-259.

George, K.K. & Gwyther, L.P, (1986). Caregiver well-being: A multidimensional of family caregivers of demented adults. *The Gerontologist* 26, 253-259.

Gerdner, L.A., Tripp-Reimer, T., & Simpson, H.C. (2007) Hard lives, God's help, and struggling through: caregiving in Arkansas Delta. *Journal of Cross-Cultural Gerontology* 22, 355-374.

Gitlin, L.N., Winter L., Corcoran M., Dennis M.P., Schinfeld S., & Hauck W.W. (2003). Effects of the home environmental skill-building program on the caregiver-care recipient dyad: 6-month outcomes from the Philadelphia REACH intiative. *The Gerontologist* 43(4), 532-546.

Haley, W.E., Gitlin, L.N., Wisniewski, S.R., Feeny-Mahoney, D., Coon, D.W., Winter, L., et al. (2004). Well-being, appraisal, and coping in African-American and Caucasian dementia caregivers: findings from the REACH study. *Aging & Mental Health, 8*(4), 316-329.

Harrell, R.M., Lee, K.L., Califf, R.M., Pryor, D.B., & Rosati, R.A. (1984). Regression modeling strategies for improved prognostic prediction. *Statistics in Medicine 3*(2), 143-152.

Hayes, J., Boylstein, C., & Zimmerman, M.K. (2009). Living and loving with dementia: Negotiating spousal and caregiver identity through narrative. *Journal of Aging Studies, 23*, 48-59.

Hellstrom, I., Nolan, M., & Lundh, U. (2005a). Awareness context theory and the dynamics of dementia: Improving understanding using emergent fit. *Dementia, 4*(2), 269-295.

Hellstrom, I., Nolan, M., & Lundh, U. (2005b). 'We do things together': A case study of 'couplehood' in dementia. *Dementia, 4*(1), 7-22.

Hellstrom, I. Nolan, M., & Lundh, U. (2007). Sustaining 'couplehood': Spouses' strategies for living positively with dementia. *Dementia, 6*(3), 383-409.

Herbek, T.A. & Yammarino, F.J. (1990). Empathy building for hospital staff nurses. *Group & Organization Management, 15*(3), 279-295.

Hirschfeld, M. (1983) Homecare versus institutionalization: family caregiving and senile brain disease. *International Journal of Nursing Studies 20*(1), 23-32.

Hooker, K., Manoogian-O'Dell, M., Monahan, D.J., Frazier, L.D., & Shifren, K. (2000) Does type of disease matter? Gender differences among Alzheimer's and Parkinson's disease spouse caregivers? *The Gerontologist 40*(5), 568-573.

Izal, M., Montorio, I., Marquez, M., & Losada, A. (2005) Caregivers' expectations and care receivers' competence Lawton's ecological model of adaptation and aging revised. *Archives of Gerontology and Geriatrics 41*, 129-140.

Judge, J.O., Schechtman, K., & Cress, E. (1996). The relationship between physical performance measures and independence in instrumental activities of daily living. *Journal of American Geriatrics Society* 44(11), 1332-1341.

Kasper, J. D., Steinbach, U., & Andrews, J. (1994). Caregiver role appraisal and caregiver tasks as factors in ending caregiving. *Journal of Aging and Health, 6*(3), 397-414.

Kesselring, A., Krulik, T., Bichsel, M., Minder, C., Bech, J. C., & Stuck, A.E. (2001). Emotional and physical demands on caregivers in home care to the elderly in Switzerland and their relationship to nursing home admission. *European Journal of Public Health* 11(3) 267-273.

Kiecolt-Glaser, J. K., Dura, J. R., Speicher, C. E., Trask, J., & Glaser, R. (1991). Spousal caregivers of dementia victims: longitudinal changes in immunity and health. *Psychosomatic Medicine, 53*, 345-362.

Kim, Y., Schulz, R., & Carver, C. S. (2007). Benefit finding in the cancer caregiving experience. *Psychosomatic Medicine, 69*, 283-291.

Kinney, J.M., & Stephens, M.P. (1989). Hassles and uplifts of giving care to a family member with dementia. *Psychology and Aging, 4*(4), 402-408.

Klein, S. (1989). Caregiver burden and moral development. *IMAGE: Journal of Nursing Scholarship, 21*(2), 94-97.

Kneeshaw, M.F., Considine R.M., & Jennings J. (1999). Mutuality and preparedness of family caregivers for elderly women after bypass surgery. *Applied Nursing Research* 12(3), 128-135.

Kramer, B.J. (1993a). Expanding the conceptualization of caregivng coping: The importance of relationship-focused coping strategies. *Family Relations* 42(4), 383-391.

Kramer, B.J. (1993b). Marital history and the prior relationship as predictors of positive and negative outcomes among wife caregivers. *Family Relations* 42(4), 367-375.

Kramer, B.J. (1997). Differential predictors of strain and gain among husbands caring for wives with dementia, *Gerontologist, 37*(2), 239-249.

Kramer, M. K. (2005). Self-characterizations of adult female informal caregivers: Gender identity and the bearing of burden. *Research and Theory of Nursing Practice: An International Journal, 19*(2), 137-161.

Lawrence, R.H. Tennstedt S.L., & Assmann S.F. (1998). Quality of the caregiver-care recipient relationship: Does it offset negative consequences of caregiving for family caregivers? *Psychology & Aging 13*, 150-158.

Lawton, M.P., (1988). Instrumental activities of daily living (IADL) Scale: Original observer-rated version. *Psychopharmacology Bulletin* 24, 785-787.

Lawton, M.P., & Brody, E.M. (1969). Assessment of older people: self-maintaining and instrumental activities of daily living. *The Gerontologist* 9(3), 179-186.

Lawton, M.P., Kleban, M.H., Moss, M., Rovine, M., & Glicksman, A. (1989). Measuring caregiving appraisal. *Journal of Gerontology; Psychological Sciences, 44*(3), 61-71.

Lawton, M.P., Moss, M., Kleban, M.H., Glicksman, A., & Rovine, M. (1991). A two factor model of caregiving appraisal and psychological well-being, *Journal of Gerontology, Psychological Sciences, 46*(4), 181-189.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.

Lee J., Friedmann E., Picot S.J., Thomas S.A., & Kim C.J. (2007). Korean version of the revised caregiving appraisal scale: a translation and validation study. *Journal of Advanced Nursing 59*(4), 407-415.

Leinonen, E., Korpisammal, L., Pulkkinen, L., & Pukuri, T. (2001). The comparison of burden between caregiving spouses of depressive and demented patients. *International Journal of Geriatric Psychiatry, 16*, 387-393.

Lewinsohn P.M., Seeley J.R., Roberts R.E., & Allen N.B. (1997). Center for epidemiologic studies depression scale (CES-D) as a screening instrument for depression among community-residing older adults. *Psychology and Aging 12*(2), 277-287.

Lyons K.S., Sayer A.G., Archbold P.G., Hornbrook M.C., & Stewart B.J. (2007). The enduring and contextual effects of physical health and depression on care-dyad mutuality. *Research in Nursing & Health 30*, 84-98.

Mason, J. (2006). *Qualitative Research*. Thousand Oaks; Sage.

Miles, M.S., & Crandall, E.K.B. (1983). The search for meaning and its potential for affecting growth in bereaved parents. *Health Values: Achieving High Level Wellness, 7*(1), 19-23.

Montgomery, R. J., Gonyea, J. G., & Hooyman, N. R.,(1985). Caregiving and the experience of subjective and objective burden. *Family Relations, 34*(1), 19-26.

Montgomery, R. J., & Kosloski, K. (1994). A longitudinal analysis of nursing home placement for dependent elders cared for by spouses vs adult children. *Journal of Gerontology: Social Sciences, 49(2)* , S62-S74.

Motenko, A. (1989). The frustrations, gratifications, and well-being of dementia caregivers. *The Gerontologist, 29*, 166-172.

National Alliance for Caregiving & AARP (2004). *Caregiving in the US*. Retrieved on September 7, 2008 from http://www.caregiving.org/data/04finalreport.pdf

National Institute of Neurological Disorders and Stroke (2008). *NINDS Parkinson's disease information page*. Retrieved on 13 October 2008 from http://www.ninds.nih.gov/disorders/parkinsonsdisease/parkinsonsdisease.htm

National Parkinson Foundation (2010). *Parkinson disease overview*. Retrieved from http://www.parkinson.org/parkinson-s-disease.aspx on 26 June 2010

Nietzsche, F. (1998). *Twilight of the idols: or how to philosophize with a hammer*. New York: Oxford University Press.

Nolan, M., Grant, G., & Keady, J. (1996). *Understanding family care*. Philadelphia: Open University Press.

Nolan, M., Ryan, T., Enderby, P., & Reid, D. (2002). Towards a more inclusive vision of dementia care practice and research. *Dementia, 1*(2), 193-211.

Norman, I., Redfern, S., Briggs, K., & Askham, J. (2004). Perceptions and management of change by people with dementia and their carers living at home. *Dementia, 3*(1), 19-44.

Nussbaum R.L., & Ellis C.E. (2003). Alzheimer's disease and Parkinson's disease. *New England Journal of Medicine* 348(14), 1356-1364.

O'Reilly F., Finnan F., Allwright S., Smith G.D., & Ben-Shlomo Y. (1996). The effects of caring for a spouse with Parkinson's disease on social, psychological and physical well-being. *British Journal of General Practice 46,* 507-512.

O'Rourke N., & Tuokko H.A. (2003). Psychometric properties of an abridged version of the zarit burden interview within a representative canadian caregiver sample. *The Gerontologist 43*(1), 121-127.

Park, C.L. (1998). Stress-related growth and thriving through coping: The roles of personality and cognitive process. *Journal of Social Issues, 54*(2), 267-277.

Park, C.L., & Folkman, S. (1997). Meaning in the context of stress and coping, *Review of General Psychology, 1*(2), 115-144.

Perry, J., & O'Connor, D. (2002). Preserving personhood: (Re)membering the spouse with dementia. *Family Relations, 51*(1), 55-62.

Pearlin, L.I., Mullan, J.T., Semple, S.J., & Skaff, M.M. (1990). Caregiving and the stress process: an overview of concepts and their measures. *The Gerontologist, 30*(5), 583-594.

Picot, S.J. (1995a). Rewards, costs, and coping of African American caregivers. *Nursing Research, 44*, 147-152.

Picot, S.J. (1995b). Choice and social exchange theory and the rewards of African American caregivers. *Journal of National Black Nurses Association, 7*(2), 29-40.

Pinquart, M., & Sorensen, S. (2003). Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychology and Aging, 18*(2), 250-267.

Pinquart, M., & Sorensen, S. (2004). Associations of caregiver stressors and uplifts with subjective well-being and depressive mood: a meta-analytic comparison. *Aging & Mental Health* 8(5), 438-449.

Plassman, B.L., Langa, K.M., Fisher, G.G., Heeringa, S.G., Weir, D.R., Ofstedal, M.B., et al. (2007). Prevalence of dementia in the United States: the aging, demographics, and memory study. *Neuroepidemiology, 29*(1-2), 125-132.

Radloff, L.S. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement* 1(3), 385-401.

Rait, G., Walters, K., Bottomley, C., Petersen, I., Iliffe, S., & Nazareth, I. (2010). Survival of people with clinical diagnosis of dementia in primary care: cohort study. *British Medical Journal, 341*: c3584. doi:10.1136/bmj.c3584

Raschick, M., & Ingersoll-Dayton, B. (2004). The costs and rewards of caregiving among aging spouses and adult children. *Family Relations* 53(3), 317-325.

Reker, G. T. & Chamberlain, K. (2000). *Exploring existential meaning: Optimizing human development across the life span*. Thousand Oaks: Sage.

Rhoads, D.R., McFarland, K.F. (2000). Purpose in life and self-actualization in agency-supported caregivers. *Community Mental Health Journal, 36*(4), 513-521.

Robinson, K.M., Adkisson, P., & Weinrich, S., (2001). Problem behavior, caregiver reactions, and impact among caregivers of persons with Alzheimer's disease. *Journal of Advanced Nursing, 36*(4), 573-582.

Rodriguez, G. De Leo, C., Girtler, N., Vitali, P., Grossi, E., & Nobili, F. (2003). Psychological and social aspects in management of Alzheimer's patients: an inquiry among caregivers. *Neurological Science, 24*, 329-335.

Rudd, M.G., Viney, L.L., & Preston, C.A. (1999). The grief experienced by spousal caregivers of dementia patients: The role of place of care of patient and gender of caregiver. *International Journal of Aging and Human Development, 48*(3), 217-249.

Ryff, C. D. (1989). In the eye of the beholder: Views of psychological well-being among middle aged older adults. *Psychology & Aging, 4*(2), 195-201.

Rymer, S., Salloway, S., Norton, L. Malloy, P., Correia, S., & Monast, D. (2002). Impaired awareness, behavior disturbance, and caregiver burden in Alzheimer disease. *Alzheimer Disease and Associated Disorders, 16*(4), 248-253.

Savundranayagam, M.Y., Hummert, M.L., & Montgomery, R.J.V. (2005). Investigating the effects of communication problems on caregiver burden. *Journal of Gerontology, Social Sciences, 60B*(1), S48-S55.

Schulz, R., Hebert, R.S., Dew, M.A., Brown, S. L., Scheier, M.F., Beach, S.R. … & Nichols, L. (2007). Patient suffering and caregiver compassion: New opportunities for research, practice, and policy. *The Gerontologist, 47*(1), 4-13.

Schulz, R., & Sherwood, P.R. (2008). Physical and mental health effects of family caregiving. *American Journal of Nursing, 108*(9 suppl), 23-27.

Schumacher, K. L., Stewart, B. J., & Archbold, P. G. (2007). Mutuality and preparedness moderate the effects of caregiving demand on cancer family caregiver outcomes. *Nursing Research, 56*(6), 425-433.

Schumacher, K. L., Stewart, B. J., Archbold, P. G., Caparro, M., Mutale, F., & Agrawal, S. (2008). Effects of caregiving demand, mutuality and preparedness on family caregiver outcomes during cancer treatment. *Oncology Nursing Forum, 35*(1), 49-56.

Shim, B., Landerman, L. R., & Davis, L.L. (2011). Correlates of care relationship mutuality among carers of people with Alzhiemer's and Parkinson's disease. *Journal of Advanced Nursing (In print)*

Schulz, R., & Beach , S.R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *Journal of the American Medical Association* 282(23), 2215-2219.

Siegel, K., & Schrimshaw, E. W. (2007). The stress moderating role of benefit finding on psychological distress and well-being among women living with HIV/AIDS. *AIDS and Behavior, 11*, 421-433.

Siegel, K., Schrimshaw, E. W., & Pretter, S. (2005). Stress-related growth among women living with HIV/AIDS: Examination of an explanatory model. *Journal of Behavioral Medicine, 28*(5), 403-414.

Singer, J.D., & Willett, J.B. (2003). *Applied longitudinal data analysis. Modeling change and event occurrence*. New York: Oxford University Press.

Skaggs, B.G., Yates, B.C., Hertzog, M., Barron, C.R., Norman, J., & Pozehl, B. (2007). Meaning in heart disease: Measuring the search for meaning. *Journal of Nursing Measurement, 15*(2), 145-160.

Speziale, H. J. S., & Carpenter, D. R. (2007). *Qualitative research in nursing; Advancing the humanistic imperative* (4th Ed.). Philadelphia; Lippincott Williams & Wilkins.

Spitzer, D., Neufeld, A., Harrison, M., Hughes, K., & Stewart, M. (2003). Caregiving in transnational context "My wings have been cut; where can I fly?" *Gender and Society, 17*(2), 267-286.

Steadman P.L. Tremont G., & Davis J.D. (2007). Premorbid relationship satisfaction and caregiver burden in dementia caregivers. *Journal of Geriatric Psychiatry and Neurology 20*(2), 115-119.

Talkington-Boyer, S., & Snyder, D.K. (1994). Assessing the impact on family caregivers to alzheimer's disease patients. *The American Journal of Family Therapy, 22*(1), 57-66.

Tanji H., Anderson K.E., Gruber-Baldini A.L., Fishman P.S., Reich S.G., Weiner W.J., & Shulman L.M. (2008). Mutuality of the marital relationship in Parkinson's disease. *Movement Disorders 23*(13), 1843-1849.

Taris T.W. (2000). *A primer in longitudinal data analysis*. London:Sage.

Tedeschi, R. G., Park, C. L., & Calhoun, L. G. (1998). *Posttraumatic growth: Positive changes in the aftermath of crisis*. New Jersey: Lawrence Erlbaum Associates.

Torti, F. M., Gwyther, L. P., Reed, S. D., Friedman, J. Y., & Schulman, K. A. (2004). A multinational review of recent trends and reports in dementia caregiver burden. *Alzheimer Disease and Associated Disorders, 18*(2), 99-109.

Trice, L. B. (1990). Meaningful life experience to the elderly. *Image: The Journal of Nursing Scholarship, 22*(4), 248-251.

Vitaliano, P. P., Young, H. M., Russo, J., Romano, J., & Magana-Amato, A. (1993). Does expressed emotion in spouses predict subsequent problems among care recipients with Alzheimer's disease? *Journal of Geriatrics, 48*, 202-209.

Wakabayashi, C., & Donato, K.M. (2006). Does caregiving increase poverty among women in later life? Evidence from the Health and Retirement survey. *Journal of Health and Social Behavior, 47*(3), 258-274.

Wallsten S.S. (2000). Effects of caregiving, gender, and race on the health, mutuality and social supports of older couples. *Journal of Aging and Health* 12(1), 90-111.

Williamson, G. M., Shaffer, D. R., & Schulz, R. (1998). Activity restriction and prior relationship history as contributors to mental health outcomes among middle-aged and older spousal caregivers. *Health Psychology, 17*(2), 152-162.

Williamson, G.M., Shaffer, D.R.., & The Family Relationships in Late Life Project. (2001). Relationship quality and potentially harmful behaviors by spousal caregivers: How we were then, how we are now. *Psychology and Aging* 16(2), 217-226.

Wuest, J., Ericson, P. K., & Stern, P. N. (1994). Becoming strangers: the changing family caregiving relationship in Alzheimer's disease. *Journal of Advanced Nursing, 20,* 437-443.

Zarit, S. H., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist*, *20*(6), 649-655.

Biography

Bomin Shim was born in Seoul, Korea on January 20, 1978. She holds a BSN from Inje University and MSN in Gerontological Nursing from Seoul National University.

Publications & Presentations

Shim, B., Landerman, L.R., & Davis, L.L. Correlates of care relationship mutuality among carers of people with Alzheimer's and Parkinson's disease. *Journal of Advanced Nursing* (In print).

Song, M., Lee, M., & **Shim, B**. (2010). Barriers to and facilitators of self-management adherence in Korean older adults with type 2 diabetes. *International Journal of Older People Nursing, 5*(3), 211-218.

Translation (to Korean) of *Primary Care of the Older Adult 2 Ed*. (Eds) MM Burke & JA Laramie. by M. Song, M. Gu, MS. Kim, SM. Kim, JH. Kim, JI. Kim, HS. Kim[1], HS. Kim[2], HJ. Kim, S. Ryu, MS. Park, MJ. Park, YH. Park, J. Oh, Y. Eun, M. Lee, N. Cho, **B. Shim**. (2006) (Chapter in Book)

Podium presentation at the 62nd Gerontological Society of America annual Conference (11/18/09). Title: *Changes in Mutuality among Alzheimer's and Parkinson's disease Caregivers*.

Podium presentation at Duke School of Nursing Research Conference (03/24/09) Title: *Spouse caregivers who find positive outcomes in Alzheimer's disease caregiving*, offered for C.E.U.

Duke Medicine Board of Visitors Meeting, Student speaker representing School of Nursing, invited to present dissertation topic (01/17/08).

Poster presentation at 2007 Southern Nursing Research Society Annual Conference (2/22/07) Galveston, Texas, *'Barriers to adherence to self-management in older adults with Type 2 Diabetes'*.

Scholarship & Honors

2006	Five year Graduate Scholarship with Stipend, Duke University
2007	Induction, Epsilon Chapter, Sigma Theta Tau International Honor Society
2008	2007-2008 Scholarship, Korean Nurses Association of Southern California
2009	Fellowship, Leadership in an Aging Society Program, Duke Aging Center
2009	Conference Travel Fellowship, Duke University Graduate School