

DISSERTATION

DISTANCE CAREGIVERS OF PEOPLE WITH ALZHEIMER'S DISEASE AND RELATED
DEMENTIA: A PHENOMENOLOGICAL STUDY

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WE HEREBY RECOMMEND THAT THE DISSERTATION PREPARED UNDER OUR
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ABSTRACT

DISTANCE CAREGIVERS OF PEOPLE WITH ALZHEIMER'S DISEASE AND RELATED DEMENTIA: A PHENOMENOLOGIAL STUDY

The population of distance caregivers of people with dementia/Alzheimer's disease has not been extensively researched. This research study focused on exploring the lived experience of people caring for someone with dementia/Alzheimer's disease from a distance (defined as 2 or more hours away) to help shed light on this caregiving population. Ten participants (all adult children caring for a parent with dementia/Alzheimer's disease) were involved in this qualitative, phenomenological study. Each participant took part in two individual interviews, the first interview being conducted in person (in most cases) and the follow-up interview being conducted over the phone. After the interviews were transcribed, I analyzed the data using Moustakas's (1994) modified Van Kaam Method. Each interview (initial and follow-up) was analyzed separately. The findings from each participant's two interviews were combined, and then data from all 10 participants were pooled together. Results have been written in story form, and may help readers understand the overall experience of being a distance caregiver for someone with dementia/Alzheimer's disease (including the struggles these caregivers might encounter and the resources they have found). The results of my study, recommendations for future research, and implications for health care professionals are discussed.

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Chapter One: Introduction

In the United States, 3.4 million individuals, aged 71 and older were, estimated to have dementia in 2002 (Plassman et al., 2007). Plassman et al. (2007) found that approximately 2.4 million of those individuals had Alzheimer's disease and that the prevalence of dementia increased with age. Specifically, 5% of those aged 71 to 79 had dementia while 37.4% of those aged 90 and older had dementia. According to the Alzheimer's Association, there are almost 10 million informal caregivers in America for people with dementia/Alzheimer's disease (http://www.alz.org/alzheimers_disease_facts_figures.asp). This resulted in a total of 8.5 billion hours of unpaid care, about a \$94 billion dollar value to the nation, in 2008. Overall, caregivers of people with Alzheimer's disease and related dementia (ADRD) provide more hours of care than other caregivers, and the amount of care provided increases as the disease progresses. For example, studies have found that 40% of caregivers of people with ADRD provide more than 40 hours of care a week. Only 28% of caregivers for other populations provide more than 40 hours of care a week (http://www.alz.org/alzheimers_disease_facts_figures.asp). These numbers show that a large number of Americans are affected by Alzheimer's disease and related dementia.

As the population ages, the number of needed informal and formal caregivers for those with Alzheimer's disease and dementia will increase. Hasselkus and Murray (2007) found that the majority of people with Alzheimer's disease and related dementias are cared for by family and friends in the community. In today's ever increasingly mobile society and rapidly aging population, more Americans are going to be faced with the dilemma of providing care to a loved one with dementia/Alzheimer's disease from a distance (Watari et al., 2006).

Roff, Martin, Jennings, Parker, and Harmon (2007) highlighted the importance of exploring long-distance caregiving, noting that at least 5 million Americans provide care to an elderly family member living an hour or more away. Harvard Women's Health Watch (2004) noted that the stress caregivers feel when trying to balance the care receiver's needs, the needs of their own families, and their work demands may be increased when trying to care for a loved one far away. According to their estimates, 7 million caregivers in America are in this predicament. Koerin and Harrigan (2002) stated that, "Providing care for parents or elderly relatives nearby often is more physically exhausting than long distance care, while long distance care often causes more psychological stress" (p. 66).

Informal caregivers (friends and family members providing unpaid care) of people with ADRD are a unique population that face distinctive challenges and struggles. With today's aging population and increasingly mobile society, more people will be faced with providing care to loved ones with ADRD from a distance. It is important for health care professionals to have an understanding of their lived experiences so they can offer them better support and educational materials and resources. This can include educating caregivers on the progression of ADRD and the difficulties they may encounter with their loved one over time. Such information may enable caregivers to provide effective, quality care. They then could be better prepared to face caregiving demands as both their needs and the needs of the care receivers are more likely to be met. This may lead to an overall higher quality of life for both caregivers and care receivers.

While research has been conducted on caregivers of people with ADRD and on distance caregiving, little has been studied on ADRD caregivers providing care from a distance. The majority of research focuses on people with ADRD (including the medical progression of the disease, medication trials, and intervention strategies) and not necessarily their caregivers. The

general challenges distance caregivers face has been researched, but usually not caregivers for a specific population. The qualitative, phenomenological study conducted exploring the lived experiences of caregivers providing distance care to people with ADRD could greatly add to the current literature and give health care professionals a better understanding of their caregiving situations. Better recommendations and assistance could then be provided to caregivers so their needs and the needs of their loved ones are more likely to be met.

Problem Statement and Context

The increasing prevalence of dementia and Alzheimer's disease in the United States, combined with the increased mobility of Americans, makes caregiving for people with Alzheimer's disease/dementia from a distance an important and relevant topic for research. This includes exploring the unique struggles that those caring for a loved one with Alzheimer's disease/dementia from a distance experience. There is currently little research specifically addressing distance caregiving for the ADRD population.

Purpose Statement

The purpose of this phenomenological, qualitative study was to explore the lived experience of those caring for someone with Alzheimer's disease or related dementia from a distance. This included looking at the unique challenges and struggles these caregivers face living two or more hours away from the care recipient, as well as studying the resources they have found and utilized. Findings may help health care professionals better understand what these caregivers are going through and enable them to provide more effective recommendations to ensure that the needs of caregivers and those receiving care are being met.

Research Questions

1. What factors lead to someone providing care to one with Alzheimer's disease or related dementia from a distance [antecedents]?

2. What is the lived experience of someone caring for someone with Alzheimer's disease or related dementia from a distance?
 - a. Explore what resources are available to people providing care to someone with Alzheimer's disease or related dementia from a distance
 - b. Explore the unique struggles/challenges distance caregivers of people with Alzheimer's disease or related dementia face
3. What recommendations do distance caregivers providing care to someone with Alzheimer's disease or related dementia have for health care professionals?

Definitions of Terms

Alzheimer's Disease: The most common form of dementia, those with Alzheimer's disease have a continuing decline of their memory and exhibit decreased judgment, reasoning and ability to perform familiar tasks (<http://www.alzheimer.ca/english/disease/dementias/intro.htm>). It accounts for approximately 60-80% of all dementia and is the seventh leading cause of death in the United States (http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf). Plaques and tangles form in the brain that affect areas related to memory and learning, which eventually inhibit communication between nerve cells (http://www.alz.org/alzheimers_disease_facts_figures.asp). The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition- Text Revision (American Psychiatric Association, 2007) criteria for a diagnosis of Alzheimer's disease is as follows:

- A. The development of multiple cognitive deficits manifested by both
 - (1) memory impairment (impaired ability to learn new information or to recall previously learned information)
 - (2) one (or more) of the following cognitive disturbances:
 - (a) aphasia (language disturbance)
 - (b) apraxia (impaired ability to carry out motor activities despite intact motor function)
 - (c) agnosia (failure to recognize or identify objects despite intact sensory function)

(d) disturbance in executive functioning (i.e., planning, organizing, sequencing, abstracting)

B. The cognitive deficits in Criteria A1 and A2 each cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning.

C. The course is characterized by gradual onset and continuing cognitive decline.

D. The cognitive deficits in Criteria A1 and A2 are not due to any of the following:

(1) other central nervous system conditions that cause progressive deficits in memory and cognition (e.g., cerebrovascular disease, Parkinson's disease, Huntington's disease, subdural hematoma, normal-pressure hydrocephalus, brain tumor)

(2) systemic conditions that are known to cause dementia (e.g., hypothyroidism, vitamin B12 or folic acid deficiency, niacin deficiency, hypercalcemia, neurosyphilis, HIV infection)

(3) substance-induced conditions

E. The deficits do not occur exclusively during the course of a delirium.

F. The disturbance is not better accounted for by another Axis I disorder (e.g., Major Depressive Episode, Schizophrenia) (page 157).

Caregiver: “A caregiver is a person that an adult needing care is dependent upon for his/her safety. Without that caregiver, the quality of life for the adult needing care would be diminished or endangered” (<http://www.theribbon.com/articles/definecare.asp>).

Dementia: “Dementia is a syndrome consisting of a number of symptoms that include loss of memory, judgment and reasoning, and changes in mood and behavior. These symptoms may affect a person's ability to function at work, in social relationships or in day-to-day activities” (<http://www.alzheimer.ca/english/disease/dementias-intro.htm>). Types of dementia include Vascular Dementia, Dementia with Lewy Bodies, Frontotemporal Dementia, Alzheimer's disease, and Mixed Dementia (Alzheimer's disease and Vascular Dementia together). Dementia is also common in people with Parkinson's disease, Huntington's disease, Creutzfeldt - Jakob disease (Variant Creutzfeldt-Jakob Disease is commonly known as “Mad Cow Disease”), Mild Cognitive Impairment, Normal Pressure Hydrocephalus, and in those who have had physical injury to the brain.

Health Care Professionals: Include, but are not limited to, physicians, nurses, physical therapists, occupational therapists, speech and language pathologists, recreational therapists, respiratory therapists, certified nursing assistants, laboratory technicians, dietitians, recreational therapists, counselors, and pharmacists.

Informal Caregiver: One providing unpaid care to a friend or family member (Schulz & Martire, 2004; Hasselkus & Murray, 2007).

Distance Caregiver: One providing care to someone from two hours or more away.

Primary Caregiver: The caregiver that provides the most care and assistance to the care receiver.

Related Dementia: Refers to various forms of dementia outside of Alzheimer's disease, including vascular dementia, mixed dementia (Alzheimer's disease and vascular dementia together), Parkinson's disease, dementia with Lewy bodies, dementia caused from trauma to the brain, Huntington's disease, Creutzfeldt-Jakob disease, and frontotemporal dementia (list of dementias from <http://www.alzheimer.ca/english/disease/dementias-intro.htm>).

Limitations and Assumptions

Limitations of the study included the researcher not being able to ensure that participants provided accurate, truthful, and thorough information during the research process. A desire to “look good” for the researcher and to appear to be in control may have hindered the participants from divulging more sensitive information and emotions. Given the manner in which participants were recruited, most participants were caregivers from Colorado and Wyoming. This may alter some of the challenges they experienced when compared to caregivers living in the eastern United States (e.g., access to health care may be more limited out west where there are more rural areas, when compared to the east). Participants also had to have a telephone or cell phone, and the methods used to locate participants (e.g., those who have contacted the Alzheimer's Association) may limit the ability to generalize to all distance ADRD caregivers. As this was a qualitative research study taking a phenomenological approach, generalizability is not possible, and therefore not a goal. The impact of some of these limitations may have been decreased by ensuring confidentiality and establishing rapport with the participants. Asking non-judgmental, open-ended questions that were sensitive to the emotions and feelings of participants also was essential.

A few limitations encountered during the research process included poor recording quality of a couple of the interviews, making transcription difficult. The use of a professional

transcriptionist helped in these cases. Furthermore, a few participants simply forgot the scheduled time for an interview, necessitating that the interview be rescheduled. For some participants, this made the time between their initial and follow-up interview over a month (the planned time frame between interviews). Finally, one participant's follow-up interview was delayed a few months when her parent (the one she was caring for) passed away the night the interview was scheduled. Despite delays, two interviews were conducted with all participants.

The skills I have and my personal and professional background may have affected my ability to critically and appropriately analyze data. Using the concept of bracketing when coding data, keeping a researcher's journal, and engaging in peer-review and collaboration throughout the research process assisted in decreasing the impact of my background. Member checking with participants was also conducted.

Significance of the Study

More people will develop Alzheimer's disease or related dementia as society ages (Marin et al., 2003). As most people with Alzheimer's disease or related dementia are cared for by informal caregivers, such as family members or friends, the demand for family members to provide care for this unique population will increase (Hasselkus & Murray, 2007). More family members today are living farther apart for reasons such as work or retirement (Watari et al., 2006). This makes providing care for loved ones more challenging as caregivers are forced to provide care to their loved one from a distance. This creates further barriers to providing effective and timely care. It has become essential for health care professionals, and researchers in the field, to explore and understand the challenges that caregivers for people with Alzheimer's disease/dementia face in general, the unique challenges these caregivers may face when their loved one lives at a distance, and what health care professionals can do to ensure that caregivers

of people with Alzheimer's disease/dementia are taking care of their needs and the needs of their loved ones.

My research on the lived experience of caregivers for people with Alzheimer's disease or dementia who are providing care from a distance (two or more hours away) may provide health care professionals with a greater understanding of the needs of the care receivers and caregivers and enable them to provide more effective intervention. The phenomenological, qualitative approach of this study may offer new and important insights into the experience of caregivers providing long distance care. Butcher, Holkup, and Buckwalter (2001) stated that, "The quantitative emphasis in the body of family ADRD caregiving research has constrained the capacity of health care professionals to fully understand the caregiving experience and the shared meanings family members attribute to their experience as caregivers" (p. 35). The different research approach I have taken may provide new and insightful information for health care professionals so they can better provide effective care to ensure that caregivers and care receivers are having their needs met.

Investigator's Perspective

I have strong professional and personal reasons for researching caregivers who are providing care to those with Alzheimer's disease or dementia from a distance. I have been a practicing occupational therapist for almost 8 years in hospital settings, including 4.5 years in Michigan and 3 years in Colorado. Especially in Colorado, I have assisted family members who live at a distance deal with the declining health of loved ones. The geographical distance increases already emotionally and physically trying times. While I have done my best to support these caregivers, I came to the realization that there is not enough research and information available for health care professionals to offer quality recommendations that are practical and useful. This has been frustrating for not only me, but for the caregivers I am trying to help.

Through the stories family members and patients have told me, I have a small glimpse at how challenging distance caregiving can be and want to help.

My focus on Alzheimer's disease and dementia comes from more personal reasons. My grandmother (my father's mom) has Alzheimer's disease. For a variety of reasons my grandmother was placed in a nursing home. She lives in Ohio and my father lives in Michigan. I have seen my father and aunt (who lives in Ohio) struggle to provide adequate care for their mother. They have felt helpless and unsure of how to best help my grandmother. This has led to negative consequences for my grandfather (my father's father), my father, my aunt, my mother, myself, and, more than anyone, my grandmother. Having no legal rights as the granddaughter, combined with living 20 hours away in Colorado, I have felt a wide range of emotions. I have felt guilty at moving so far away from her (particularly when she tells me on the phone "I'd give anything for you to live closer"). I have felt helpless as I cannot regularly see her and check in on her. I have felt sad that someone who, to me, has always been a pillar of wisdom, strength, encouragement, and compassion could be forced into a nursing home. It frustrates me that the health care professionals my aunt and father have encountered have, overall, been cold and callous. They do not look at her as a person who has led an incredible life, full of both ups and downs. The health care professionals do not appear to engage with her as a person, or to do anything that might enhance the quality of her life. To them, my amazing grandmother is yet another patient to check on and document on until their day is through. They do not understand what my grandmother and my family have gone through. For example, my grandmother grew up in a Masonic home after her parents were unable to take care of her, and her first husband (my grandfather) and his brother were killed together in a car accident when they were in their mid 40s. On the whole, moving to Colorado 3 years ago has only exacerbated the concerns I have

about the care my grandmother receives. I always wonder how well my grandmother is being taken care of and what could be done better.

The struggles I have seen patients and family members experience, along with what I have personally experienced and observed with my grandmother, have made me passionate and excited to research and learn about the experiences of those providing care to a loved one with Alzheimer's disease or dementia from a distance. I hope my research will help me better understand the lived experiences of distance caregivers for people with Alzheimer's disease and related dementia and what suggestions can be made to better meet their needs.

Chapter Two: Review of the Literature

This literature review begins with exploring the physical dimension of Alzheimer's disease and the general characteristics of those with Alzheimer's disease. Descriptive statistics of Alzheimer's disease and related dementia, including the amount of caregivers needed for the population, are discussed. Informal caregivers are then defined and explored in general terms and as it relates to those caring for someone with Alzheimer's disease or related dementia. Existing research and issues surrounding distance caregiving are reviewed next. Quality of life issues are then examined for both caregivers and care receivers. Finally, the health care professionals working with this population are discussed. This includes looking at the unique ways therapists and doctors may view and assist people with Alzheimer's disease and their caregivers. A list of resources available for caregivers is provided and reasons why these resources may not be utilized is discussed. General conclusions and gaps in the research are then described.

Alzheimer's Disease

An in-depth review of Alzheimer's disease (AD) is included to obtain a better understanding of the challenges that caregivers and care receivers face. "A progressive and fatal brain disease ... Alzheimer's destroys brain cells, causing problems with memory, thinking, and behavior severe enough to affect work, lifelong hobbies, or social life" (http://www.alz.org/national/documents/brochure_basicsofalz_low.pdf). The hallmarks of AD are plaques and tangles, which occur with normal aging but are seen to a greater degree in those with AD. Plaques build up between nerve cells containing deposits of a protein fragment called beta-amyloid. Tangles are twisted fibers of a protein called tau, which form inside dying cells. Plaques and tangles tend to form in predictable patterns, beginning in areas important to memory and learning. They block communication among nerve cells and disrupt activities that cells need to survive. As the transfer of information at the synapses begins to fail, the number of synapses

declines and cells eventually die

(http://www.alz.org/national/documents/brochure_basicsofalz_low.pdf). Dramatic shrinkage can be seen in the brain from cell loss and widespread debris from dead and dying neurons. Those with AD may also have inflammation and oxidative stress in their brain tissue as the result of damage from oxygen-containing products of cellular metabolism

(<http://health.nytimes.com/health/guides/disease/alzheimers-disease/causes.html?print=1>, & http://www.alz.org/national/documents/brochure_basicsofalz_low.pdf). Early clinical symptoms may include having trouble remembering names and recent events, apathy, and depression (http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf). Those in the later stage may exhibit impaired judgment, disorientation, confusion, and behavior changes. They may also have difficulty speaking, swallowing and walking

(http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf).

Challenges those with Alzheimer's disease may face.

General problems those with AD experience include forgetfulness severe enough to affect ones' ability to function at work, home, or in hobbies, confusion (e.g., disorientation to time and place), getting lost in familiar places, misplacing things, trouble with language (including gradually being unable to follow written or spoken directions, forgetting simple words and substituting unusual words, or forgetting the name/use of common objects), forgetting whole experiences, memory loss (e.g., forgetting recently learned information more often and an inability to recall information later), difficulty performing familiar tasks (e.g., unable to care for self or complete everyday tasks), poor and decreased judgment (e.g., dressing inappropriately for the weather, refusing bathing/grooming tasks , making inappropriate financial decisions, or demonstrating sexual inhibition), and problems with abstract thinking

(http://www.alz.org/national/documents/brochure_basicsofalz_low.pdf). Changes in mood,

behavior, and personality may also be seen. Rapid mood swings may come on for no apparent reason, or the person with AD may become aggressive and angry. Personality changes may include increased feelings of suspicion, fear, or paranoia, and they may experience delusions and/or hallucinations (http://www.alz.org/national/documents/brochure_basicsofalz_low.pdf, & Silveri, 2007). The emergence of psychotic symptoms is considered to predict faster cognitive and functional decline as well as an increased risk of mortality (Silveri, 2007). People with AD may lose initiative and become more passive, sleeping more and not engaging in their usual activities (http://www.alz.org/national/documents/brochure_basicsofalz_low.pdf). They may eventually become incontinent and immobile, literally forgetting how to move. In a follow-up study of participants in the Baltimore Longitudinal Study of Aging, Brookmeyer, Corrada, Curriero, and Kawas (2002) found that the median survival times for those with AD was 8.3 years for those who were 65 years old and 3.4 years for those who were 90 years old.

Causes of Alzheimer's disease.

Increasing age is the greatest known risk factor for AD (http://www.alz.org/national/documents/brochure_basicsofalz_low.pdf; Harciarek & Jodzio, 2005). The likelihood of developing AD approximately doubles every 5 years after age 65 and the risk is about 50% after age 85 (http://www.alz.org/national/documents/brochure_basicsofalz_low.pdf). One in eight people 65 or older have AD, and someone in America is diagnosed with it every 70 seconds (http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf). It is more common in women, which may be attributed to the loss of Estrogen that women experience in menopause as well as their longer life expectancy (Harciarek & Jodzio, 2005; http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf). Sixteen percent of females aged 71 or older have AD, compared to 11% of males

(http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf). Family and personal history is also a risk factor. Those with a parent or sibling who have AD are two to three times more likely to develop the disease

(http://www.alz.org/national/documents/brochure_basicsofalz_low.pdf). Those with a lower educational level, a family history of Down's syndrome, or who smoke or drink also have an increased risk (Harciarek & Jodzio, 2005). The alcohol risk factor is controversial, however, as mild/moderate drinking might actually protect against dementia/Alzheimer's disease (Fratiglioni, Winblad, & Strauss, 2007). People with malnutrition or food absorption problems may have lower levels of Vitamin B-12 and foliate, which has been found to increase the risk of AD by two-fold (Fratiglioni et al., 2007). People who have sustained a serious head injury or who are in certain occupations have a greater risk of developing AD (Fratiglioni et al., 2007; Harciarek & Jodzio, 2005). For example, there is an increased risk for those doing manual work in goods production industry, likely related to being exposed to pollutants and other toxins (Fratiglioni et al., 2007). Furthermore, those with a limited or poor social network have a 60% increased risk of dementia (Fratiglioni et al., 2007). This may be due to having decreased communication with others, which can result in decreased cognitive stimulation. Diabetes, heart disease, stroke, high blood pressure, and high cholesterol also increase ones risk of Alzheimer's disease (Fratiglioni et al., 2007; http://www.alz.org/national/documents/brochure_basicsofalz_low.pdf). Finally, when looking at genetics, a gene has been identified that increases the risk of AD but it does not guarantee the person will get the disorder. Certain rare genes (such as Apolipoprotein E, or APOPE) have been identified that virtually guarantee the person will develop AD, however they account for less than 5% of cases and have only been found in a few hundred extended families worldwide (http://www.alz.org/national/documents/brochure_basicsofalz_low.pdf; Fratiglioni et

al., 2007). In sum, the vast majority of cases of AD are caused by a complex combination of genetic and non-genetic influences.

Statistics on Alzheimer's disease and related dementia.

Brookmeyer, Johnson, Ziegler-Graham, and Arrighi (2007) stated that there were 26.6 million people with Alzheimer's disease in the world in 2006 with an increase to 106.8 million expected by the year 2050. The World Alzheimer Report 2010 estimated that roughly 35.6 million people worldwide have dementia, and anticipated that 115.4 million people will have dementia worldwide in 2050

(http://www.alz.org/documents/national/World_Alzheimer_Report_2010.pdf). Three point four million individuals in the United States aged 71 and older were estimated to have dementia in 2002 (Plassman et al., 2007). The Alzheimer's Association's 2010 Facts and Figures document provided further details on Alzheimer's disease

(http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf). The document reported that Alzheimer's disease is the most common form of dementia (accounting for 60%-80% of dementia cases), estimated that 5.3 million Americans have Alzheimer's disease and that it is now the seventh leading cause of death, and that roughly 70% of people with ADRD live at home. According to the Alzheimer's Association, there are nearly 10 million Americans aged 18 and over currently providing unpaid care to people with Alzheimer's disease

(http://www.alz.org/alzheimers_disease_facts_figures.asp). Xu, Kochanek, Murphy, and Tejada-Vera (2010) found that Alzheimer's disease was the sixth leading cause of death in 2007. Marin et al. (2003) reported that the incidence of Alzheimer's disease is anticipated to almost double every 5 years. These numbers show that a large number of Americans are or will be affected by Alzheimer's disease and related dementias.

The Informal Caregiver

Schulz and Martire (2004) stated that, “A broadly inclusive definition that characterizes caregiving in terms of providing ‘informal’ care to an ill or disabled family member or friend of any age yields estimates of approximately 52 million caregivers annually in the United States.” They noted that approximately 75% of care provided in the home to Americans with Alzheimer’s disease is done by friends and family. Increased life expectancy, the aging population, changes in healthcare reimbursement, and medical technology advances are some of the reasons they give behind the high rate of family caregivers. They reported that adult daughters and daughter-in-laws are more likely to provide care, and more hours of care, than sons and sons-in-laws. In addition, most care is provided by one individual instead of several family members.

Hasselkus and Murray (2007) found that the majority of people with Alzheimer’s disease and related dementia (ADRD) are cared for by family and friends in the community (who shall be referred to as informal caregivers). According to Scott (2006), there are more than 52.4 million informal caregivers in the United States who

... care for their aging friends, spouses, extended family and children with severe disabilities well into their retirement. The roles that informal caregivers play are not only important to the people for whom they provide care, but also the overall economy of the state and the nation. (p. 1)

Scott acknowledged that informal caregivers are often unrecognized and do not receive sufficient support from various government levels, and that they experience emotional, physical, and financial struggles. This in turn leads to caregivers neglecting their own health and emotional state, including experiencing sleep deprivation, poor eating habits, decreased exercise, and not taking care of medical needs and appointments. All of this may result in depression, exhaustion, and an inability function in their personal and professional lives (Scott, 2006). It is

also important to note that the average length of time to provide care for a family member over the age of 50 is 8 years (Smith, 2006).

The average informal caregiver is female (61%) and between the ages of 50 and 63 (Scott, 2006). Of note, the National Institute on Aging (2007) has noted that more and more men are becoming caregivers. Caring for a parent is the most common informal caregiving relationship, as seven million or more Americans care for a parent every day (Scott, 2006). Scott (2006) found that 14% of informal caregivers provide 40 or more hours of care a week. The total economic value of the care that informal caregivers provide is estimated at \$257 billion annually (Scott, 2006). Scott reported that 59% of caregivers work or have worked while providing care, and that 12% of working caregivers must quit their jobs to provide full-time care. Nayak and Mulchandani (2003) reported that the annual cost of caring for one person with mild Alzheimer's disease is roughly \$18,408 and \$36,132 for those with severe Alzheimer's disease, and families spend an average of \$12,500 a year for at-home care. They noted that Alzheimer's disease cost United States employers more than 61 billion dollars in 2002, which included factors such as absenteeism, lost productivity, and staff replacement costs. People aged 65 and older with ADRD had three times the healthcare costs when compared to those 65 and older without dementia/Alzheimer's disease (\$15,145 compared to \$5,272) (http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf). This includes payment from all sources, such as Medicare, Medicaid, and private insurance. In 2010, "total payments ... are expected to be \$172 billion" (p. 34, http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf).

When looking at adult women and caregiving, Himes, Jordan, and Farkas (1996) discussed how the role of women is changing in society and possibly affecting the ability of

women to care for parents. The factors discussed include an increased number of women being in the labor force, an increasing attachment women are feeling to the labor force, and women child bearing at later ages which increases the likelihood of having young children that need care at the same time their parents may need care. They noted that “this combination of factors has led to some analysts to question the ability of families to continue to provide high levels of informal care to elderly persons with impairments” (Himes et al., 1996, p. 350). Using data from the 1987-1988 National Survey of Families and Households, Himes et al. (1996) interviewed a randomly selected adult from each household, with the dependent variable being caring for a parent with a chronic illness. They discovered that caregivers were older than the noncaregivers (mean age of 42.9 years versus 35.4 years), more likely to be in intact marriages (63.1% versus 61.6%), less likely to have both parents alive (42% versus 67%), and living an average distance of 149 miles from the closest parent (compared to 690 miles for noncaregivers). Factors not significantly related to caregiving included number of siblings, employment, health, and the presence of children. When looking at the duration of care, the researchers found that women who had provided some level of care for at least 6 months were older, in poorer health, less likely to be employed, and more likely to live closer to their parents. Duration of care, rather than intensity of care, had the greatest impact on these variables. Distance from a parent was not significant when looking at short-term, intense care.

Lawrence, Tennstedt, and Assmann (1998) explored how the quality of the caregiver-care receiver relationship may affect the negative consequences of caregiving (e.g., depression). After conducting individual interviews with disabled older care receivers and the people they identified as their primary caregiver, the researchers discovered that a high quality relationship did not assist in decreasing the stress felt when the care receiver exhibited stressor problem behaviors.

Problem behaviors exhibited by the care receiver were also found to lead to increased feelings of role captivity. Interestingly, as the sense of role captivity increased in caregivers, depression also increased when the quality of the relationship and other stressors were controlled. However, higher quality relationships were associated with significantly lower levels of depression.

Informal caregivers of people with Alzheimer's disease and related dementia.

The roughly 11 million Americans providing unpaid care to people with Alzheimer's disease or dementia gave about 12.5 billion hours of care in 2009 (http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf). This equates to roughly 144 billion dollars worth of care (http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf). When looking at informal caregivers of people with Alzheimer's disease/dementia, 94% take care of a relative (including 62% of those taking care of a parent/parent-in-law), 60% were females, and the average age was 51 years old (http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf). Caregivers of people with dementia are a frequently neglected population. Approximately 49% of informal Alzheimer's/dementia caregivers reported that "the person's Alzheimer's or other dementia was his or her main health problem" (http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf, p. 24). Health care professionals and other family members tend to ignore the needs of the caregiver and focus solely on the person with ADRD. Specifically, Dooley and Hinojosa (2004) reported that depression is often overlooked in caregivers. They state that caregivers experience higher rates of depression overall, even after the care receiver has gone to an institution or has passed away. Depressive symptoms among caregivers for people with dementia have been found to range from 28-55% (Beeson, Horton-Deutsch, Farran, & Neundorfer, 2000). Further adding to depression is

the fact that caregivers usually receive little or no thanks or signs of appreciation from the care receivers or other family members (Hasselkus & Murray, 2007).

Caregiving also takes a toll physically. For example, increased depressive symptoms and reaction to care receiver problem behaviors has been found to significantly predict the development of cardiovascular disease in caregivers of people with dementia within 18 months when known risk factors for cardiovascular disease are controlled (Mausbach, Patterson, Rabinowitz, Grant, & Schultz, 2007). Informal caregivers of people with ADRD are more likely to rate their health as fair or poor when compared to non-caregivers and more likely to state that caregiving has decreased their overall health when compared to caregivers of other populations (http://www.alz.org/alzheimers_disease_facts_figures.asp). ADRD caregivers also tend to have higher levels of stress hormones, reduced immune function, slower wound healing, new hypertension, and new coronary heart disease when compared to other caregivers (http://www.alz.org/alzheimers_disease_facts_figures.asp). Specifically, providing care for someone with dementia can affect the caregiver's immune system for up to 3 years after the caregiving role ends (Smith, 2006). As caregivers are immersed in caregiving they will frequently neglect or not notice the physical and emotional strain they are under (Nayak & Mulchandani, 2003).

In addition to mental and physical health challenges, caregivers of people with ADRD may experience difficulty managing work duties. Approximately 60% of ADRD caregivers work either full or part time (http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf). Their professional life may suffer as they spend more time providing care, resulting in less time for work-related endeavors. As a result, their financial stability (including retirement savings) and overall income may be at risk. Reducing work hours or even quitting their job to provide

care may be required. In general, ADRD caregivers are more likely to have to quit or reduce their work hours than other caregivers (31% more likely if their loved one does not have behavioral symptoms and 68% if their loved one does have behavioral symptoms) (http://www.alz.org/alzheimers_disease_facts_figures.asp). About 18% of these caregivers take a leave of absence, 13% reduce their work hours, 8% turn down promotions, and 8% quit entirely (http://www.alz.org/alzheimers_disease_facts_figures.asp). The annual cost of caring for a person with mild Alzheimer's disease is roughly \$18,408 and \$36,132 for someone with severe Alzheimer's disease (Nayak & Mulchandani, 2003). Furthermore, families spend an average of \$12,500 a year for at-home care for someone with ADRD (Nayak & Mulchandani, 2003). It may be hard for caregivers to meet such financial demands if they must live on a reduced income resulting from decreased work hours or quitting work. The current economy in the United States has also made taking time off of work for caregiving more challenging as caregivers may fear losing their job (http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf).

Sewar (2007) noted that health care professionals may underestimate the amount of care the caregiver must provide. Caregiving demands can lead to physical, emotional, and financial difficulties as the caregiver might have to give up his/her job and other activities such as outings with friends. Overall, caregivers of people with ADRD provide more hours of care than other caregivers and the amount of care provided increases as the disease progresses. For example, studies have found that 40% of caregivers of people with ADRD provide more than 40 hours of care a week. Only 28% of caregivers for other populations provide more than 40 hours of care a week (http://www.alz.org/alzheimers_disease_facts_figures.asp). Caregivers of people in the early stages of Alzheimer's disease may spend 18-21 hours a week providing care. This can increase to 10 hours a day during the middle stages of the disease. As the care receiver's mental

and physical functions decline, more and more hands-on-care is needed (Sewar, 2007). This may force caregivers to take on new and challenging roles (e.g., starting to manage finances or being more of a disciplinarian). Caregivers for those with ADRD are also more likely to assist with activities of daily living (ADLs) when compared to caregivers of other population, including things like shopping, meal preparation, medication management, assistance with legal or financial affairs, and dressing tasks

(http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf). For example, 38% of caregivers were assisting with three or more ADLs compared to 27% of other caregivers (http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf). Forty six percent of ADRD caregivers assist with arranging and monitoring hired care, compared to 33% of other caregivers (http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf).

Caregiving for someone with Alzheimer's disease or related dementia also poses unique challenges. More supervision must be provided, which goes along with Ory, Tennstedt, and Schulz (2000) findings that people caregiving for someone with dementia/Alzheimer's disease report having less physical activity, rest, and sleep when compared to noncaregivers. As more supervision and assistance with daily living skills such as bathing and toileting is required, caregivers may experience increased stress, depression, and negative physical health effects. For example, the emotional stress of caregiving is rated high or very high by more than 40% of informal caregivers of people with dementia (versus 28% of caregivers of other populations) (http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf). Finally, the progression of Alzheimer's disease/dementia can last for an extended period of time. According to the Alzheimer's Association, 32% of informal caregivers for people with ADRD have been providing care for 5 or more years and 12% have been providing care for 10 or more years

(http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf). The extended period of caregiving may prolong grief reactions. This leads to the concept of “dual dying” (Sanders, Ott, Kelber, & Noonan, 2008). The caregiver may grieve the “death” and loss of the person they have known and loved as the disease progresses, and then grieve again when the care receiver actually dies. All of this stress, burden, depression, and grief may lead to impairments in work and social roles. For example, Beeson et al. (2000) noted that caregivers gradually lose the exchanges of intimacy, goals, and social activities that they use to share with the care receivers. It is important to note that intervention to assist caregivers before the death of their loved one may assist in caregiver bereavement. A study by Schulz, Boerner, Shear, Zhang, and Gitlin (2006), examining the bereavement of dementia caregivers, found that reducing and treating caregiver depression before the death of their loved one and providing psychosocial or skill-training caregiver intervention assisted caregivers in coping after the care receiver’s death.

Research has been done looking at how certain factors affect caregiving or are affected by caregiving. Edwards, Zarit, Stephens, and Townsend (2002) explored how work demands may impact the role strain and stress experienced by those caring for family members with cognitive impairments. Their study of 101 employed and 101 non-employed caregivers revealed that one’s experiences at work play a larger role in role strain and stress than the actual act of working. Caregivers who experienced job conflict experienced higher levels of role overload, worry, and strain. They also exhibited more depressive symptoms. Those with positive work experiences reported having the greatest difficulty dealing with time constraints and psychological demands. Edwards et al. (2002) noted that positive work experiences may help buffer against caregiver depression and provide a reprieve from caregiving demands.

Lieberman and Fisher (1999) examined how caregiving may affect the marital relationship of caregivers. Their study was part of a longitudinal project accessing how the health and well-being of multigenerational family members was impacted by Alzheimer's disease or vascular dementia. They utilized the Careburdens Scale to assess a caregiver's subjective reactions to the demands of caring for their parent and the Marital Strain Scale to evaluate marital strain. Multiple regression equations revealed that spouses of someone caring for a parent with Alzheimer's disease or dementia had greater marital strain as the amount of perceived burden by the caregiver increased ($\beta = .22, p = .005$). The strain was felt even more by males with a wife caring for a parent ($\beta = .27, p = .01$). The researchers speculated that this could be because a male may have to take on more household responsibilities and that he may be impacted more by the reduced time his spouse has to devote to their marriage when she is a caregiver. The severity of the care receiver's illness (obtained from six patient measures and assessed by outpatient clinics using uniform criteria) was not found to be significant. Organized cohesiveness (measured by the Organized Cohesiveness Questionnaire scale and Intergeneration Fusion Scale) was also significantly and negatively associated the marital strain felt by the spouses of caregivers ($\beta = -.28, p = .01$). Family emotion management was assessed rating three items individually on a 5-point rating scale (emotional distance, avoidance of conflict, and guilt). Emotional distance and conflict avoidance were found to be significantly related to caregiver strain ($\beta = -.38, p = .01$ and $\beta = .42, p = .03$).

Researching caregivers for those who Alzheimer's disease or related dementia, Beeson et al. (2000) explored the relationship among loneliness, depression, quality of the past relationship with the care receiver, relational deprivation, quality of the current relationship with the care receiver, and distance felt due to caregiving. They defined loneliness as a feeling experienced

when one does not have the relationships he/she desires, including when current relationships (or anticipated future relationships) are deemed inadequate compared to past relationships or relationships that others have. The researchers used the single item “I felt lonely” from the Center for Epidemiologic Studies Depression Scale (CES-D) to measure loneliness, the CES-D scale to measure depression, and six questions obtained from a previous research study to measure relational deprivation. Quality of relationship was measured by three separate questions looking at the caregivers perceptions of the quality of their relationship with the care receivers before and after symptoms of dementia arouse. The responses were measured on a 4-point Likert scale. The researchers found that loneliness, depression, quality of the past relationship, relational deprivation, quality of the current relationship, and distance felt to caregiving were significantly related. Relationship deprivation was significantly and positively related to quality of the current relationship ($r = .46, p < .001$ - the more relational deprivation reported the poorer the relationship), loneliness ($r = .36, p < .001$), and depression ($r = .34, p < .001$). There was a significant negative relationship between relational deprivation and distance felt due to caregiving ($r = -.26, p < .001$). This indicates that those with stronger feelings of relational deprivation felt more distant from the care receivers. Loneliness was also significantly related to quality of the current relationship ($r = .34, p < .001$) and depression ($r = .66, p < .01$). As loneliness increased, there was poorer quality of the current relationship and greater feelings of depression. Depression was significantly related to relational deprivation ($r = .34, p < .001$) and quality of the current relationship ($r = .32, p < .001$) and quality of the past relationship was strongly related to the quality of the current relationship ($r = .46, p < .001$). They found that 59% of participants reported the current relationship had declined, 39% reported it remained the same, and 2% reported it had improved. Finally, a significant negative relationship was found between

the quality of the current relationship and distance felt due to caregiving ($r = -.40, p < .001$), indicating that caregivers felt more distant from the care receivers when the relationship was considered poor. When looking at gender and relationship roles (e.g., daughter, wife, or husband), females had higher rates of depression, loneliness, and relational deprivation, with caregiving wives having the highest depression scores. Caregiving husbands reported better quality of past and current relationship and the least amount of relational deprivation, loneliness, and depression. This is consistent with Stolley, Reed, and Buckwalter's (2002) study that found female caregivers have a higher levels of burden when compared to men.

Hogan, Lisy, Savannah, Henry, Kuo, and Fisher (2003) looked at eight caregivers of people with Alzheimer's disease and identified some of the role changes they experienced after taking on the caregiving role. Areas explored included participation in leisure activities, relationships, household management tasks, and overall health and wellness. Themes that emerged were feeling guilty at leaving the care receiver, role reversal (e.g., the child becomes the parent taking care of his/her mother or father), increased household management responsibilities, decreased social contacts, and decreased ability and time to take care of their own personal health needs. Feelings of guilt resulted in decreased engagement in leisure activities and time for personal enjoyment. Role reversal caused feelings of sadness for caregivers as the relationship they had with the care receivers changed. The care receivers could no longer participate in relationships as they had in the past, leading to a decrease in the quality of relationships. Caregivers also reported having less time for household management tasks but being forced to take on more of them. Finally, social relationships declined in general. The care receivers frequently engaged in inappropriate behavior, leading to social isolation. Friends and community members also tended to shy away from the caregivers and care receivers. Thus, research by

Hogan et al.'s (2003) showed that taking on the caregiving role may result in one having to radically adjust roles and role expectations.

Clark and Bond (2002) explored 163 caregivers and their spouses with dementia. Their findings revealed that one's self-belief in his/her physical ability to provide care affects the perceived caregiver burden and ability to carry out daily tasks. People are more likely to successfully carry out their various roles if they believe they are physically able to do so. The researchers also found that, as the severity of dementia increased in the caregivers' spouses, domestic care and household maintenance demands increased while their social participation decreased. This supports the findings of Chenoweth and Spencer (1986), who found that the emotional stress caregivers of people with dementia experience differs and takes on various forms throughout the different stages of the disease. This can result in numerous role changes and challenges for caregivers.

Stolley et al. (2002) conducted a study of caregivers and intervention techniques. Most of the care recipients had Alzheimer's disease. Two groups were compared, one of whom received intervention including a specific care plan and education tailored to the specific caregiver's needs while the other group received general information about Alzheimer's disease and a list of resources. Caregivers in the first intervention group had lower levels of perceived impact (e.g., intrusion) of caregiving into daily life, increased positive appraisal of the caregiving situation, and lower perceived burden scores (measured by the Philadelphia Geriatric Center Caregiving Appraisal Scales). Overall, women had higher burden levels when compared to men, the stage of Alzheimer's disease the care receiver was in did not have any significant affect, and increasing hours of caregiving had a negative impact on caregiver appraisal. Finally, older caregivers experienced less of an impact when compared to younger caregivers.

Distance Caregiving

According to the Alzheimer's Association, 6 % of ADRD caregivers live one-to-two hours away and 9% live two or more hours away from the care recipient (http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf). "Depending on the definition of 'long-distance caregiving,' these numbers indicate that 981,000 to 1.6 million caregivers of people with Alzheimer's and other dementias are 'long-distance caregivers'" (http://www.alz.org/documents_custom/report_alzfactsfigures2010.pdf). Roff et al. (2007) highlighted the importance of exploring distance caregiving, reporting that at least 5 million Americans provide care to an elderly family member living an hour or more away. Harvard Women's Health Watch (2004) noted that the stress caregivers feel when trying to balance care receiver needs, the needs of their own families, and work demands may be increased when trying to care for a loved one far away. According to their estimates, 7 million caregivers in America are in this predicament. Koerin and Harrigan (2002) stated that, "Providing care for parents or elderly relatives nearby often is more physically exhausting than long distance care, while long distance care often causes more psychological stress" (p. 66).

Watari et al. (2006) reported that the average caregiver lives about 304 miles from the care recipient and travels about 4 hours to provide care. They explained that the number of people providing care from a distance is expected to grow as family structures continue to change. Factors affecting caregiving and family structures include (a) an increased number of women in the work force, (b) greater geographic mobility of adult children and older parents (e.g., children moving for jobs and older parents moving for retirement), (c) delayed childbearing (which may result in one caring for an elderly parent and a child at the same time, the "sandwich generation"), (d) smaller families, and (e) higher rates of divorce (which may create tensions between parents and children) and single parenthood (Watari et al., 2006, p. 63). Factors that

increase the likelihood of providing care from a distance include having an advanced education, older age, having remarried parents, living in a residential location in the western United States, and having a history of moving (Lawton, Silverstein, & Bengtson, 1994; Lin & Rogerson, 1995; Rogerson, Weng, & Lin, 1993, as cited in Watari et al., 2006, p. 63).

Family structure changes are important to consider when discussing long-distance caregivers as they may affect the resources available to caregivers. For example, distance caregivers might not have the ability to regularly fly or drive to see the care receiver due to obligations they have to their children (e.g., school or other academic/athletic commitments). Divorced caregivers may have fewer financial resources available, less emotional support, and a decreased ability to take time off work to provide care from a distance. This may increase their feelings of stress, depression, or guilt. Thus, the challenges of distance caregiving may be amplified as the result of family structure changes.

In addition to the general challenges ADRD caregivers face, caregivers providing care from a distance face unique challenges. Assessing the needs of the care receiver and knowing when help is required is more difficult because distance caregivers may not see the care receiver on a regular basis. Adult children living closer to their parents are better able to see the assistance their parents require, while children living farther away are not as aware of deteriorations in physical and mental health (Joseph & Hallman, 1998). Thus, the care adult children living farther away provide is more likely to be crisis-driven (Joseph & Hallman, 1998). Parents may also try and hide the difficulties they are having because they don't want to worry their children. This makes it especially difficult for distance caregivers to get an accurate picture of the care receiver's needs. As the level of assistance the person with ADRD requires increases throughout the disease process, recognizing and meeting his/her needs may become harder and harder for

distance caregivers. When comparing genders, Joseph and Hallman (1998) found that women provided more hours of care when compared to men (4.55 hours a week versus 3.14 hours), and that the hours per week women provided care does not fall significantly with increasing distance like it did for men. Women traveling 1-30 minutes provided an average of 4.66 hours of care a week, while those traveling 31-120 minutes provided an average of 4.63 hours. For men, it was 3.55 hours and 2.75 hours.

Locating services available for the care receiver and then monitoring them can also be challenging from a distance. Caregivers may not be familiar with services available in the care receiver's community and could have difficulty locating them. It is also difficult to judge the quality of the care being provided. There is no guarantee that the care that is being requested and ordered is being carried out. For example, a person with ADRD may have special diet needs or requests that are not being followed (e.g., they are being given thin liquids to drink instead of the necessary thickened ones, increasing their risk of aspirating and getting pneumonia, or they are being given foods they do not like to eat and are thus not eating). Living at a distance, the caregiver may never know. Policies and procedures might also vary from state to state or even from county to county, making it harder for distance caregivers to know exactly what steps they need to take for their loved ones to get things such as health insurance coverage.

One must also recognize that it takes a great deal of time and energy to set up and manage care. After it has been organized, caregivers must make sure that the plan of care is being carried out and that increasing care is arranged as the care receivers' needs increase. Smith (2006) found that caregivers who use services spend about 3 ½ hours a week arranging services and 4 hours a week monitoring care. Arranging and monitoring care for a loved one with ADRD requires frequent communication between caregivers, health care professionals, and those

providing hired assistance. This is difficult when the caregiver lives at a distance. Different schedules, time zone differences, and access to communication methods like the internet all come into play. While the internet can help caregivers communicate with others and assist in arranging care, caregivers may not have or understand how to utilize the technology required to complete such tasks. Some caregiving tasks might also need to be done in person per facility or organizational policy (e.g., certain types of paperwork), requiring the caregiver to travel. It is also important to note that those with ADRD may refuse hired assistance. For example, they may deny that they need help or be paranoid and think the hired person is there to harm them or steal from them. This makes it extremely difficult for caregivers to ensure that the care receiver is being taken care of, particularly when they are at a distance.

Financial matters also need to be considered with long-distance caregiving. The added expenses that long-distance caregivers must take into account could include the cost of traveling (such as lodging and gas or airfare), paying for telephone bills or an internet connection, and paying for hired help. Martin, Jennings, Parker, and Harmon (2007) found that long-distance caregivers spend an average of \$392 a month in care-related costs such as travel. This is an addition to providing an average of 22 hours a month of care. For example, more than three-fourths of distance caregivers help with instrumental activities of daily living, including transportation, shopping, and managing finances (Roff et al., 2007). Providing such care may require taking time off work, which could result in a reduced income and ability to meet financial obligations. According to Morris (2004), about half of caregivers work either full time or part time. Taking care of legal and financial issues (e.g., power of attorney, wills, and medical insurance) are other areas that frequently need to be addressed and paid for.

Koerin and Harrigan (2002) stated that “providing care for parents or elderly relatives nearby often is more physically exhausting than long-distance care, while long-distance care often causes more psychological stress” (p. 66). Emotions that long-distance caregivers may face include feelings of helplessness and guilt (Dang, Badiye, & Kelkar, 2008). Caregivers may be at a loss as to how they can help and where to go to for help when their loved one lives at a distance. There may also be constant feelings of doubt about whether they are doing enough for their loved one, and guilt at not always being there to provide care. On the flip side, caregivers might also feel guilty about not being there for other family members when they are away providing care. In addition, distance caregivers are likely not able to provide the daily physical and cognitive stimulation that people with ADRD need to stay as physically and mentally sharp as possible. This may be distressing to caregivers, increasing their feelings of guilt and helplessness. Finally, when distance caregivers are with their loved ones, much of the time may be spent taking care of business. Whether it’s going to doctor’s appointments, setting up pill boxes for medications, or taking time to arrange further care, their time is frequently not spent in leisurely or enjoyable pursuits. They are likely not able to enjoy the company of their loved one and focus on the role of daughter, son, or whatever it might be (Coste, 2003). This may be emotionally, physically, and mentally draining and difficult to endure.

When looking at long-distance caregiving, it is important to recognize that those in need of care may not want to move, or they may not want to live with their family. The care recipient may lose good friends if he/she moves, or worry about being a “burden” to loved ones. Furthermore, the situation of each caregiver is unique. A caregiver’s circumstances may make having a loved one move in with him/her impractical for a variety of reasons, including financially or personally. The importance of personal history and relationships between all

involved, including those of the adult children, is also crucial to recognize (Roff et al., 2007). These relationships may affect how caregiving tasks are divided up. Joseph and Hallman (1998) reported that a sibling who lives closer to his/her parents will be asked to assist more in providing care than a sibling living farther away. Children living farther away are more likely to help financially, to assist with short-term crises, and to offer emotional support to their siblings and parents. There can also be confrontations between siblings when one sibling feels the other is providing inadequate care. There may be arguments about who is the best person to coordinate and manage the care of a parent. Siblings or other family members may all want to be in charge, or no one may want to direct care. This makes it difficult for any care to be arranged and managed. All of these factors may cause strife in the life of caregivers and care receivers, particularly if care is being provided from a distance.

A study by MetLife Mature Market Institute and the National Alliance for Caregiving (2004) highlighted the struggles long-distance caregivers may go through. They studied 1,130 long-distance caregivers and found that the average distance between care receivers and caregivers was 450 miles, or 7.23 hours of travel one-way. Fifty-one percent of these caregivers visited at least a few times a month. Financially, participants in their study spent an average of \$386 per month if the care recipient lived one to three hours away and \$674 per month if he/she lived more than three hours away. Twenty-three percent of the caregivers studied reported being the only or primary care provider. Eighty-percent worked either full or part-time, with more than 40% having to rearrange their work schedule to accommodate caregiving responsibilities and 12% taking a leave of absence. Furthermore, Koerin and Harrigan (2002) found that 61.4% of long-distance caregivers reported at least one negative impact on employment and over half reported that they had given up vacations, hobbies, or other leisure activities. Nearly one-third

reported they had less time for other family members. These studies show that many caregivers may have to radically adjust their life to provide care for a loved one.

Quality of Life

With all the challenges people with Alzheimer's disease/related dementia and their caregivers face, it is essential to look at quality of life issues. While it is difficult to define quality of life, the World Health Organization's Quality of Life assessment group uses the following definition (found in Butler and Ciarrochi, 2007): "individuals' perception of their position in life in the context of the culture and the value system in which they live in and in relation to their goals, expectations, standards, and concerns" (p. 607).

Evaluating the quality of life for people with ADRD and their caregivers is a challenging task. For example, Scocco, Fantoni, and Caon (2006) found that care receivers tend to rate their quality of life differently (sometimes higher) than their caregivers and healthy people of similar age. Thus, it is important to look at the quality of life of caregivers and care receivers from multiple view points and assessments. In an effort to further understand caregiver burden and quality of life, Neil and Bowie (2008) developed a carer self-report questionnaire called the Behavioural and Psychological Symptoms Questionnaire (BPSQ). Neil and Bowie determined that the BPSQ provides useful information with respect to carer distress, which they state maybe currently under recognized and can lead to a lower quality of life for caregivers. In addition, Trigg, Skevington, and Jones (2007) developed the Bath Assessment of Subjective Quality of Life in Dementia (BASQID). The BASQID measures the self-reported quality of life for people with mild to moderate dementia. Scores from two field tests were responsive to changes in quality of life over three months. Assessments such as the BPSQ and BASQID better enable health care professionals to determine how people with ADRD and their caregivers view their current quality of life and what areas they may be struggling with.

Other researchers have utilized existing tools to explore how caregivers and care receivers may view the care receivers' quality of life differently. Hoe, Katona, Orrell, and Livingston (2007) had caregivers and care receivers complete the Quality of Life-Alzheimer's Disease Scale (QOL-AD). They found that family caregivers rated the care receivers' quality of life higher when the care receiver had fewer depressive symptoms, less irritability, less apathy, and less daily living impairment, and when care receivers lived at home. Fewer depressive symptoms, living at home, and taking Acetyl cholinesterase-inhibitors (AChEI) predicted higher care receiver-rated quality of life.

When looking at how those with dementia/Alzheimer's disease rate their overall quality of life, Katsuno (2005) found that people with early-stage dementia generally rate their perceived quality of life as good. Katsuno examined 23 people from a dementia-specific adult day care centre in a mid-western United States residential-care facility. Twenty-one of his subjects rated their current quality of life as 'good' or better. The main concerns of subjects included dealing with the negative public view and stigma of dementia. This included a fear of the term "Alzheimer's disease," and the possibility of devaluation, mistreatment, social exclusion, and loss of friends. Egan, Hobson, and Fearing (2006) also found in a review of the literature related to occupational therapy and dementia that those with dementia and Alzheimer's disease may fear embarrassment, loss of control over life decisions, loss of independence (e.g., ability to drive and manage finances), changes in family relationships, and an increased need for supervision.

In a study by Hancock, Livingston, and Orrell (2006), self-reported higher quality of life on the QOL-AD for people with dementia in residential care homes was significantly correlated with less depressed mood, anxiety, less anxiety, fewer unmet needs, and more cognitive impairment. Their ratings were most strongly influenced by mood. Higher staff-rated QOL-AD

scores were significantly correlated with less physical disability, less cognitive impairment, fewer neuropsychiatric symptoms, lower levels of depression and anxiety symptoms, and fewer unmet needs. There was a strong association between staff perception of residents' quality of life and level of dependency and challenging behaviors. It is important to note that there was a poor association between staff ratings and individual ratings of quality of life.

There are discrepancies when looking at how a person with Alzheimer's disease or related dementia rates his/her quality of life and how formal or informal caregivers rate that individual's quality of life. Thus, staff and individual ratings of quality of life cannot be assumed to provide a suitable proxy for someone with dementia" (Hancock, Livingston, and Orrell, 2006, p. 464). For example, in Hancock et al.'s (2006) study of 238 people over the age of 60 with memory deficits, lower ratings of quality of life as rated by the care receiver were predicted by the presence of depression and anxiety symptoms, while lower quality of life ratings by caregivers were associated with higher levels of dependency and behavioral problems. Furthermore, studies looking at staff proxy ratings have found lower quality of life ratings for residents living in long-term care institutions compared to those living in the community and for those who had orientation disturbances, physical dependency, and anxiolytic treatment (treatment for anxiety) (Hancock et al., 2006, p. 464).

Another area of research has been looking at what factors affect the quality of life of care receivers. Missotten et al. (2007) conducted a study looking at the quality of life of 365 demented people aged 65 or older over a 3 year period using the Alzheimer's Disease Related Quality of Life assessment (ADRQL). Their research revealed no direct relationship between clinical state and quality of life in their subjects. While clinical state variables tended to indicate declines in function, ADRQL scores fluctuated and actually increased during some assessment

intervals. Overall the effect of clinical scores on quality of life was limited or inconsistent, demonstrating that other factors play an important role in quality of life. Missotten et al. (2007) speculated other factors could include the physical and social environment in which subjects live. The researchers noted that clinical variables play a bigger role in the more advanced stages of the disease while physical and social environment variables seem to be particularly important in the mild to moderate stages of dementia. Their research is consistent with the findings of Trigg et al. (2007), who found a low association between the BASQID they devised and the Mini-Mental State Examination. Trigg et al. (2007) suggested the low association demonstrates that cognitive function may influence quality of life but it is an indirect measure of the quality of life experienced during dementia.

Vellone, Piras, Talucci, and Cohen (2008) conducted a phenomenological study exploring the quality of life of caregivers for people with Alzheimer's disease (AD). The 32 participants had cared for a relative or a friend with AD for at least 2 years. Factors identified by the participants as improving their quality of life included the care receiver being in good health, having more independence and personal time, and having assistance from others in caring for their loved ones. Factors participants identified as decreasing their quality of life included worrying about the future and the progression of the disease (including the uncertainty of how long the disease will take to progress) and stress. When asked what quality of life means to them, participants noted things like having feelings of serenity, tranquility, and psychological well-being, having freedom (e.g., the ability to do what one desires when desired), and having general well-being, good health, and good financial status .

Caregivers and Health Care Professionals

It is essential for health care professionals to look at how caregivers are coping with the demands of caregiving as it affects both caregivers and care receivers. Research has shown that

care receivers are impacted by how caregivers are feeling. For example, Dooley and Hinojosa (2004) noted that the quality of life of care recipients is related to caregiver burden. Caregivers are able to provide higher quality care if they are taking care of their own physical and emotional needs. This includes the ability to provide a supportive physical and social environment, which Missotten et al. (2007) discussed as being factors that affect the quality of life of people with Alzheimer's disease.

While every caregiver and care receiver has a unique situation that needs to be respected, there are common reactions that health care professionals can expect. Wuest, Ericson, Stern, and Irwin (2001) discussed the emotions that many people with Alzheimer's disease/dementia and their caregivers might experience as the person with dementia declines. The stages include dawning, holding on, gaining control, and letting go. The caregiver and the care receiver realize that something is not quite right during the dawning stage. They may try to find plausible reasons for odd behaviors and cover them up to maintain a sense of normality until an event or behavior occurs that makes covering up implausible. Holding on includes trying to maintain a high quality of life and sustain relationships. During this stage the caregiver may have to gain control of the care receiver by utilizing such strategies as setting routines to ensure the care receiver's needs are being met. This may drain the caregiver's resources emotionally, physically, or cognitively and impact his/her ability to provide high quality care. The relationships the caregiver has with other friends or family may also be in jeopardy as providing care becomes top priority. Letting go is the final stage, where a caregiver might conclude that his/her loved one can no longer be cared for at home. This can include the process of separating (where the caregiver establishes criteria for being unable to provide care) or triggering (where an event or behavior occurs that makes providing care impossible).

When looking at caregiver grief, Sanders et al. (2008) found seven themes in their study exploring grief in caregivers of people with Alzheimer's disease/dementia. They were: yearning for the past, regret and guilt, isolation, restricted freedom, life stressors, systemic issues (e.g., professionals not meeting the needs of the patient- like waking him/her up at 7 AM for breakfast when he/she has never eaten breakfast), and coping strategies (including spiritual faith, social support, and pets). Karlin, Bell, and Noah (2001) identified seven themes as part of the caregiving experience. The themes, derived after interviewing 51 family caregivers of people with Alzheimer's disease, included areas such as (1) identifying the caregiver role (e.g., the daughter becoming more of a mother figure to a parent), (2) having unmet needs or feeling burdened (e.g., lack of emotional support or experiencing great caregiver demands), (3) seeking additional support sources and resources (e.g., friends, staff at care facilities, or adult day care programs), (4) support group issues (e.g., wanting to go and talk about things outside of Alzheimer's, not feeling free to share during the meetings, or getting the opportunity to meet others and make contacts), (5) protection, nursing home placement, and guilt issues (e.g., trying to protect the family member from the reactions of others, trying to keep the family member safe, feeling guilty about placing the family member in a facility, or being concerned about the quality being provided where the family member lives), (6) research awareness and participation (e.g., keeping updated on Alzheimer's research), and (7) additional contributions of being a caregiver (e.g., trying to be a competent caregiver or make contributions to those with Alzheimer's and their caregivers).

When looking at the overall experience of caregiving for someone with Alzheimer's disease, Butcher et al. (2001) delineated eight essential structural elements to describe the lived experience. They were enduring stress and frustration, being immersed in caregiving, finding

meaning and joy, integrating Alzheimer's disease/dementia into their lives (such as researching the disease and monitoring the care receiver), moving with continuous change (such as taking on new responsibilities), preserving integrity, gathering support, and suffering through the losses. It is important for health care professionals to understand the different stages caregivers and care receivers go through. Health care providers can be a source of support, influence the process of gaining control, and reinforce the caregivers' feelings of worthiness and ability to provide care.

Toth-Cohen (2000) interviewed four occupational therapists regarding their views and roles as therapists providing education and support for caregivers for people who have dementia. The therapists interviewed stressed that, when working with caregivers, health care providers must recognize and explore the different perspectives and values family members and caregivers place on caregiving. This may impact the type of recommendations made. For example, caregivers may view dressing and bathing the care receiver as a time for bonding. Working on increasing the care receiver's independence with dressing and bathing would not be a priority like it might be to a caregiver who has no interest in bathing or dressing the care receiver, or who sees them as daunting tasks. Furthermore, fully exploring and addressing the needs of those with Alzheimer's disease and their families in the environment they live in is essential. It will not do any good to make recommendations that are not realistic or helpful in the care receiver's environment. Health care professionals must cultivate a culture of flexibility and openness among health care professionals, caregivers, care receivers, and family members to make recommendations that are appropriate and likely to be utilized.

A study by Bourgeois, Schulz, Burgio, and Beach (2002) reinforced the importance of individualized interventions. The researchers conducted a study of 63 people who were caring for their spouses with Alzheimer's disease that included a 12- week intervention with two

experimental groups (self-change or patient-change group) and one control group. Bourgeois et al. (2002) concluded that, “This study demonstrated the effectiveness of teaching caregivers specific behavioral skills to enable them to cope with specific caregiving challenges” (p. 70). There was a significant reduction in mean frequency of observed problem behavior in the patient-change group when compared to the control group, $F(1, 37) = 11.83$ and 7.32 at 3-month and 6-month follow-ups respectively, $p < .05$, and the patient-change group had significantly more positive mood than the control group at the posttest, $F(1, 47) = 4.11$, $p < .05$ and $F(1, 47) = 17.05$, $p < .01$. When comparing the self-change group to the control group, the self-change group had significantly improved mood ratings, $F(1, 47) = 7.47$ and 12.47 , $p < .01$ at 3-month and 6-month follow-ups and fewer problem behaviors, $F(1, 47) = 5.56$, $p < .05$ and $F(1, 47) = 7.83$, $p < .01$. The Behave-AD (the Behavior Pathology in Alzheimer's Disease Rating Scale) was used to subjectively measure problem behaviors of the care receiver (as rated by the caregiver) and caregiver mood was assessed with a single item rated on a scale from 1 (very depressed) to 9 (very happy).

Caregiver and health care professional interactions.

Collaboration between caregivers, care receivers, family members, and other health care professionals is crucial in improving the quality of life of caregivers and care receivers and in ensuring that the needs of both parties are being met. Health care professionals should acknowledge caregivers and family members as experts (Toth-Cohen, 2000). While this may stretch the professional skills of health care professionals, it is important to realize that caregivers may have already tried some of the recommendations commonly made (e.g., using pill boxes for medications) to no avail. Having this knowledge will provide more insight into the caregiver and care receiver situation.

Toth-Cohen (2000) provided health care providers with suggestions for interacting with caregivers. First, it is essential to listen to the caregiver and hear what they have to say. Only then will you be able to get a clear picture of what the caregiving situation is like and how both the care receiver and care recipient are feeling and coping. Secondly, there must be collaboration with caregivers. New ideas and strategies will arise when caregivers and health care providers work and problem-solve together. Thirdly, it is important to validate the efforts of caregivers. This includes helping them see what strategies are working and carrying those strategies over to other areas when able. Helping caregivers realize the value of what they are doing and how they are helping the care receiver also validates caregiver efforts. Finally, reframing the caregiving situation is an essential part of interacting with caregivers. This involves letting the caregivers know they need to take time for themselves, helping them release expectations of both themselves and the care receivers, and providing them standards by which to judge the effectiveness of their strategies (e.g., going to support groups and looking for small successes).

In addition to having good communication with caregivers, Dilworth-Anderson (2001) discussed the importance of looking at the socio-cultural context to get a better idea of the beliefs and attitudes of caregivers. This includes exploring how they may view dependency, which can affect ones' willingness to provide care. She also addressed what she calls the personal context. This refers to the personal characteristics of the caregiver, such as his/her education, income, employment status, overall physical and mental health, and feelings of mastery in the caregiving role. These areas affect the ability of caregivers to provide high quality care.

Perspectives from Individual Health Care Professions

The following is a description of how some health care professions may work with clients who have dementia and their families. It is not meant to be an all-inclusive list.

Physicians.

The various types of physicians that can assist with people with Alzheimer's disease or related dementia include geriatricians (specialize in the care of older adults), neurologists (work with those with a stroke, Parkinson's disease, or other neurological disorders and have training in the diagnoses and treatment of people with Alzheimer's disease), Psychiatrists (have experience with depression, psychosis, and other psychiatric disorders), and clinical neuropsychologists (measure memory and other intellectual abilities) (<http://www.namenda.com/sections/about-alzheimers-disease/choosing-alzheimers-specialist.aspx>). Such professionals can assist with managing medical issues that people with Alzheimer's disease and related dementia face, including prescribing medications and making referrals to other health care professionals as needed. Evaluations that such professionals may use to make the diagnoses of Alzheimer's disease or dementia include the Mini-Mental State Examination, the Mattis Dementia Rating Scale, and the Clock Drawing test (<http://adam.about.com/reports/Alzheimer-s-disease.htm>). Physical tests that may be conducted include electroencephalography to look at brain-wave activity or imaging tests such as magnetic resonance imaging (MRI), positron-emission tomography (PET), and single photon emission computed tomography (SPECT) to rule out other disorders (<http://adam.about.com/reports/Alzheimer-s-disease.htm>).

Physicians will prescribe different medications to people based on the stage of Alzheimer's disease they are in. For example, those in the mild to moderate stage of Alzheimer's disease may be prescribed cholinesterase inhibitors to help manage behavioral symptoms and delay the progression of symptoms (<http://www.nia.nih.gov/Alzheimers/Publications/medcationsfs.htm>). Razadyne® and Aricept® are examples of such cholinesterase inhibitors. For those in the moderate to severe stages of Alzheimer's disease, Namenda® is an N-methyl D-aspartate receptor antagonist frequently

prescribed to help preserve activities of daily living functions and delay disease progression, (<http://www.nia.nih.gov/Alzheimers/Publications/medcationsfs.htm>). In a study of 1,222 people with dementia who lived with their caregivers, Belle, Zhang, Czaja, Burns, and Schulz (2004) found that 31% used cognitive enhancement medication at baseline. Within a year 14% started and 30% quit taking such medications, with those who started taking medications being more like to have spouse-caregivers, more education, and fewer impairments in activities of daily living at baseline. Those who quit taking medications had greater activities of daily living deficits at baseline and were less able to perform daily living tasks at follow-up.

Physical therapists.

When examining physical therapy and Alzheimer's disease, the focus is on the importance of exercise and the benefits exercising provides (<http://www.geriaticspt.org/clients/PTadult.cfm>). These benefits include increased cardiovascular fitness, increased endurance and strength, maintenance of motor skills, decreased falls, reduced rate of disease associated with mental decline, and improved behavior, memory and communication skills. While physical therapists customize therapy interventions to meet the individual needs of their patients, therapy sessions generally include exercises to increase flexibility, balance, and strength. Physical therapists will also work with caregivers and care receivers to recommend home modifications and adaptations and to provide positioning, transfers, and walking education, advice, and practice (<http://www.geriaticspt.org/clients/PTadult.cfm>). Improved functioning and decreased depression have been shown when comparing people engaging in such exercise with medical management to those receiving medical management alone (<http://physicaltherapy.about.com/od/typesofphysicaltherapy/ss/Alzheimers.htm?p=1>).

Occupational therapists.

Dooley and Hinojosa (2004) have noted that individualized occupational therapy intervention can be effective in increasing the overall quality of life of caregivers and care receivers with ADRD. In general, an important aspect of occupational therapy intervention includes identifying and working with the strengths of care receives to promote a higher quality of life (Dooley & Hinojosa, 2004; Glantz & Richman, 2007). This helps the care receiver and caregiver see that the care receiver is not helpless and that he/she can do certain things to help out. This eases caregiver burden and helps take away the negative stigma and feelings of inadequacy care receivers may have of themselves. Glantz and Richmand (2007) reinforced this when they discuss doing care with the care receiver, not for the care receiver. This philosophy empowers both the care receiver and caregiver. Feeling empowered may assist in increasing quality of life by decreasing feelings of helplessness, rolelessness, and uselessness (Glantz & Richman, 2007).

Occupational therapy suggestions for caregivers usually fall into three categories (Dooley & Hinojosa, 2004). Caregivers typically receive recommendations in all three categories, which are environmental modifications, caregiver approaches, and community-based assistance. Environmental modifications include providing visual cues such as labels, posting phone numbers, and using pill boxes. It also involves removing throw rugs and clutter and possibly taking locks off doors so the care receiver cannot get locked into a room. Addressing caregiver approaches includes exploring ways caregivers can interact with care receivers to create more opportunities for successes in daily living tasks. Ways to accomplish this involve structuring daily routines (e.g., breaking down tasks and using one-step directions), including care receivers in household chores, and providing cues so care receivers can perform to their highest potential. Community-based assistance includes referring caregivers to resources available in the area.

Resources many include support groups offered by the Alzheimer's association, programs that offer home-delivered meals such as Meals on Wheels, going to Senior Centers and Adult Day Programs, and organizations that offer financial assistance for things like medications and reduced rates on home maker services.

It is essential to look at how occupational therapy recommendations can affect the quality of life of the caregivers and care receivers. Dooley and Hinojosa (2004) conducted a study to determine the extent to which adherence to occupational therapy recommendations would increase the quality of life of persons with Alzheimer's disease living in the community and decrease the burden felt by family members caring for them. Dooley and Hinojosa found that those in the occupational therapy treatment group had higher levels of positive affect and independence in self-care while caregivers had significantly lower levels of burden. Overall, the quality of life of care recipients was related to caregiver burden. There were also fewer upsets by patients if their abilities fit with the environmental demands and opportunities. Dooley and Hinojosa explained that effective occupational therapy intervention involves looking at the person-environment fit model and finding a good match between the care receivers' abilities and environmental demands. This can lead to an overall higher quality of life for care receivers.

Speech therapists.

Speech therapy may assist those in the mild stage of Alzheimer's disease with maintaining their verbal skills (http://adam.about.com/reports/000002_7.htm). Engaging those with AD in various cognitive tasks during speech therapy can assist in keeping their mind active. As the disease progresses, speech therapists can work on teaching caregivers different communication techniques and strategies for interacting with their loved one. For example, a speech therapist may recommend that a caregiver speak slower or in short, simple sentences for easier comprehension by the person with AD (Malugani, 2008). In the late stage of ADRD,

people may forget how to swallow (http://adam.about.com/reports/000002_7.htm). Speech therapists can assist in making diet recommendations to ensure the safety of people with Alzheimer's disease (e.g., thickened liquids or a pureed diet).

Music therapists.

According to the American Music Therapy Association's website, "music therapists structure the use of both instrumental and vocal music strategies to improve functioning or facilitate changes that contribute to life quality" (<http://www.musictherapy.org/factsheets/MT%20Alzheimers%202006.pdf>). The website states that music therapy has been shown to reduce depression among older adults, can be structured to work on social/emotional skills and recall/language skills, and that it can decrease problem behaviors such as agitation and aggression for those with Alzheimer's disease and related dementia. Music is thought to promote feelings of acceptance and belonging, and can have a calming influence. Forgeron (1999) noted that, "Alzheimer's disease patients can continue to participate in organized music activities, even though they exhibit deteriorating levels of functioning; also, Alzheimer's sufferers may be able to retain musical perception, and learn new information when presented in a musical context" (p. 1). Kirkland (1998) reported that music provides a method of communication for this population, and that they may exhibit increased eye contact, vocal activity, and physical movement during and after music therapy.

Social workers.

In their phenomenological study looking at siblings' caregiving for parents, Roff et al. (2007) highlighted the important role social workers play in assisting caregivers. Social workers can assist caregivers in making living arrangements for care receivers after a hospital stay (e.g., transitioning to an acute rehabilitation facility, an assisted living facility, or a nursing home) or in obtaining in-home support. This includes assisting family members in looking at the care

receiver's needs and available resources, and dividing up caregiving tasks. Part of a social worker's job may also involve helping those providing care understand each others' strengths and weaknesses, and assisting caregivers in overcoming difficult emotions (Roff et al., 2007). For example, a caregiver may feel guilt and frustration at living far away from their loved one and not being able to provide more direct care (Roff et al, 2007).

Educating Distance Alzheimer's Disease and Related Dementia Caregivers

Educating caregivers of people with ADRD is essential. In addition to enabling them to provide high quality care, educating caregivers can help them learn how to take better care of themselves and handle caregiving challenges. Techniques to promote the health and happiness of the care receiver, to improve the quality of caregiving experiences, and to help save time are readily utilized by caregivers and can be taught to them (Gray, Horowitz, O'Sullivan, Kharasch Behr, & Abreu, 2007). Areas to address when educating caregivers include the ADRD process, what support and assistance their loved one with ADRD will likely need and how best to provide it, how to take care of their own personal needs, and information on community resources. Providing such education can be challenging when a caregiver is providing care from a distance. Ways to educate these caregivers in directing, coordinating, and providing care can include utilizing educational internet websites, distributing educational brochures or pamphlets, and proving them with information on community resources and programs available both where they live and where the care receiver lives (Dang et al., 2008).

Distance caregivers can be directed to internet sites for support and education. This could include websites that have information on ADRD, community resources, and basic strategies for assisting someone with ADRD. Some websites even allow communication with other caregivers, enabling them to obtain support, ideas, and information from people going through similar situations. For example, they can share information on the quality of available community

resources and health-care practitioners and facilities. Brochures and pamphlets with educational information can also be available at physicians' offices, nursing homes, assisted living facilities, hospitals, group homes, day program centers, support group meetings, and places like local Alzheimer's Association offices and community organizations on aging. Finally, both brochures and internet website can list books for caregivers to utilize.

With today's technology, it is also possible for courses and informational sessions to be broadcast live on the internet. When this is available, caregivers may get on the internet and view the sessions live and interact with others in real time to ask questions and express concerns. PowerPoint presentations and recorded speeches and presentations can be posted on the internet as well for caregivers to access whenever it is convenient for them (Glueckauf & Loomis, 2003). Of course, caregivers must have the technology available to them and the knowledge of how to use the resources for such programs to be useful. This may or may not be the case. In addition, Glueckauf and Loomis (2003) noted in their study of online support programs for Alzheimer's caregivers that things like technological difficulties (e.g., computer breakdown or internet connection difficulties) and software upgrades can cause frustration for caregivers. They reinforced the need to further study the efficacy of such interventions.

In addition to brochures and websites, telephone help lines can be established to assist caregivers. For example, the telephone-linked computer system was a telephone-based intervention used during the Resources for Enhancing Alzheimer's Health research project (Wisniewski et al., 2003). It included access to a voicemail caregiver bulletin board and an ask-the-expert call option. The bulletin board allowed caregivers to post messages or send messages to others to get information, support, and advice. The ask-the-expert option connected caregivers to a geriatric nurse specialist's voicemail where they could leave a message requesting advice or

information when needed. Organizations like the Alzheimer's Association or hospitals can setup similar programs for caregivers. This could be extended to have an option for conference calls. In addition to being a valuable source of educational information and support, telephone programs could help reduce the social isolation that caregivers can experience (Wisniewski et al., 2003). It is important to note that information on websites and in brochures for caregivers may also help alleviate family conflict and disagreement, which Watari et al. (2006) found to be the greatest barrier long distance caregivers face. With internet websites and brochures, everyone can have access to the same information and help make informed decisions.

Overall, the educational tools and resources local and distance caregivers are similar. Watari et al. (2006) studied 90 distance caregivers (defined as people living outside of Los Angeles) and 187 local caregivers of people with ADRD in Los Angeles. They found that services being used by distance and local caregivers did not significantly differ. Services being utilized included primary care physicians, physicians that specialize in dementia or who are neurologists, the Alzheimer's Association Safe Return program, and in-home care. Written materials, the Alzheimer's Association's Service Resource Guide (which lists adult day care centers, in-home service agencies, and support groups), and a telephone helpline were both used equally by local and distance caregivers. When looking at caregivers' satisfaction with available services, distance caregivers had statistically higher satisfaction ratings. The authors attributed this to distance caregivers feeling like their needs were finally being met. Overall, distance and local caregivers were found to have similar service needs (e.g., in-home care and adult day care), many of which could be addressed or provided by Alzheimer's Association programs no matter where the caregiver lived.

Information to provide caregivers.

Educational websites and brochures/pamphlets can and should address many areas.

Caregivers need to be educated on ADRD and the different stages their loved one may go through (Williams-Schroeder, 1984). This will prepare them for the cognitive, behavioral, emotional, and personality challenges and struggles all involved may experience (e.g., wandering or sundowning), as well as what type of support the care receiver will need (Ching-Ching Chung, 1997). The different financial and legal issues caregivers may face throughout the disease process also need to be addressed and discussed. For example, obtaining advance directives and determining wishes on the utilization of life support and medical procedures should be recommended (Dang et al., 2008). Health care professionals can discuss the importance of these issues with caregivers directly, and it can be reinforced on internet sites and/or brochures. Distance caregivers could easily have access to both. Such information may enable caregivers to provide better care and to better handle the challenges and strain caregiving may present.

Education should also be provided on home safety, which can include information on proper ergonomic setup for homes (e.g., bed and desk heights) to ensure the physical well-being of caregivers and care receivers (Gray et al., 2007; Dooley & Hinojosa, 2004). Setting up a supportive, safe environment can be done by caregivers from a distance when they visit their loved one. This can include removing obstacles like throw rugs to prevent tripping and getting rid of unnecessary clutter to make access around the house easier. A safer environment for the care receiver may help reduce some of the caregiver's anxiety about him/her being home alone.

For emotional and social psychological health, stress management techniques and coping strategies can be provided, as well as information on support groups (Gray et al., 2007). Such strategies and techniques can be utilized no matter where the caregiver lives, as long as the caregiver is aware of his/her options and available resources. Support groups are often very

helpful as they “provide the opportunity to share personal feelings and concerns, encourage mutuality and validation, and overcome feelings of social isolation” (Sorensen, Duberstein, Gill, and Pinquart, 2006, p. 964). They enable group members to share their experiences and offer suggestions to those going through similar situations. Websites and brochures can have information detailing when and where such groups meet, as well as a contact person to call to join the group or to ask further questions. Educational sources can also recommend being involved in religious practices, which have been found to decrease depression and grief and increase the mental health of caregivers of people with dementia (Hebert, Dang, & Schulz, 2006). Simply attending a religious service has been found to have a more significant impact than ones’ religious beliefs and prayer routines (Hebert et al., 2006). This is thought to be the result of being around a supportive group of people with similar beliefs and values, and having the ability to access religious leaders like ministers and rabbis before or after a service.

Many caregivers become so absorbed in the caregiving role that they neglect to take care of their own needs. This can lead to physical and emotional strain as well as social isolation (Scott, 2006). Educating caregivers about the importance of taking care of their needs is essential. They will be better able to provide care to their loved one if their personal needs are met. Information on the importance of respite care, stress management, and support groups may help caregivers take better care of themselves and provide more effective care.

A challenge many caregivers face is when to place a loved one with AD/DRD in a nursing home or similar facility. Advice and education on how to go about determining when to move the care receiver to a facility and information on some of the logistics of the process should be provided in reference materials for caregivers. This could include examples of what to look for when touring a facility (e.g., are the residents actively participating in activities or sitting in their

rooms, which can give caregivers an idea of how stimulating the environment is) and what questions to ask facility staff (e.g., what is the staff to resident ratio and what is the staff turnover rate, with a low staff to resident ratio and low staff turnover rate usually demonstrating a more positive environment for both staff and residents). Seeking out a social worker to help with the process can also be recommended (Roff et al., 2007). Social workers can provide a list of facilities for caregivers to tour and assist with insurance issues that might arise.

The importance of communicating with the care receivers' health care professionals also needs to be stressed to caregivers. Health professionals can be an invaluable source of information and support for caregivers, and caregivers can be an invaluable source of information for health care professionals. Caregivers may be able to give health care professionals a better picture of the care receivers' situation and strengths and weaknesses (Toth-Cohen, 2000). This includes information on how well medications and other suggestions that are recommended work for their loved one, which can help health care professionals problem solve more effectively. With caregiver input, health care professionals are better able to offer relevant and practical suggestions that are likely to be utilized and beneficial in the care receiver and caregivers' environments. For distance caregivers, telephone and e-mail communication with health care professionals can assist in ensuring that the care receivers' needs are being met. Of note, the 26 Alzheimer's Association chapters can refer distance caregivers to chapters in their area and the area of the care recipient (Watari et al., 2006). Chapters in both areas can then work together to provide care and assistance to the caregiver and the care receiver. Such collaboration can help ensure communication between health care professionals and caregivers.

Factors to consider in caregiver education.

Certain factors need to be considered when looking at educating caregivers of people with ADRD and referring them to community services. The educational background of a

caregiver may impact his/her ability to understand the material being presented. For example, some caregivers may have great difficulty comprehending the disease process and require more detailed explanations of the material being presented if they do not have a medical background. Language barriers may also play a role (Yeo & Gallagher-Thompson, 2006). Caregivers who are being presented information in a language that is not their native language might have difficulty accurately interpreting the material. Furthermore, different cultures and societies view caregiving differently (Dilworth-Anderson (2001). Recommendations made in literature or on internet websites might not appropriate in all cases. For example, referrals and information on home health care might be ignored by family caregivers in cultures that see it as the family's duty to provide care.

The finances of caregivers may also impact the resources available and recommended. For example, families spend an average of \$12,500 a year for at-home care for someone with ADRD (Nayak & Mulchandani, 2003). Taking into account the fact that many caregivers must reduce their work hours or quit working to provide care, it may be financially unfeasible for caregivers to pay for certain resources or to utilize recommended programs (http://www.alz.org/alzheimers_disease_facts_figures.aspx). As a result, it may be important to educate caregivers with limited finances about grants to get financial assistance and organizations that offer reduced rates for services (or that base their rates on a sliding scale). This could include applying for things like Medicaid. Financial constraints might also make it difficult for caregivers to obtain recommended adaptive equipment such as shower chairs. Referrals to loan closets where such equipment can be borrowed might be helpful in such cases.

The educational needs of caregivers might also vary depending on their gender. For example, Stolley et al. (2002) found that women had higher caregiver burden levels than men.

Thus, information on respite care, support groups, and relaxation techniques might be especially beneficial for women. It is also extremely important to consider the environments that the caregiver and care receiver live in (Toth-Cohen, 2000). Recommendations made in educational resources may not always be appropriate or realistic to implement given the unique situations of the care giver and care receiver. For example, a care receiver might not be able to use a wheelchair in his/her bathroom because it is too small. Caregivers need to be aware that they might not be able to follow all recommendations given due to their specific circumstances.

Providing care from a distance has been found to be more psychologically stressful than providing care locally (Koerin and Harrigan, 2002). Thus, referrals to support groups and education on relaxation techniques and respite care may be extremely beneficial to distance caregivers. Another factor to consider in educating caregivers is that family caregivers may not recognize themselves as caregivers (O'Connor, 2007). They may see themselves as the son or daughter carrying out their duties as adult children. As a result, they may not self-identify as caregivers and they may not seek out caregiving resources. Relevant material that could help them might not be utilized.

The caregiver's ability to access educational resources and assistance must also be taken into account. Accessing materials or support groups may involve driving to a library or health care facility, requiring a car and the ability to drive (or a driver). A computer and internet access are needed to view website material. While one can go to libraries, coffee shops, or similar places to use a computer and the internet if he/she doesn't personally own a computer, it is important to note that not everyone knows how to use such technology. In addition, caregivers might also have difficulty following various telephone commands and prompts if using a

telephone support system. Such factors must be taken into account whether one is providing local or distance care.

Caregiver Resources

Please refer to Table 2 for a list of internet and book resources for those with Alzheimer's disease and related dementia caregivers.

Barriers to caregivers accessing support and resources.

It is important to for health care professionals to understand why caregivers or care receivers may be unable or unwilling to access community support and services. One reason may be that people do not identify themselves as caregivers. They may feel they are just a son or daughter helping mom or dad, performing duties all adult children "should" do as needed (O'Connor, 2007). Winslow (2003) found barriers to caregivers accessing community services included care receiver resistance (e.g., embarrassment or refusing to let service providers assist), reluctance of the caregiver (e.g., guilt, shame, feelings of responsibility, or worry about the care receiver's safety), concerns about finances, concerns over quality, and hassles for the caregiver (e.g., red tape in obtaining services, lack of time, or family conflict over what services should be used). Yeo and Gallagher-Thompson (2006) also noted that, in an increasingly diverse society, many caregivers and care receivers may not understand the various resources available due to language barriers. For example, they may look at the literal translations of questions asked by health care professionals or educational material provided to them instead of conceptual translations (e.g., when asking caregivers how they have grown as a person, some might literally think about how they have physically grown). For distance caregivers, these challenges may be even more difficult to overcome and address. Ultimately, the caregiver and/or care receiver may feel that the caregiver is the only one who can provide effective assistance. Understanding some

of these concepts will better enable professionals to make recommendations that are practical and likely to be utilized.

Resources for Enhancing Alzheimer's Caregiver Health Research Program

The Resources for Enhancing Alzheimer's Caregiver Health (REACH) research program was sponsored by the National Institute on Aging and the National Institute on Nursing Research from 1995 to 2000 with the goal of carrying out social and behavioral research interventions for those with Alzheimer's disease and related disorders (Schulz, Burgio, et al., 2003). Six sites in the United States (Boston with 100 participants, Birmingham with 140 participants, Memphis with 245 participants, Miami, with 225 participants, Palo Alto with 257 participants, and Philadelphia with 255 participants) were utilized. The REACH program

developed and evaluated a variety of multicomponent interventions for family caregivers of persons with AD at the mild or moderate level of impairment. The interventions implemented across the six sites included: (a) Individual Information and Support Strategies, (b) Group Support and Family Systems Therapy, (c) Psychoeducational and Skill-Based Training Approaches, (d) Home-Based Environmental Interventions, and (e) Enhanced Technology Support Systems. (Schulz, Burgio, & et al., 2003, p. 514)

Caregivers were family members at least 21 years of age who lived with the care receiver and had a telephone, and who had been providing care for at least 4 hours a day for 6 months or longer. The care receivers had Mini Mental State Examination Scores of less than 24 or a documented diagnosis of dementia and at least one limitation in six basic activities of daily living (e.g., bathing or dressing) or at least two of eight instrumental activities of daily living (e.g., cooking, cleaning, or shopping) (Hebert et al., 2006). Caregivers were randomized to control or intervention groups. The interventions, lasting about 6 months, were geared towards

changing the nature of specific stressors (e.g., problematic behaviors of the person with AD), the caregiver's appraisal of the stressors, and/or the caregiver's response to stressors. (Schulz, Burgio, et al., 2003). Guided by diverse theoretical frameworks, sites implemented different strategies and interventions were meant to meet the needs of caregivers from both majority and minority racial/ethnic groups. A met-analytic analysis of intervention results revealed that active interventions helped reduce caregiver burden and interventions emphasizing active caregiver engagement had the greatest impact in reducing caregiver depression (Schulz, Burgio, et al., 2003). Compared to similar members in control groups, women and those with high school or lower education reported reduced burden and those who were Hispanic, non-spouses, or who had less than a high school education reported lower depression scores. Looking at participants from the Miami site, Mitrani et al. (2006) found that "family functioning significantly contributed to distress in the overall sample and partially mediated the relationship between objective burden and distress" (p. 97).

Conceptual/Theoretical Framework

Throughout the study, participants' various roles (e.g., caregiver, son/daughter, spouse, parent, friend, employee) were taken into account. The personal and societal expectations of each role a caregiver has may affect the resources and support (including financial or emotional) available to him/her. When looking at the experiences of those providing care to someone with ADRD from a distance, Goode's (1960) role theory provides a valuable framework. Caregivers are frequently juggling their role of caregiving with other roles, which may include spouse, parent, friend, or employee (Fairbanks, 2005). Balancing these roles may become increasingly difficult for distance caregiver as the needs of the care receiver increase over time. The global role strain reported by family caregivers has been associated with caregiving role demand overload (Fairbanks, 2005). Exploring the lived experience of distance ADRD caregivers

through the roles they have (including the caregiving role) may assist in capturing the essence of the struggles and challenges they face.

Role theories in general look at how people carry out the various roles they have in their lives and what behaviors can be expected under varying circumstances (Brookes, Davidson, Daly, & Halcomb, 2007). This involves looking at peoples' attitudes and perceptions towards roles and role expectations, including role behaviors, characteristics, norms, and values (Brookes et al., 2007). Goode's role theory in particular looks at role strain and bargaining. Role strain occurs when one is unable to accomplish or is having difficulty accomplishing all of the demands various roles place on him/her (Goode, 1960). This could be the result of things like role overload or psychological conflict (Edwards et al., 2002; Goode, 1960). Role overload may occur when the demands placed on someone exceed what he/she is able to do for various reasons, including lack of time, energy, education, or resources (Brookes et al., 2007; Mui, 1992; Fairbanks, 2005). Psychological conflict may arise when there is pressure to behave in a certain way that is contradictory towards another role, or when performing one role makes it impossible to perform a different role (e.g., taking the time to provide care to someone while at the same time needing to be working for financial reasons) (Edwards et al., 2002; Mui, 1992). Goode's scarcity hypothesis discusses such concerns. The scarcity hypothesis states that the resources people have, including time, emotional resources, social resources, and physical resources, may not be sufficient to fulfill the multiple obligations that one has from their roles (Fairbanks, 2005, & Mui, 1992). Such role overload may result in role strain (Fairbanks, 2005, & Mui, 1992).

Role strain may occur for a variety of reasons. People have their own personal expectations of how to perform each role, as does society, and role insufficiency and conflict may result when there is a difference between the actual performance and the performance the

person or society expects of that role (Brookes et al., 2007; Hogan et al., 2003). For example, health care professionals may have expectations of what a client's caregiver should do and a caregiver may feel strain and stress if he/she is unable to meet these expectations. Mui (1992) noted that caregivers frequently have various societal and cultural roles to fulfill, including being an employee, a spouse, and a parent, and role strain may occur when caregiving demands make it difficult to fulfill other roles.

Emotional, physical, vocational, social, and financial demands and stresses may also affect a caregiver's ability to provide adequate care (Mui, 1992). This may result in role strain as the caregiver wishes he/she was able to do more for the care receiver. Role ambiguity can also occur when a person is unsure about the demands and expectations of a particular role (Brookes et al., 2007). For distance caregivers, this could happen if a caregiver is not sure of how to help their loved one from so far away. Finally, each person has a unique set of role obligations that may also result in different role strains (Goode, 1960). The quality of roles and certain role combinations may positively or negatively affect one's well-being, as does how various roles are organized (Marks & MacDermid, 1996). These factors can lead to the role stress and strain discussed in Goode's role theory (Brookes et al., 2007).

Goode's role theory also discusses the various ways people may attempt to overcome role stress and strain. He noted that the choices made after encountering role strain may enable a person to function well or poorly overall, and that the overall collaboration of roles and role bargaining determines outcomes (Goode, 1960). In role bargaining, one determines where to allocate his/her energy and resources to complete various role demands (Goode, 1960). It is important to acknowledge that each person has different values and ideas about his/her roles and role obligations, which affects the decisions he/she makes (Goode, 1960).

Role bargaining occurs for many reasons. Role demands may require various physical, mental, and emotional resources, and fulfilling them usually requires several actions and responses to take place (Goode, 1960). Some role demands may conflict with each other or have different norms, and determining a plan of action may be difficult (Goode, 1960). As stated previously, meeting the demands of one role may result in being unable to fulfill the demands of other roles (Goode, 1960). For example, fulfilling the caregiving role may result in an inability to fulfill a parenting role like attending a child's swimming meet. According to Goode (1960), role bargaining will occur in such situations. The benefits of fulfilling each role must be weighed against the consequences of not fulfilling the other one. The limited resources a person has will be allocated to respond to the various demands placed on him/her to satisfy role obligations as much as possible (Goode, 1960). People react to the various demands placed on them with the ultimate goal of keeping role strain as low as possible (Goode, 1960).

Goode (1960) noted that the final "role price" (one's role performance) is based on a combination of personal desires, pre-existing commitments, expectations of rewards or punishment for fulfilling or neglecting various role demands, and the impact one's performance will have on others. People are more likely to perform roles that they find valuable or intrinsically motivating and that they are likely to be rewarded for performing or punished for not fulfilling (Goode, 1960; Libbey & Carlson, 1973). Roles that are less challenging, mutually supportive, minimally conflicting with other roles, and personally gratifying are also usually selected and help reduce role strain (Goode, 1960). The long-term consequences of fulfilling certain obligations, such as financial or emotional rewards, may also direct one to fulfill certain role demands over others (Libbey & Carlson, 1973). Of course, there are certain roles that must be performed due to societal expectations and demands (Goode, 1960). For example, people need to

perform bathing and dressing tasks as part of their self-care role to function adequately in society. Furthermore, one may experience role strain, worry, anxiety, and internal pressure or pressure from others if more resources are spent on a role than deemed necessary (Goode, 1960). This occurs when the perceived cost and energy being used to fulfill a role is not seen as worth the benefits (Goode, 1960).

One's decision on how to allocate his/her energy and resources to fulfill role demands are also affected by situational factors (Goode, 1960). For example, when a mother falls and fractures her hip, her adult son/daughter may initially focus on the caregiving role and take time off work to provide care. As she heals and is able to care more for herself, the caregiver may devote less time to the caregiving role. Societal and organizational structures may also determine what course of action one takes (Goode, 1960). For instance, insurance policies may place a greater burden on caregivers if less formal care (such as inpatient rehabilitation with intensive physical and occupational therapy) is covered by insurance. In such cases, if the care receiver is unable to take care of his/her needs, the caregiver may be forced to provide care (which could mean taking time off of work and time away from children) or arrange for care to be provided.

Norms and values placed on roles may also direct a caregiver to perform a certain way (Goode, 1960). For example, a society may place high value on providing care to family members. This may increase the likelihood of someone taking on the caregiving role if he/she lives in that society. It is also important to note that certain roles must be performed to fulfill the demands of other roles (Goode, 1960). For example, a mother or father might have to work to be financially capable of caring for his/her children. Thus, he/she might have to put work over parenting tasks at certain times. Other factors beyond a person's control may also direct or dictate that he/she behave a certain way (Goode, 1960). Such factors could include one's gender

and age. For example, it might be easier for a retired 70-year-old to provide care to a parent than a 40-year-old with children and a job.

The impact family has on determining roles and role allocation is also important to consider (Goode, 1960). Role obligations are usually linked to family members, systems, and subsystems (Libby & Carlson, 1973). This is largely true because one is held accountable by their family members in terms of how they spend their time, energy, and money (Goode, 1960). This may lead one to act in a certain way to best meet the overall needs of his/her family. For example, it may be deemed that the single adult child of a parent is better suited to provide care to his/her parent than other siblings who are married with children. Thus, the single adult may take on the caregiving role. The family unit can also provide a safe place to explore and try out various role alternatives as there is usually little daily change (Goode, 1960). This gives one the opportunity to learn how to balance role demands in a relaxed environment (Goode, 1960). Goode (1960) also noted that family members are important to consider when looking at role strain because it is very difficult to formally withdraw from a family role like daughter, son, mother, or father. While informal withdrawal from such roles is possible, feelings of guilt may arise and societal pressures may make it very difficult to do so (Goode, 1960). Thus, one may see it as the duty of a son or daughter to provide care for a parent and take on the caregiving role.

Goode's role theory (1960) also discusses the various ways people may deal with role strain. The first possibility is compartmentalization. This is where one may ignore or set aside a role demand or problem based on the context and urgency of the situation, allowing him/her to deal with the issue at a time deemed more convenient. Another method is to delegate some of the role demands. It is important to keep in mind that not all role demands can be delegated. For instance, most healthy people cannot delegate their self-care tasks (such as bathing) to others. A

third possibility for dealing with role strain is role elimination. For example, one could stop volunteering at church or quit their job if needed. As with delegating, not all roles can be eliminated. It may not be financially feasible for one to quit his/her job, and most people would not eliminate their role as mother or father. Some roles are also not likely to be eliminated because of the social status or personal satisfaction they provide. This could include volunteering activities or one's personal career. Lastly, another possibility Goode (1960) presents is to extend one's roles. In this case, taking on another role may assist in meeting the needs of other roles. For example, a caregiver may take on the role of starting up and leading a caregiver's support group. While taking on another role and more role obligations, the support group may offer him/her the support and resources needed to adequately fulfill his/her role as a caregiver.

Goode's (1960) role theory is a useful framework to view the lived experiences of ADRD caregivers. It can provide a theoretical lens through which to better understand the challenges and struggles distance ADRD caregivers face and how they may react to them. Such understanding can better prepare health care professionals to equip caregivers with the information and resources they need to provide effective care and to meet their personal needs. In the study, the roles participants have were discussed during the interviews and on the caregiver questionnaire. For example, participants who reported that they have younger children on the questionnaire were asked what it is like to have to care for children and an adult parent with Alzheimer's. Taking on parenting and caregiving roles might make it difficult to fulfill each role to society's expectations or to ones' personal satisfaction, perhaps increasing personal stress and draining personal and financial resources.

Conclusion

Providing care to people with Alzheimer's disease/disease is a challenging and difficult undertaking. In today's increasingly mobile society, more and more caregivers must provide care

to their loved one from a distance. This creates even more barriers to providing effective and timely care. It has become essential to explore the challenges that caregivers for people with Alzheimer's disease/dementia face in general, the unique challenges caregivers may face when their loved one lives at a distance, and what health care professionals can do to ensure that caregivers of people with Alzheimer's disease/dementia are taking care of their needs and the needs of their loved ones.

Researching the lived experience of caregivers for people with Alzheimer's disease or dementia who are providing care from a distance (2 or more hours away) may provide health care professionals with a greater understanding of the needs of the care receivers and caregivers and enable them to provide more effective intervention. The phenomenological, qualitative approach of this study intended to offer new and important insights into the experience of caregivers providing long distance care. Butcher et al. (2001) stated that, "The quantitative emphasis in the body of family AD/DRD caregiving research has constrained the capacity of health care professionals to fully understand the caregiving experience and the shared meanings family members attribute to their experience as caregivers" (p. 35). Taking a fresh approach will provide new and insightful information for health care professionals so they can better provide effective care to ensure that caregivers and care receivers are having their needs met.

Chapter Three: Methodology

A qualitative, phenomenological approach was taken to explore the lived experience of distance Alzheimer's disease and related dementia (ADRD) caregivers. The study included 10 participants who were each involved in two interviews, conducted about a month apart. After combining the individual themes from each participant's two interviews, overall themes were developed based on all of the participant interviews.

Design

To explore the lived experiences of distance caregivers of people with ADRD, a phenomenological, qualitative approach was employed. Creswell (2007) explained that a "phenomenological study describes the meaning for several individuals of their lived experiences of a concept or phenomenon" (p. 57). In this research study, the phenomenon was distance caregiving for someone with ADRD. The goal of a phenomenological study is to describe the commonalities among the experiences of participants and the "universal essence" of the experience (Creswell, 2007). This includes what they experienced and how they experienced the phenomenon (Creswell, 2007). Researchers taking such an approach conduct their studies without preconceived notions of results until they start to gather and analyze data (Creswell, 2007). A phenomenological approach also takes the viewpoint that the reality of an object or experience is perceived and given meaning by the individual. Willis (2007) stated that

Phenomenology [is] focused on the subjectivity and relativity of reality, continually pointing out the need to understand how humans view themselves and the world around them. ... Phenomenologists distinguish ... phenomena (the perceptions or appearance from the point of view of a human) from noumena (what things really are). (p. 53)

It is the participants' perception of reality and their experience that are being studied, and no attempt is made by the researcher to equate it with external reality (Willis, 2007).

Creswell (2007) identified the basic steps phenomenological researchers take. They include identifying whether the phenomenological approach is the best choice to explore the research problem (as opposed to other qualitative research approaches such as grounded theory, narrative, or ethnography), identifying the phenomenon to be studied, identifying the philosophical assumptions of phenomenology, collecting data from participants who have experienced the phenomenon being studied (including asking them what they have experienced in terms of the phenomena and what contexts or situations have influenced or affected their experiences of the phenomenon), engaging in data analysis, and writing up findings. Challenges researchers engaging in phenomenological studies may encounter include having difficulty totally bracketing and separating their personal reactions and beliefs from those of the participants, finding appropriate subjects who have experienced the phenomena under investigation, and having a firm understanding of the philosophical viewpoints of phenomenological research (Creswell, 2007).

Getting more specific about the research methods of this research study, a transcendental or psychological phenomenological approach was taken. This involves focusing more on describing the data collected rather than interpreting it (Creswell, 2007). Such an approach frequently includes the researcher engaging in epoche. Also referred to as bracketing, epoche requires the researcher to set aside his/her personal biases and preconceptions and focus on the information and data being collected by participants (Creswell, 2007). This enables the researcher to have a “fresh” perspective and outlook on the phenomenon being studied, leading to the term transcendental approach (Creswell, 2007). Textural and structural descriptions are developed after data analysis. Textural descriptions refer to what participants experience(d) and structural descriptions refer to how they experience(d) the phenomenon (e.g., conditions,

situations, contexts) (Creswell, 2007). The combination of textural and structural descriptions assists in capturing the essence of the phenomenon, including its' distinct and common attributes (Carpenter & Suto, 2008).

In the completed study, a phenomenological approach was deemed the best method to research the lived experiences of distance caregivers for people with ADRD (the phenomena being studied). It provided the opportunity to hear the experiences distance caregivers have gone through, including the struggles they encounter and the resources they have found. Such information may offer health care providers rich insight into what their lives are like and the ability to offer caregivers better support and information. The results will hopefully add to the current literature what has been, overall, a missing component to research: what the daily life of distance ADRD caregivers is like.

Participants

After approval from Colorado State University's Institutional Review Board was obtained, participants were chosen using purposeful, criterion sampling techniques (as recommended by Creswell, 2007). Ten participants were included in this study (within the range recommended by Moustakas, 1994, and Creswell, 2007). To be eligible for the study, participants had to be providing unpaid care to someone living 2 or more hours away who has a medical history of ADRD. Of note, 2 participants providing care to someone with dementia/Alzheimer's disease locally were included in the study. This was due to their interest in participating in the study and because of their past experience providing care to the person with dementia/Alzheimer's disease from a distance. In those two cases, care was taken to focus on what their experience was like providing care from a distance. While the MetLife Mature Market Institute and National Alliance for Caregiving's study of distance caregivers (2004) used an hour to define distance caregiving, two hours was deemed more appropriate for this study as someone

could realistically commute an hour or more daily in today's society to assist a loved one. Participants had to have been providing care for at least 6 months (based on research conducted by Hogan et al., 2003).

Participants were located by contacting the Alzheimer's Association, the Larimer County Office on Aging, and skilled nursing facilities and assisted living facilities in Fort Collins and Loveland, Colorado. It was thought that such organizations and facilities could assist in locating ADRD caregivers who live in the Fort Collins/Loveland area or who are providing care from a distance to someone in the Fort Collins/Loveland area. For example, the 26 Alzheimer's Association chapters refer distance caregivers to chapters in their area and the area of the care recipient. Both chapters are then involved in assisting the care receiver and caregiver (Watari et al., 2006). I visited the Fort Collins Alzheimer's Association and the Larimer County Office on Aging to inform them of the proposed research study, and attended two support groups in the Denver/Fort Collins area. A letter outlining the proposed study was provided to each facility. The draft of the letter, included in Appendix A, guided the initial contact I had with these organizations. Organizations were asked to forward this letter via e-mail or mail to potential participants. They were also given a flyer to display and distribute as able to potential participants. The flyer had a brief summary of the study and my contact information. Those interested in participating were asked to contact me via phone. A similar process was used when I contact nursing home and assisted living facilities. Approximately 10 facilities were contacted in Loveland and Fort Collins. They were identified using the Alzheimer's Association Senior Housing Profile Finder (http://alz.org/we_can_help_senior_housing_finder.asp). Participants could not be family members or caring for the same person. Finally, ADRD caregivers who

heard of the study through friends or family and expressed an interest in participating were included.

Procedure

Potential participants contacted me via phone to discuss the research study. This included ensuring that they met participant criteria and that they were willing and able to be involved in the study. Please see Appendix B for an outline of these phone calls. All participants that contacted me were eligible and included in the study until data saturation was felt to have been reached.

Once someone agreed to become a participant, he/she was sent a pre-interview questionnaire to complete before an initial interview. The questionnaire was returned in person during the initial interview, or in many cases filled out right before the initial interview. Please see Appendix C for the caregiver letter and questionnaire. A consent form, approved by CSU and the Human Research Committee, was reviewed and signed by participants at the beginning of the initial interview. Initial interviews were done individually and in person. I traveled to the participants' homes or a pre-arranged meeting area where the participant felt comfortable. This included coffee shops and places of employment. One initial interview was conducted over the phone due to geographical distance between the participant and me. In this case forms were faxed to the participant and faxed back to me prior to the initial interview. Initial interviews were audio recorded with participant permission for transcription afterwards, and usually took between an hour and an hour and a half to conduct. The interviews were unstructured, and the participant questionnaire was used at times to initiate conversation and to help develop rapport. Questions asked of participants were mostly open-ended, and some were combined or added for future participants based on information provided from participants and the type of data that was received. Such an approach is supported by Moustakas (1994), who explained that

The phenomenological interview involves an informal, interactive process and utilizes open-ended comments and questions. Although I may in advance develop a series of questions aimed at evoking a comprehensive account of the person's experience of the phenomenon, these are varied, altered, or not used at all when the co-researcher [the participant] shares the full story of his or her experience ... (p. 114)

Data Collection

The following questions were used during the initial interviews. They were based on previous research and addressed areas that I felt were likely to reveal important aspects of distance caregiving for someone with ADRD. Questions asked during the interview included (in no particular order):

- What is your caregiving story?
- How did you come to provide care from a distance?
- What it is like to be a caregiver at a distance?
- Who would you say is the primary caregiver for _____?
- I used the word "caregiver" in this study. What is your word or phrase for what you do?
- How are caregiving tasks divided up or negotiated among you, your siblings or other parties?
- What percentage of the tasks are your responsibility? You siblings' responsibilities? Others?
- As you think about the caregiving you are providing, what have you learned or reaffirmed about yourself as a result of these experiences?
- How close were you and your _____ (the care receiver) before he/she was diagnosed with Alzheimer's disease or related dementia?

- How would you describe your relationship with _____ before you became his/her caregiver?
- In what ways, if any, has the quality of your relationship with you and your _____ changed since he/she was diagnosed with ADRD?
- How has your relationship with family members like your siblings or your friends changed since you began providing care?
- What hopes and fears do you have for yourself?
- What hopes and fears do you have for your loved one?
- What adjustments have you had to make in your life since you took on the caregiving role (such as changes at work, in relationships, or in leisure activities)?
- What are the greatest challenges you face as a distance caregiver?
- Who provides support for you? How does that support get expressed?
- What resources do you draw upon (e.g., meals on wheels, adult day care, senior centers)?
- What have you gained from caregiving?
- What are some of the benefits of caregiving that you have experienced?
- What, if any, have been the effects of caregiving on your own physical health?
- What, if any, have been the effects of caregiving on your relationships with others?
- What would you like health care professionals to know or understand about your _____ (the person you are caring for) that you think they may not know or understand?
- What would you like health care professionals to know about distance caregiving for someone with ADRD?
- If you were to give health care professionals some advice about distance caregiving, what would you say?

- How could health care professionals better support you?
- How could health care professionals better support your loved one?
- What have I not asked about that would be important for me to know about your experience in distance caregiving?
- Is there anything from the questionnaire that you would like to ask me about?
- Is there anything we haven't addressed that you would like to discuss?

While the focus of the interviews was on the caregiver, not the care receiver, obtaining information on the overall physical and mental status of care receivers was obtained to better understand the caregiving demands being placed on participants. The overall health of the caregiver was also addressed in some interviews in terms of how it is or has been impacted by their caregiving experience.

A second interview was conducted with each participant about a month after his/her initial interview. Due to extenuating circumstances (e.g., the death of the care receiver), 2 follow up interviews were held about 2 months after the initial interview. The intent of the second interview was to address any issues or concerns that might have arisen since the last interview, and to discuss anything the participant would like to add or clarify from the first interview. Findings from a participant's initial interview guided the questioning of his/her second interview. The main issues and concepts gleaned from the initial interview after data analysis were addressed and reviewed as a form of member checking to ensure accuracy during the latter part of the second interview. With permission from participants, phone conversations were recorded for later transcription. Second interviews lasted approximately 30 minutes. Participants were also made aware that, with their permission, I could contact them for follow up questioning or to ask them to clarify/expand on information provided during their interviews.

I wrote and journaled about my personal reactions to the interview for bracketing purposes as needed. This helped separate my personal feelings from the data and provided me with the opportunity to express the wide range of intense emotions I experienced. Meetings with members of my dissertation committee to discuss the reactions I had after interviews were arranged as needed. All in all, there were 10 participants included in the study. No potential participants were excluded during the course of the study. All participants were adult children caring for parents. Please see Table 1 for participant demographic information.

Data Analysis

Each interview was audio recorded with participant permission. Interviews were transcribed as soon as possible after being conducted. A professional transcription service was used. Participants were made aware of this and the transcriptionist signed a confidentiality form. Each interview was coded individually (line-by-line) by me. Coding entailed the process of horizontalization (Creswell, 2007; Moustakas, 1994). As the transcripts were read by me, those statements that were deemed significant (e.g., they were relevant and helped one understand the experience of distance caregivers of someone with ADRD) were highlighted. Significant statements included those that provided insight into the distance ADRD caregiving experience and the struggles these caregivers face. After the interview was coded, similar statements were clustered together and given a name (e.g., emotions experienced, resources utilized, etc.). These were the themes, or meaning units, of the data (Creswell, 2007). Structural and textural statements and themes were created. Both interviews were coded the same way and the themes were combined for each participant. After all interviews were conducted and analyzed, the major themes and codes from each participant were combined to capture the overall experience of distance caregiving for someone with ADRD.

Moustakas's (1994) modified Van Kaam Method of analyzing phenomenological data was used as a guideline throughout the data analysis process. Providing a more structured outline for coding, it has seven steps. The first step involves listing all statements that are significant to the experience being studied (the horizontalization of data). Next, statements are reduced or eliminated. Statements are kept if they are "necessary and sufficient" to understand the phenomenon, if they can be summarized and labeled, and if they are not redundant (Moustakas, 1994). Those statements remaining, referred to as the invariant constituents, are then grouped together into themes. During this step of data analysis related statements are clustered together and become a theme. The resulting themes become the core themes of the phenomenon. The fourth step is to look at the overall data from the participant and make sure that each theme and invariant constituent is expressed in the data or compatible with the data. Statements not represented in the data or not compatible with the data are eliminated. From the remaining themes and invariant constituents, individual textural descriptions of the experience are created. Verbatim examples are included. Using the individual textural descriptions and imaginative variation (where different frames of references and perspectives are considered), individual structural descriptions are then constructed. The seventh and final step is to construct a textural-structural description of the experience. Based on the invariant constituents and themes developed, it provides a description of the meanings and essence of the experience. After the individual textural-structural descriptions are created for each participant, a composite description can be developed representing the meanings and essences of the experiences of all participants. In this research study, this was done after an overall textural-structural description was created for each participant by combining the themes of his/her two interviews.

When analyzing data, Goode's (1960) role theory was the conceptual framework from which I viewed data. I explored the demands placed on one providing care to someone with Alzheimer's disease/dementia from two or more hours away, and how that caregiving role may affect other areas of that caregiver's life. Other areas included work, self-care, and relationships with others. How the demands of the caregiving role were fulfilled was also reviewed during the data analysis process.

Triangulation was utilized throughout the coding process. Members of my doctoral dissertation committee reviewed the transcripts and themes developed by me after my first initial interview and after the overall themes had been created. The participants also assisted in ensuring the accurate coding of data by member checking. The individual themes derived from a participant's initial interview were discussed with him/her during the second interview. Changes were made as needed based on participant feedback. Those willing to review the final themes developed across participants were asked to do so. Final themes were sent via e-mail to the participants for their feedback, which was provided to me via phone or in the written form of e-mail. Of note, negative cases (those that provide data contradicting the majority of cases) were noted and discussed in the final data analysis.

The final written product of the proposed research study describes in detail the main themes found among distance ADRD caregivers. Specific examples and quotes from participants are provided. The demographic information of participants is also included, such as the age ranges of caregivers, how many hours a month caregivers provide care, and the relationships between caregivers and care receivers (e.g., mother and daughter). Any information that could potentially identify participants was excluded. The results of my study will be written in story form. I did this in an effort to personalize the data as much as possible, and to best portray the

sentiments and experiences of my participants. Hooper (2002) utilized a similar approach; stating that, in her study, “Selective coding involved building an overall theoretical ‘story’ that described how the categories related to one another and the propositions of the theory they forwarded” (p. 53). I found this to be true during my data analysis process as well. Palmadottir (2009) used an approach similar to mine when writing up the results of her research on breast cancer survivors. Furthermore, Wolcott (2010) has discussed “stories” in his research in an effort to explore such things as motives behind the behaviors of people. Finally, Carless and Sparkes (2008) wrote the results of their study on mental illness in story form. They stated that, “As a means of educational report, stories can provide a means by which those truths, which cannot otherwise be told, are uncovered” (p. 195). Furthermore, Carless and Sparkes (2008) felt that, “The use of stories provides a direct focus on the voices of those who personally live the experience. ... In this sense, the stories provide one avenue for service users’ to be heard by academics, health professionals, and lay audiences” (p.207). Thus, writing my results in story form is supported by previous research.

Conclusion

In summary, 10 participants were included in the current study. A qualitative, phenomenological approach was taken to better understand the lived experience of distance caregivers (defined as those living 2 or more hours away) of people with dementia/Alzheimer’s disease. Two interviews were conducted with each participant, and Moustakas’s (1994) modified Van Kaam Method of analyzing phenomenological data was used for data analysis. Goode’s (1960) role theory was used as the conceptual framework for the study. This study is the first step in what I hope will be a lifelong commitment to assisting those with ADRD and their caregivers.

Chapter Four: Results

Introduction

I have written the results of my research in story form (similar to techniques used by Hooper, 2002; Palmadottir, 2009; Wolcott, 2010; & Carless and Sparkes, 2008). This approach was not meant to imply generalizability, but rather my preferred method of writing. I feel it best conveys the overall experience of being a distance caregiver for someone with dementia/Alzheimer's disease. I have used the term "orchestrator in the background" to define such caregivers, based on the fact that a great deal of their time is spent monitoring and arranging care or services, and not providing direct care. As all 10 participants in my current study were providing care to parents, "orchestrator in the background" in this context will refer to those who provide care to parents with dementia/Alzheimer's disease from 2 or more hours away. Examples provided are from participants. More interpretation might be included in this results section than is typical, due to the manner in which I have written the results.

I have devised a pseudonym for each participant, and will weave quotes from participants throughout my "story." Unless otherwise noted, each participant lives over 8 hour drive away from the parent(s) he/she for whom she/he is caring. First, let me introduce the 10 participants.

1. "Amy" is married, working full-time, and caring for her father who lives alone in his home. Her father is declining to move into an assisted living facility, despite others' concerns over his safety.
2. "Lisa" is married, working full-time, and caring for her mother who lives in a nursing home about 6-7 hours away. Lisa's biggest challenge is the lack of communication she

has with the nursing home staff. She frequently hears “no change” when she inquires about her mother’s condition.

3. “Kristen” works part-time, goes to graduate school, is in a romantic relationship, and cares for her mother who lives at home with her father. Seeing the physical and cognitive decline of her mother is very difficult for Kristen to handle.
4. “Michelle” and her husband live over 8 hours away from her parents, both of whom are in a nursing home and have cognitive deficits. Assisting her parents as much as possible, while trying to live her own life, is something Michelle struggles with.
5. “Sara” works part-time, is married, has a young child at home, and cares for her father. Her father lives with her step-mother “Abby,” and a priority for Sara is supporting Abby and ensuring that Abby does not get burned out providing care.
6. “Jessica” is a single woman caring for both her mother and father, both of whom have dementia. Jessica, over time, determined she could not keep managing her parents’ care from a distance (which was over 8 hours away), and moved them into a nursing home near her. She has been a caregiver for family members, in some capacity, for much of her life.
7. “Bella” is in a romantic relationship, working full-time, and caring for her mother who lives at home with her father. Bella’s family has often been resistant to strategies and suggestions she has made in an attempt to assist her mother and involve family members. She believes they are in denial about her mother’s cognitive status.
8. “Rose” is married, works part-time, and cares for her father who lives in a nursing home (Rose’s mother is still alive, and living independently). Rose is very close to her father,

who has been a huge source of support for her throughout her life. Losing that support has been difficult for her.

9. “Fran” cares for her father, who lives at home with her mother. Married, working part-time, and raising a young child, Fran has found managing her father’s care challenging, while she tries to deal with other life events (e.g., health and relationship issues that arise).
10. Last, “Scott” is caring for his mother, who lives in a nursing home close to him. He is married, working full-time, and has teenage children. Scott cared for his mother from a distance (over 8 hours away) for about a year before she moved to be near him. Scott reports feeling guilty that he is unable to care for his mother in his home, largely due to the amount of care she needs.

The rest of this Chapter contains the combined caregivers’ story, organized around six shared themes. And now, let me share their story.

The “Orchestrator in the Background”

Different paths may guide one to take on the “orchestrator in the background” role.

Whatever the reason, becoming an orchestrator (or one of the orchestrators) of a parent with dementia/Alzheimer’s disease from a distance involves taking on a demanding commitment and role with large responsibilities.

Background and titles for orchestrator role.

Several factors may lead to one orchestrating the care of a parent with Alzheimer’s disease/dementia from afar. For example, parents may move for retirement, have medical conditions or procedures that make the dementia more evident (e.g., after having back surgery or having a stroke), or the death of one parent may reveal that the deceased parent was covering for

a parent with dementia. The orchestrator might also have moved away from his/her parents at one point for work or school, or out of desire to move to another part of the country.

Orchestrators have various titles for their role as distance caregiver, including “son” (Scott), “daughter” (Amy, Lisa, Kristen, Rose), “companion” (Sara), or “friend” (Sara). Some feel that “caregiver is a good term for it [because] I’m still the one taking care of them” (her parents) emotionally, financially, and physically (Jessica). Some state that “caregiver” is a formal term (Kristen), and that they don’t give themselves the credit of being a caregiver (Michelle).

Orchestrators may feel that,

... when I talk about it in professional terms, it’s caregiver. And it’s important to put the long distance on there ... at other times it’s just that I’m just a daughter who cares ... and I’m just doing what my dad taught me, and my mom. ... It’s very hard sometimes to use the word caregiver because I’m not there to do what I want. (Rose)

Some may say, “You hire caregivers, right? So that doesn’t quite fit, to me ... it’s not the whole picture ...” (Scott). “I’m really just more of an orchestrator in the background. I’m not really on the front line” (Bella). No matter what the title, orchestrating (or helping orchestrate) the care of a parent with dementia/Alzheimer’s disease from a distance involves common duties and tasks.

Orchestrator demands.

A large part of the orchestrator role involves organizing and coordinating the care of the care receiver. They may say, “My role is ... talking on the phone, helping them [my parents] out, mostly following along with day-to-day stuff ...,” (Fran) so “most of what I did was take care of business” (Jessica).

Í get a phone call and I worry about it and I try to figure out answers and I call back. ... It takes up my time but I am not physically running around doing stuff, I'm not physically caring ... (Michelle)

Orchestrators spend time on the computer and phone arranging and monitoring things for their parents, including finances and bills, hired care, doctors' appointments, housekeepers, and health insurance; or dealing with medical issues that rise and the parents' home (e.g., selling or renting it). This is true whether the parent lives in their own home or in a nursing home facility.

Overall, orchestrators hope to boost the care their mother/father receives, and to support any caregivers who are in the parent's community. This includes working with both parents- the parent with Alzheimer's disease/dementia and his/her spouse, if the non-involved spouse is still alive and involved. It is important for the orchestrator to work with the spouse to help ensure that the spouse is not burnt out and is getting the assistance and information he/she needs. This involves doing what one can to support and care for the healthy parent, including educating them (e.g., educating them on resources, adaptive equipment, and the disease process), cooking meals when visiting, and encouraging them to go out with friends, to get hired help, or to go to support groups. Orchestrators may report that,

I feel like I'm not just taking care of my father, but I do everything I can to take care of my stepmother ... I tried to come up with other things that I could do that would be helpful ... for both of them, but particularly [to] make it easier for her to take care of him. (Sara)

For the distance caregiver, providing such support and trying to help the healthy parent figure out what to do is necessary because "this has been a huge change for her" (Fran). This may be

because, in many cases, there is role reversal of the parents. Orchestrators might feel that “it has been really, really difficult ... but interesting] to watch my parents switch roles. ... It was really interesting watching my dad become the dependent one, and my mom become the strong one” (Rose).

Communication.

Doing this “telemedicine from afar” (Lisa) can involve lots of time on the phone communicating with those around the care receiver, or with those who are also involved in the parent’s care. This can include nursing home staff, parents, friends and neighbors of parents, or siblings. Such communication between the orchestrator and others is crucial to determine what needs the parent with dementia/Alzheimer’s disease might have and to determine how the parent is doing. This helps the orchestrator successfully arrange and coordinate care because they will better know what needs their parent has and how they may be able to assist their parent(s). They “need to know as much as possible” (Bella) to do this. Part of the process also involves researching or talking to others about the Alzheimer’s disease/dementia process and available resources (e.g., support groups). Having such knowledge and communication on a regular basis may help prevent crises from arising or escalating. Honest communication between orchestrators and caregivers is essential so they can make informed choices. Orchestrators may say, “I want somebody to be completely honest with me. I don’t want somebody to sugarcoat it ...” (Sara). “I’m pretty straight up, it’s like tell me what I’m dealing with so I know what to do ... don’t dance around it” (Jessica).

Orchestrators may also feel they need to be kept informed and because “when someone has dementia ... you can’t do all the healthcare teaching to them. You’ve got to do it to the primary caregiver, because they [the person with dementia] don’t know,” (Amy) or they won’t

recall information, and the healthy parent might not be the best advocate (e.g., they may resist suggestions or be in denial about their spouses' condition). As a result, the distance caregiver needs to be educated as well. Such communication and education also enables health care professionals and others to offer suggestions on how to handle situations that arise and how the orchestrator can help. Orchestrators "can always use advice ourselves on how to handle some of the things that come up," (Michelle) and they want to be given suggestions and made aware of available options and resources (e.g., information on the Alzheimer's disease process). This better enables them to help their parents. Orchestrators might say, "I hope that they [health care professionals] rely on us, and use us to help because ... we're in a unique position to be able to help him because we know him so well and he has an emotional connection to us" (Sara). "Know that I'm willing and ready to do whatever ... I can do" (Bella).

Having frequent communication between the orchestrator and those present with the care receiver is important to make sure the parent's needs are being met (e.g., having shoes that fit and that are in good condition) and that the orchestrator is keeping up with ongoing things that arise and doing as much as he/she feels he can. This frequent communication with parents and others may be a change for some. For example, one might say, "I went from ... occasionally calling them [my parents] to ... calling every week and then more and more often. Now I call just about every day, and sometimes more than once a day" (Fran). Orchestrators do this because they are "trying to make sure that we're doing everything we can to make life what it can be for them," (Michelle) and though they are at a distance, "you still do" (Lisa) what you can. They keep working on making sure that everything that can be done is done because "I know there's things I can do. ... [I want to do] whatever I [can] do that's in support of my mom" (Bella).

Communication challenges.

Having good communication with others and determining what needs their loved one has is not always an easy task for the orchestrator. It may require “detective work” (Kristen) to figure out what is happening with their parent. One must look for signs and hidden messages, and try to piece things together because “it is different with someone when you’re dealing with dementia at a distance, it’s even harder ... the signs are, in a way, more subtle ...” (Fran). The parent with dementia/Alzheimer’s disease may not be able to communicate their needs or recognize problems they are having. Orchestrators may say, “The difficulty being long distance is I don’t get to see how my dad’s doing. ... I can’t call him because he can’t hold the phone on his own ...” (Rose). As a result, you may not be able to see or notice the changes in a parent as they occur. “It’s really hard”(Bella). “Probably the biggest thing is you don’t know what’s true. And with his dementia ... he makes stuff up and you don’t know whether he’s saying it to bait you in, to manipulate you, or if that’s his reality of what he perceives as real” (Amy). Parents might also be hiding or covering things in an effort to convey that everything is fine. Orchestrators may say, “I don’t think she’s [my mom] gonna be ...unloading or divulging what she really thinks,” (Bella) and “the signs are so subtle that it’s ... really hard to know” (Rose). “You really have to rely on the person who’s there to be telling you what’s going on” (Fran).

Orchestrators might also experience “not knowing what was [or is] really going on ... [and] getting different stories. Not having the right information” (Jessica). Being at a distance, orchestrators must rely and depend on others to tell them things, to be their “eyes and ears,” (Jessica, Bella) yet they can never be sure the information they are getting is “adequate, correct, or timely” (Lisa). Some may later learn that “nobody was really saying there was a problem. ... [Their] reports were well meaning but they really just couldn’t see it. ... [They] were kind of unrealistic about what was going on, day-to-day” (Scott). Furthermore, orchestrators may have a

difficult time questioning or pressing those present with the care receiver because they are trying to help and “you don’t want to lose the only real contact you have, even if you don’t completely trust it” (Scott). Thus, it can be difficult for orchestrators to rely on those that are present to provide full and accurate information. They might feel like, “nobody can ever do things to your satisfaction when they’re that detailed” (Scott). For example, a sibling might not find out everything the orchestrator wanted to know or tell the doctor everything the orchestrator wanted the doctor to know. The orchestrator may say that it is difficult

... somehow instilling in, for example, my brother, the need to ask these different questions, when it wasn’t really his need. He looked at it differently, he trusted the physician more ... he kind of approached it with, everything’s gonna be alright, and ... the medical system knows what it’s doing, and I had totally the opposite perspective. You use your perspective to make important decisions, and to try to form a perspective based on somebody else’s perspective doesn’t work. (Scott)

Finally, the person present (e.g., the health parent) might also have difficulty comprehending things, so “I have to ... really rely on my mother’s observations and then help her to put it together ...” (Fran). This can further complicate the orchestrator’s quest for truth.

It can be difficult to communicate with health care professionals as well, because the orchestrator cannot always go to appointments. Orchestrators might not know the quality of the health care professionals as the parent can’t always communicate how they are being treated or what they are being told. As a result of all of these challenges, the orchestrator does not always get the information he/she wants and needs. When the orchestrator does not know what needs to be done, it can be a “scramble” (Lisa) to get needs taken care of once they are recognized. They

may feel like, “you’re depending everything on what they’re telling you and if they’re not telling you, oh my gosh, it could be a real shocker” (Lisa). “It’s been really difficult, there’s no information exchange. ... There’ve been trips that I’ve needed to take ... to go down and try to ... find out what was going on ...” (Rose).

Often times my decision to go back was based on, I’m not getting a story that I can figure out what’s happening ... and most of the time I went back because now they’re in crisis and I didn’t have the information ... I can’t deal with it without the information and when I’m not getting it, I had to go back and get it. And most of the time ... I had to lay eyes on them to get it. Which is inappropriate. (Jessica)

Some orchestrators would like health care professionals to take more initiative in communicating with them. Orchestrators may say, “We’ve told the caregivers, call us anytime ...,” (Sara) and “I don’t care how small it is, you call. If something’s going on, you call” (Jessica).

It is important to note that interacting and communicating with a parent providing care might also be difficult for orchestrators. In addition to the challenges mentioned above, the orchestrator must respect (if there is one) the healthy parent’s wishes and abilities and what he/she willing to do. This involves giving up control. The healthy parent may resist help from others or fire hired people for various reasons (e.g., they want privacy or they may be in denial about the condition of their loved one). Furthermore, he/she may not challenge the person with Alzheimer’s/dementia in order to keep things as simple as possible, which may lead to quicker decline. Being at a distance, orchestrators must

... hand this over to my dad, he doesn’t want to do a lot of these interventions. ... That’s okay, that’s his decision and I’m going to support him supporting her [my mother], and

that was important for me, it helped me rest into not feeling so guilty or ... angst filled ...
(Kristen)

In addition, interacting with the parent with Alzheimer's disease/dementia may also be difficult. There is a role shift as "he's more like a child, I'm more like a parent," (Fran) and it is "real hard to feel like you need to tell your parents what to do" (Rose). This may include being more assertive because the parent is perceived to be more passive and helpless. Overall, orchestrators may say that it has, "been kind of a gradual reversal" (Fran). This can be gratifying for some because "it's the first time he would talk to me about his problems that he was going through and would kind of let me help him. ... It was good, in a way, for me" (Fran) because the orchestrator might not have had that opportunity to share and help before.

The journey.

Given the demands placed on the orchestrator, the role is a large responsibility. Orchestrators may feel like "I'm still the one that needs to go see her" (Scott) and take care of matters like health insurance. This can be seen as "a huge commitment, it's like your whole life is put on hold to be a caregiver" (Amy) because "it's all me ... the entire caregiving is on me" (Jessica). They may feel that "somebody has to take care of her. ... I can't not do that." (Jessica). Orchestrators may report that the role is "huge, it feels overwhelming," (Rose) and that they are "on call" (Jessica) no matter what. This can lead to sentiments like

... it was a full time job ... just to manage how we were gonna manage them [both parents]. ... It was ... huge challenge to go back and forth ... There's just not enough time to do it all," (Jessica)

or, “it’s put me into a world of financial and legal issues that I never thought I was going to have to understand” (Rose). Some may feel that taking on the orchestrator role, and the circumstances around the role, has lead them and their parents on a “journey” (Amy, Lisa, Rose) or an “odyssey” (Amy).

It’s a journey ... they’re changing as the process of life and where it takes you and you don’t know how that’s going to happen or the twists and the turns and what’s expected and what’s around the corner and, you know, the ups and downs and all that, it’s a journey, and in the process of now knowing and everything you’re learning not only about them but also about yourself. ... They journey doesn’t end when they die. (Lisa)

This is not always an easy journey. Orchestrators may report that

I can tell you that this has been probably the most difficult thing to do. It has been very hard not to be able to walk the journey with my father through all of it. It has been very hard not to be able to be an advocate ... I think the hardest is not being able to help my dad through the process. ... I think my dad would have some different things right now if I could be there ... (Rose)

Things that orchestrators may also found difficult on this journey include

... not getting to hold their hands, not getting to see them. And professionals, not getting to be able to go in with my mom to the physician and say ‘mom, listen to what you just told the physician, although this is what you’ve told me and this is what I see. (Rose)

Orchestrators are also not able to always do hands-on things since they are not present. “When problems escalate then you end up on the phone a lot, trying to solve problems from far away,” (Michelle) and

... all of that takes a lot of time and energy. ... If I was closer ... [I would] ... just ... take care of it. And here, there’s all these phone calls that have to be made and then trying to be the between, between my mother and other people, trying to get her permission for us to talk to people ... (Rose)

As a result, “when you’re long distance, there is only so much you can do,” (Bella) and “so to have all these thoughts about what needs to be done and only have a limited ability to do it is scary, plus frustrating” (Scott). In addition, orchestrators can try and line things up for their parent but

If they [the healthy parent or others who are suppose to help] don’t take it up on their end, it’s just not gonna happen. And then I have to let that go, don’t get so frustrated about it. Beyond that, just do what I can do and let it go. ... I’d like to be able to be there to be more helpful and it’s just hard to be as helpful, I think. (Bella)

Thus, it can be a difficult and challenging journey to undertake.

Support on the journey.

The journey of an orchestrator frequently requires obtaining personal support. This may be obtained in various ways. Talking with spouses, friends, co-workers, and family members can be a major source of support, possibly because “sometimes just having another person to do it with you makes a big difference” (Michelle). Support groups, therapists, the Alzheimer’s Association, Hospice, and religious organizations may also be helpful sources of support. For

example, at support groups one might learn more about available resources and options. As a result, orchestrators might connect with others they wouldn't have normally associated with, and say, "You don't feel so alone" (Bella). Engaging in leisure activities such as gardening or running and playing with pets may also be a source of support and comfort. Orchestrators seek out these supports because "I want to protect my heart and my sanity. ... You've got to be able to take a break" (Amy). When talking about how others support them, orchestrators may feel that

... sometimes, it's [hearing] 'I know you're going through a hard time, I'm really sorry.'

Sometimes it's just allowing me a chance to vent ... so people help when ... they are just a part of life. (Rose)

This includes being able to talk to others about their fears, Alzheimer's disease, and the emotions they are experiencing. Friends checking in and asking how things are going, acknowledging that they are going through a hard time, or simply listening can mean a great deal to orchestrators. Spouses and others may also assist the orchestrator by arranging logistical things, such as flight arrangements, or by helping make caregiving decisions. Some spouses may even call the parent every morning, which may be seen as "an incredible gift that he's giving to me and to my stepmother and to my father" (Sara).

Some orchestrators may report that, "I support myself with myself," (Lisa) possibly because "I don't usually talk to people about it. ... There isn't a lot of support for me, but I don't rely on a lot of other people because I know it bores them" (Jessica). Orchestrators may turn inward for support because they believe people don't know how to react to them or their situation, or that others do not understand the situation. This might be one reason orchestrators state that it has

... been helpful just to go and be around other people dealing with it and kind of hearing their stories. ... It's been very helpful to talk to others who've been down this road, who remind you that [you] ... can't make it all happen the way you think it should, and that's okay. (Bella)

No matter where one turns to, support appears to be essential on the orchestrator's journey. The orchestrator demands can be time-consuming and difficult to fulfill, and such support may assist orchestrators in fulfilling the tasks and in taking care of themselves.

“We Have a lot of Good Information That Could Help Professionals”

A large part of the orchestrator role and journey entails educating health care professionals on the parent that has dementia/Alzheimer's disease. Orchestrators want others to respect and honor their loved one and his/her past. This may be difficult as the person with dementia/Alzheimer's disease may not be able to talk about or discuss the past due to dementia and confusion. As a result, the orchestrator may want to provide health care professionals information on the parent's past because professionals may “know very little of the story ... when it's a distance situation” (Scott). They might feel that health care professionals don't see their loved one as a whole person since

... each one sees him as basically ... a set of symptoms that they are looking [at]. ...

They see him only through the lens of their own specialty and what they are looking for and they don't see him. Most of them don't see him as a whole person. Most of them ... kind of miss the boat, and he won't really listen to them if he feels like they haven't really listened to him. (Fran)

Health care professionals might also “get blinded, and say, ‘We’re gonna do what they’re here for’ ... [and] never really ask or think about what’s going on long-term” (Amy).

Orchestrators may report that “we have a lot of good information that could help professionals help their patients” (Rose) as the person with dementia/Alzheimer’s disease may not be able to communicate their needs, their wants, or their past- all of which can help in arranging that person’s plan of care. Thus, when referring to health care professionals, orchestrators may say, “That’s one reason I think you [the health care professional] need to go in ready to learn way before you’re ready to give any advice about what you can provide” (Scott). Orchestrators can feel that healthcare professionals need to “talk and listen, really listen to me” (Amy) so they can provide such education. They might say

I think professionals tend to go in and ask the questions on their assessment, but not definitely get a general feel for the, you know, there’s other issues that don’t happen to be on my little assessment form. ... I’d like them to go into it wanting to learn more than wanting to tell anybody anything about the way things should be. They should always go in and say [to the orchestrator], ‘Tell me what’s going on; What’s it like; What do you think your needs are, for support; and ... The person you care for, what do you feel like their greatest needs are?’ Instead of ... saying, ‘I need to assess, and then I’ll tell you my impression.’ [Health care professionals] need to be much more asking questions in the beginning from the expert. The expert ...[being] the caregiver. ... [Questions like] ‘Fill me in; Give me some context; Tell me what this has been like;’ and ‘What do you see her or his needs as?’ (Scott)

This is especially true because everyone orchestrator's situation is different. Thus, it might be important to construct a timeline, or a story, about what has happened in the loved one's past. This can take time, and orchestrators may feel that they don't always get to explain things in enough detail so staff understands where they are coming from. In addition,

... some of them [professionals] seem to have kind of missed seeing the decline because they didn't know him before and they just kind of take him as, 'Oh I guess this is just the way he is'; and ... none of them, picked up on anything until my mother had to really ... be very assertive ... to get anything, any recognition. (Fran)

This might be because the signs of the decline can be subtle. Thus, the orchestrator might say

I wish that they would listen to people who know him. ... We have a lot of good information that could help them help their patients. My dad would have been diagnosed a lot earlier ... if the physician would have talked with me. (Rose)

Part of the orchestrator role can involve the orchestrator conveying the importance of having such information to health care professionals.

Importance of communication with health care professionals.

Orchestrators may also feel such communication is important largely because healthcare providers do not know the parent with dementia/Alzheimer's disease and his/her past. The parent "had a whole other life before ... Alzheimer's came into play ..." (Kristen).

Working from their context, a lot of times ... [health care professionals] don't know their story, so ... [professionals] don't know where the things that they do come from. And I think it'd be difficult to know those things of all of your people. And you can't know all of the things that are hidden under the surface that they [people with

dementia/Alzheimer's disease] don't talk about. ... [Health care professionals] see behavior; they know sometime diagnosis; they don't always know the life story or history, so they can't sometimes put the behavior and stuff into context for that person. (Michelle)

"They haven't had the luxury of knowing him as a more healthy person. So, they don't know kind of how to tap into that side of him and kind of bring him back" (Sara).

The caregivers don't get ...who their people were. They don't know their story. ...What they see are ...demented people. ... They don't see the brilliant man I grew up with. ... They don't know the gifts that these people have given to the world. (Jessica)

The orchestrator knows the person, and may be able to explain the person's behaviors and look at things from a different perspective.

I know her well enough to recognize some of the things that are happening that they might not know as well. ... They'll tell me stuff and I know what they're saying, yeah that happened; why it happened, I might have some insight into it that they might not have ... I see the fears and I know it could be related to her brain function changing, as well as real things that she's afraid of and has a real reason to be afraid of. (Michelle)

For example, a person with dementia/Alzheimer's disease may fear being "kidnapped," (Michelle) due to being taken to a rehab facility without their consent or the consent of his/her family. Thus, he/she might react negatively in certain situations when feeling like they are going to be taken away. The orchestrator role may involve the distance caregiver providing such information to health care professionals in an effort to improve the quality of care their loved one is receiving. Overall, orchestrators hope that health care professionals "seek out advice from us

as far as their personality and their lives that you couldn't know as a [professional] caregiver” (Michelle).

Orchestrators also want to provide information about their parent's past in an effort to help health care professionals appreciate, respect, and honor the person he/she is.

They need to see him as a person and relate to him. ... Many of ... [the health care professionals] don't seem to understand the importance of the personal, the intrapersonal, aspects of any given appointment. And ... [my parents have] been talked at in ways that just, you know, they just found completely off-putting. ... [Professionals] just don't seem to understand the situation ... [My father] just needs to have people relate to him as a person [not a child] and [have professionals] convey that they understand what ... [he is] going through. (Fran)

This includes making things comfortable and enjoyable for their parents, while preserving their parents' dignity (e.g., the parent should have their hair styled how he/she would have wanted it) and respecting what he/she would want (e.g., dressing the parent how he/she would have dressed). To do so requires health care professionals to listen to the parent, be patient, and give time for the parent to process what is being said. “You just have to be very, very patient and accept that he may or may not have understood what you said, or maybe he just can't get the words out fast enough, and you just have to be patient” (Michelle).

It is important for health care professionals to recognize that the parent may not be able to communicate the things they need or want (e.g., that they are cold and need a coat, or that they are in pain). Therefore, to successfully honor, respect, and appreciate the parent, health care professionals may need to talk with the orchestrator to better understand what the parent's needs

and wants could be. For example, professionals may not understand how important certain things, like faith, could be to a parent and they might not support him/her in those areas.

Orchestrators are aware of such things, and realize that their parents have a past, and a lifetime of wonderful experiences. As a result, the orchestrator role may involve relaying details of their parents past to health care professionals because “they don’t realize that’s who he used to be ...,” (Sara) and “everything you get to know about them and their past helps you with knowing who they are and what they want ...” (Michelle). Such details can help health care professionals realize what a great person the parent was, what an extraordinary life he/she led, and how they can best support that person in the present. Orchestrators hope that having such information may also help health care professionals make their parents’ life meaningful and have their parents’ engaged in things they enjoyed (e.g., looking at photographs of family or doing crafts). They feel that it is “in the moment,” (Sara) so it doesn’t matter if the parent recalls the activity or not.

Overall, many orchestrators feel an important part of their role is educating health care professionals on their parent’s past. They do this so better care can be provided by the professionals and so the parent can be respected and valued as a person.

A “Heartful Connection”

Given the demands of the orchestrator role, orchestrators’ relationships may change “pretty significantly” (Rose). Some may feel that their taking on the role “affects everybody I know,” (Amy) while others feel that their relationships largely stay the same. Overall, orchestrators might feel that their family is closer (including parents, spouses, and siblings). Family members may be forced to make significant decisions together, and have real conversations about things that they might not have in the past (e.g., whether a parent is safe to live at home or not). As a result, orchestrators may have stronger family connections and report

that “I feel fortunate in that I think it’s made my family ties stronger, and I imagine that’s not always the case ...” (Sara).

The parent with dementia/Alzheimer’s disease.

In the process of managing their care, orchestrators may find that they are closer to the parent with dementia/Alzheimer’s disease. They may find they have a “more heartfelt connection” (Kristen) with the parent. This could be because the parent has more time to spend with the orchestrator, the orchestrator might get to know the parent better after taking on the role, and the parent may be more “emotionally available” (Sara). They may report that, “even though we can’t really have ... sort of in-depth conversations [most of the time], ... I still feel very close to him” (Sara). While orchestrators might not be able to have the deep conversations that they would like to have (due to the cognitive deficits of the parent), they may find they can have special conversations and moments. For example, an orchestrator might say, “I got the gift of every time he [my father] would say goodbye to me, he would say, ‘Thanks for being my daughter’” (Rose). A parent might also talk to the orchestrator about how frightened he/she is of the illness and of hurting the family, or about the changes he/she is going through, giving the orchestrator an opportunity to offer support and encouragement. Orchestrators might also have conversations with their parent that it is “okay ... [to] let go ... and let the disease take over,” (Rose) and that everyone will be ok. Orchestrators may find it important that they have had such a conversation. Such experiences may lead orchestrators to describe their parent as “a gift [or] joy” (Kristen). The parent might also be more emotionally available, and express their appreciation for what the orchestrator is doing to help him/her. This could include acknowledging the orchestrator’s strengths, being more affectionate with the orchestrator, and expressing gratitude when the orchestrator visits (including how important it is for the orchestrator to visit). No matter what stage the parent with dementia/Alzheimer’s disease is in,

the orchestrator might feel that the parent “still can give, and you know, the smiles and the one-liners that she still has are worth it” (Lisa). Even when the parent does not know who the orchestrator is, they may say, “I know that he’s very much aware of how much I love him,” (Rose) and that is what may matter.

The healthy parent.

In addition to developing a closer relationship with the parent who has dementia/Alzheimer’s disease, the orchestrator might find they are closer to the parent/step-parent providing care, if such a person is involved. “It’s something we have in common, ... so I think it’s brought us together in a lot of ways,” (Sara) and together they talk about and deal with the demands the person with Alzheimer’s/dementia presents. When talking about their healthy parent, orchestrators may say, “We’ve gotten much closer” (Fran). This is why the orchestrator might try to “really work with the caregiver [e.g., the healthy parent] that might be present in a way that honors and respects them ...,” (Kristen) and orchestrators want health care professionals to do the same. This includes supporting the healthy parent as much as possible, and making sure the parent is getting the education, assistance, and respite he/she needs to prevent burnout.

After taking on the orchestrator role, orchestrators also may have more one on one time with the parent providing care, and they may have a more open relationship with the parent. For example, some orchestrators might not have had conversations with much emotional depth or honest openness in the past; they might have been more superficial. Now, a parent may confide in the orchestrator more about what is going on with the loved one who has dementia/Alzheimer’s disease and discuss how he/she is feeling given everything that is happening. This openness may go both ways. Orchestrators tend to be thankful for the care the

parent provides, and the parent is thankful for input given by the orchestrator. The parent providing care can also pass information between the orchestrator and healthcare professionals, and ask questions on behalf of the orchestrator. While a parent might initially resent information and suggestions the orchestrator offers (orchestrators may feel this is because the parent is in denial about the situation), he/she may gradually become more open to advice and information the orchestrator provides. Advice and information provided can include new ways of looking at the caregiving situation or the behaviors the parent with dementia/Alzheimer's disease is exhibiting, or new ways of handling situations that arise. Overall, working together might also help orchestrators learn how to better interact with the parent providing care, including knowing when to push her/him and when not to. Some might feel this is a "continual learning" (Rose)! Overall, orchestrators want to be there for the parent providing care. They hope the caregiving parent feels less alone and has greater comfort after sharing things together.

Spouses/Partners.

For those orchestrators who have a partner or a spouse, the spouse/partner can be a source of support. Together, they can talk about caregiving decisions that need to be made or the next step to take, and discuss issues that arise. The spouse/partner may provide suggestions or give advice and assist in providing care. For example, a spouse can call the parent with dementia/Alzheimer's disease on a regular basis to help the orchestrator and the primary caregiver. This can be seen by the orchestrator as "an incredible gift" (Sara) that brings them closer. Orchestrators may also find support when their spouse/partner tells them to do whatever they need to do to help the parent, or offers to travel with the orchestrator to visit his/her parents. Overall, having a spouse/partner who takes an active role in assisting a mother/father in-law may strengthen the relationship. Orchestrators may say that,

At times, during the past few years, I've spent a lot of time talking about this [caregiving] with my husband. ... I would talk to him at length about it and he would give me suggestions. ... That's something we would spend time together doing. (Fran)

"We talk about everything, kind of plan things together" (Scott).

Friends.

Friends also can be a source of comfort and support. Orchestrators may talk more about caregiving and their parents with friends, and become closer. "I think it's just made me closer to some friends ...[out of] necessity in a way, it's sort of like, okay, I really do need to talk to somebody about this ..." (Sara). Orchestrators may find that their friends start to better understand the caregiving situation as friends begin going through similar experiences with their own parents. Some may also get to see more of friends who live by their parents, and become closer to them.

Actually I've gotten to see ... old friends who still live near my parents. I get to see them more now because I'm back there more ... it helps me to ... be closer to them. (Fran)

As a result of the support friends can offer, orchestrators may say, "I do make time, once in awhile, to do stuff with friends ..." (Jessica).

Siblings.

Orchestrators may work together with their siblings to ensure that their parents needs are being taken care of, perhaps affecting their relationships Siblings might set aside any personal differences or past disputes for the good of their parents and rely on each others' abilities. This can result in feeling like they balance out each other with the different strengths they have from their professional backgrounds (e.g. the lawyer can handle wills, while the nurse handles medical issues) or personalities (e.g., some are better taking charge in a crisis, while some are better at

handling the emotional aspects of seeing a parent cognitively and physically decline).

Orchestrators may also try to pass on what they learn and give suggestions to their siblings (e.g., information on the disease process and what they can do to assist their parents). Supportive siblings can be a “sounding board” (Rose) for the orchestrator and help them problem-solve issues that arise. As a result, some orchestrators may find themselves closer with their siblings. “I think we’ve all gotten closer in some ways in the past few years ...” (Fran).

It is important to note that orchestrators and their siblings do not always become closer and develop a positive relationship. Disputes and arguments may erupt between siblings. For example, an orchestrator and his/her siblings may disagree about the course of action they should take with their parent who has dementia/Alzheimer’s disease, or the orchestrator may feel resentment towards a sibling who is not as involved in a parent’s care. In such cases, orchestrators may have a limited or strained relationship with their siblings.

Health care professionals.

Orchestrators can also have (or desire to have) professional relationships with health care providers. They may feel that

... the main thing is for the healthcare people to know enough to ask their patients and the spouse ... questions like, ‘Who supports you; Who else is in your family; Who do you rely on?’ And to find out that there’s a long distance caregiver and then to say, how is that person involved, how can we ... have that person be involved in your care? (Fran)

Orchestrators want health care professionals to know what they, the orchestrators, are able to do to assist the parent. Part of this includes the professionals having an understanding of what the orchestrator’s life situation is like because “healthcare workers have no ... clue what it’s like to

live your home life” (Amy). Having such an understanding can assist the healthcare professionals in being less judgmental and more understanding (problems orchestrators may experience with healthcare professionals). This is important to orchestrators, who may say, “I don’t need somebody who doesn’t know me or my mom or my family trying to make me feel bad [or guilty] about the decision I made” (Lisa). Thus, they want health care professionals to “consider how you say what you say, so that you don’t make somebody feel like they should be there more or that they’re not making the right decision ...” (Lisa). Negative experiences orchestrators may experience include being told by a physician that the parent needs to move in with him/her (which may not be possible given the caregiver’s home situation and the fact that the parent lives at a distance), or that the orchestrator needs to reconsider his/her decision not to implement an expensive toothpaste regimen that the orchestrator deemed impractical given the parent’s cognitive and physical state.

Orchestrators feel they know what is best for them and their loved one, and want professionals to be understanding, respectful, and compassionate of the situation and them. This includes recognizing that they have a life outside of managing and orchestrating the care of their parent, and that they have the extra challenge of providing care from a distance. Professionals may then have a better understanding of how the orchestrator can help the parent, and professionals can learn what information the orchestrators want to be made aware of (e.g., medications and dietary intake). Having such a rapport also may help orchestrators and health care professionals interact more effectively and efficiently in a crisis situation. Orchestrators can be supported by health care professionals when told things like “you deserve a rest, ... [and by letting orchestrators know that] they shouldn’t feel bad if they want time away” (Scott).

Orchestrators also appreciate being provided with information on support groups and other resources.

Orchestrators need connections with family members, friends, and health care providers to fulfill the orchestrator role. Such relationships may enable orchestrators to better obtain the assistance required to meet the demands of the role, including emotional support.

“A Part of Me is Changed Forever”

Having changed interactions with others, and meeting the demands of the orchestrator role, frequently leads to personal growth and increased self-awareness for orchestrators. Some may feel that “a part of me is changed forever, and parts of me have been woken up that needed to be woken up” (Rose). Increased self-confidence and social skills are a few of the attributes they may develop or recognize in themselves after taking on the orchestrator role.

Strength.

Many orchestrators find they have increased self-confidence and strength as a result of meeting the demands of the role, leading them perhaps to feel that “I’m an incredibly strong person” (Jessica). They may learn or recognize how strong they can be in difficult circumstances and how to “navigate” (Sara) challenging situations more effectively. This includes understanding how they deal with extreme stress and support themselves during challenging times. This might enable orchestrators to explore how they can support themselves in healthier ways (e.g., going for a run instead of reaching for that ice cream). Where they might have felt fear or doubt before, orchestrators now realize that “I can do this ... I can handle whatever comes down the pike. It won’t be easy, but you know, ‘Get in there and do it,’” (Michelle) and have the “recognition of how strong I can be in a difficult situation. I have surprised myself sometimes ... that I can keep it together when I’m there [visiting my parents]” (Sara).

Self-confidence and self-awareness.

Orchestrators might also find they have increased self-confidence in their abilities to learn new things (e.g., about health insurance, Alzheimer's disease, and other medical issues), and have a strong desire to learn and get as much information as possible. This may include discovering where to find help and obtain resources, and how to reach out and connect with others. Orchestrators may recognize that they can be resourceful and resilient, enabling them to handle things when they have no idea what to do initially. Developing patience may also be part of the orchestrator role, including distinguishing when they might feel more tolerant of others and when they might feel like yelling, "Come on, give me a break here" (Kristen)! When the time calls for it, they can also be more assertive than they thought possible (perhaps because this has previously been the parent's job). Furthermore, being nicer, kinder, and more caring are attributes they may recognize in themselves. Orchestrators also might realize that they tend to put the needs of others before their own, sometimes to their own personal detriment, and that they have perhaps learned how to forgive themselves for not being able to do more to help their parents.

In general, orchestrators seem to have overall increased self-awareness after taking on the role. The growth that orchestrators may experience after taking on the caregiving role can give some an "impetus" (Fran) to make changes in their life. Orchestrators may feel that "I have to do what I was taught in life," (Rose) and take steps to live the kind of life they were taught to live, albeit in their own way. This includes learning to trust oneself and "my own gut feelings and beliefs" (Michelle). It is perhaps refreshing for orchestrators to realize that they do have ideas and things to contribute. This self-confidence may lead them to take on challenges they never thought they could handle, such as joining the Governor's Council at a university.

As a result of being in the orchestrator role, some may also develop enhanced social skills and social awareness. They may say, “I can take some of [what I have learned from caregiving] and always feel very supportive of friends if they’re in a bad place” (Sara) or crisis. This can include having improved coping skills in dealing with people, which is likely the result of having to interact with family members, friends, and health care professionals during challenging times. In addition, orchestrators may feel they have a better understanding of people (including the elderly and the fears they might have), and more realistic expectations of others. Orchestrators might find that caregiving helps them “recognize the importance of somebody else’s needs and it helps you form a different perspective” (Scott). In addition, they may state that

It’s affected me and allowed me to relate to people. I do know what it’s like to be a caregiver. I do know the burden of it. ... [I understand] how family dynamics can change as a result of illness. (Jessica)

This has led some orchestrators to feel that they have a better understanding of the “circle of life,” (Michelle) and how “we really do impact each other one by one” (Rose). For example, they may better recognize how people are “interconnected,” (Bella) and learn what happens as people age and how families assist and support each other. Orchestrators may feel they had a “real wakeup call about here’s what happens in life ... [and] how do you get it taken care of” (Bella). This includes determining how and when to interact with extended family members, how to share caregiving duties and manage things when there is no support close by, and how to deal with end-of-life issues. As a result, orchestrators may say the experience has “open[ed] my eyes to life” (Bella).

Giving back.

Caregiving experiences also may reveal to orchestrators the importance and value of family relationships and giving back to others. This includes the distance caregiver helping his/her parents (“being able to do that for them ... is pretty meaningful”- Lisa), neighbors (some orchestrators may help their neighbors since they cannot physically assist their own parents), and those conducting research on caregiving or dementia/Alzheimer’s disease (“if I help ... [those conducting research on the topic], then everybody else’s parents are gonna be better off in the future ...” -Michelle). Overall, orchestrators are grateful that they can give something back to their parents, and help make their parent more comfortable. This gives them joy, satisfaction, and nourishment. They may report that

It does make me feel like I am doing something positive for my father who has done so much for me, you know, has given so much to me. I feel like I’m giving something significant back to him whether he’s consciously aware of it or not. ... I want to do this for them. (Sara)

Orchestrators also may say, “I feel useful, I feel like it’s worthwhile, I feel good about it, but it’s mostly for them” (Fran). “They’ve gotten some good care [as a result of my help], because of that its’ maybe reduced their suffering ...” (Jessica).

Some orchestrators may take their desire to help others even further and alter the course of their professional career or academic interests towards the area of caregiving and/or dementia/Alzheimer’s disease. This includes orchestrators sharing personal stories with others (e.g., students they have in their classroom) to help “make it real” (Jessica). Recognizing that perhaps caregivers need more help than is currently available, orchestrators may try and work with such clientele. They also have an increased understanding that, when working with a client

who has dementia/Alzheimer's disease, that client's reality is his/her reality, and that one can connect somehow with that person (or anyone with dementia/Alzheimer's disease) because there is always a person there. Orchestrators may say that, from caregiving, "I got the gift of knowing that it doesn't matter what the reality is, their reality is; ... and you connect there and there's always a person inside ..." (Rose).

Orchestrators may feel they have learned about relationships, how relationships may change over time, and the importance of being open to that change as a result of providing care. Personal growth also can occur as they fulfill the orchestrator role, perhaps resulting in the orchestrator's definition of success may change from having "a lot of rewards on the walls ... [to feeling that] success is ... helping people. ... Just reinforcing and giving them encouragement" (Rose).

"It Really Affected Me Deeply"

Orchestrators may experience some intense emotions while trying to meet the demands of the role. Emotions may be related to experiences such as seeing their parent decline, or related to trying to fulfill the orchestrator role.

The decline.

Given the nature of dementia/Alzheimer's disease, there is a continual decline in the orchestrator's parent. Changes orchestrators may see in their loved ones include: an inability to recognize the orchestrator, getting lost in familiar areas, not keeping up with housework, becoming incontinent, becoming physically fragile, having limited ambulation, having decreased communication skills and language abilities, having memory loss and decreased judgment (e.g., they may say, "I don't think he has any judgment anymore"- Fran), an inability to plan or carry things out, decreased initiative to do things when the parent had always lead an active life (e.g.,

the orchestrator may report that the parent “really basically does nothing – Fran-, or that “we were amazed at how we couldn’t add any meaning to her life. She rejected everything she use to do”- Scott), increased fatigue and more generalized complaints (e.g., orchestrators may say that “Every little thing bothers him” –Fran,- where before he was never sick), and decreased participation in leisure activities formally enjoyed (e.g., music, or traveling). Seeing such changes may evoke feelings of sadness and worry in the orchestrator. Some orchestrators say, “It just destroys me,” (Amy) to see the physical and personality changes in their parent. They may feel that,

When you walk in and you see this ... unkempt man, you’re just like ... who is this, you know? ... I can’t yell at him and demand that he’s the father that I remember. ... This is not my father ... and that was very ... hard to deal with. (Amy)

Orchestrators might also feel sadness and distress then they are not able to go to a parent for advice like they would have in the past, because “the person who would have given me advice is gone. ... It was really hard that it wasn’t him that I could call [to get advice] ...” (Rose). It also can be difficult for orchestrators to know and recognize that “changes are happening quickly, like astonishingly quickly,” (Kristen) in the parent. Orchestrators may feel that their parent is physically there but not really there as a person. When their loved one is towards the end of the disease process, orchestrators may say that, “She’s way gone. I don’t know where she lives, her brain is gone” (Scott).

Personality changes in a parent also may be difficult for orchestrators to handle. Personality changes could include agitation, paranoia, or anxiety; or being argumentative, combative, or violent. Such changes perhaps increase the stress orchestrators may feel. For

example, they may say, “When he’s anxious he becomes somebody who I don’t know as well, and ... dealing with him can be tough ...” (Sara). It also is hard when a parent gets mad or suspicious whenever the orchestrator asks how he/she is doing, or talks to the other parent or a social worker. Orchestrators may say,

I think the hardest part is when he’s mean to me. ... It’s hard not to take that stuff emotionally ... just as a daughter ... to have to accommodate to the personality changes when you’re already doing so much ... (Sara)

“I don’t think he knows how devastated and sad I am about him” (Amy). It is also a sad time for orchestrators when parents forget personal exchanges they used to share, such as “Thank you for being my daughter,” and “Thank you for being my father” (Rose).

Vulnerability of parents.

When visiting, changes in the parent are perhaps more noticeable to orchestrators since they likely do not see the parent regularly. This can force the orchestrator to recognize the mortality and vulnerability of their parents- it can be “right up into your face,” (Kristen) and every week can be different. It is also difficult for orchestrators because they might miss spending “precious time” (Lisa, Kristen) with their parent. Seeing changes in their parents and missing time with their parents may mean orchestrators worry more about them. With the changes that happen, orchestrators may feel that “every time you leave, you don’t know ... if you’ll have another chance to say hi and goodbye” (Rose). Furthermore,

Literally an incident happens and immediately the life is changed. I mean their lifestyle was changed, my lifestyle was changed, everything is changed in an instant. ... Things happen, and when they happen ... you have to drop everything and go. (Jessica)

“From minute to minute almost you can be in a good place or a bad place” (Sara). As a result, orchestrators may feel it is important to take things one day at a time and stay in the present because “this is the real deal, right here” (Kristen).

When orchestrators visit their parents, their parents may be doing worse than anticipated. Orchestrators may report that,

When you do go out there the reality of how bad it is, it’s kind of hard to take. ... I expect it to be bad and it’s always 100 times worse than I thought ... It’s really bad and it’s very hard emotionally to gear yourself up to go out there and face it ... It’s very hard, it’s so draining, oh my God, it’s so draining. (Amy)

Orchestrators may also feel that seeing the changes and decline in their parent

... really affected me deeply, I got kind of thrown off. I felt like I was mourning the loss of my mom because this time really felt like this is the step where she kind of disappeared ... my mom’s not there anymore. (Kristen)

It can also be difficult for orchestrators when, while talking on the phone to their loved one, the parent hands the phone away. Orchestrators may feel for the first time that the parent “didn’t really have a sense of who I was at that point. Or any connection left there.” (Rose)

Quality of life.

Orchestrators may feel that their parent has little quality of life, and nothing to look forward to, perhaps increasing their feelings of stress and sadness. This might include fear and frustration that a parent is not being challenged enough and is “withering away” (Bella) while she/he still has some mental capacities. They may say,

I'm thinking, guessing, she is knowing every day what she can't do that she use to be able to do, and has a life of wandering from one end of the house to the other, and she's much healthier than that. (Bella)

As a result, they may express that, "My hope is that their suffering ends soon" (Jessica). While orchestrators are thankful when a parent does not seem to be in any pain, they might state that

It's not a life [for my mom]. The only way she has a life is her ability to remove herself from where she is. It's a great place [she lives at], but it's a terrible way to live. ... So I really hope she won't have to do that much longer. ... It just goes on in her current state and it just doesn't seem to make sense. ... I really don't believe she has any reason to live, but then I think, 'Well, I sure don't understand life,' I don't know where she is. Maybe she's in a place of real comfort and she's at peace ... it's just hard for me to see her that way ... (Scott)

Orchestrators may feel the life their parent has is meaningless and a bad fit compared to what the parent would have wanted. Thus, they may feel that the death of their parent will be okay. Orchestrators may express sentiments like, "They have nothing to look forward to. I mean, nothing's going to get better. ... There is nothing positive in their future. ... Why prolong the suffering" (Jessica)? "What are you sustaining" (Lisa)?

Having my dad having dementia is just like this slow painful death. It's just like you're walking through it constantly. It never goes away. ... He has no life. ... [His death] would be the end of his weird odyssey. ... He would be at peace ... versus all that he's having to deal with now ... (Amy)

Orchestrators may feel their parent's death would be a "blessing," (Amy) and say that "I'm not afraid of them dying. I pray for that. I pray that they go to sleep and don't wake up" (Jessica). They also fear that their parents' wishes will not be respected. This includes the fact that their parent may have valued quality of life, not quantity of life. Orchestrators might feel that "neither of them [my parents] have any quality of life as they would have defined it. ... This is not how either one of them would have lived" (Jessica). Overall, they hope that their parent with dementia/Alzheimer's disease can still enjoy life and connect with others during the disease process. This includes understanding that there are people who love and care about him/her.

Difficult emotions.

Orchestrators also may experience strong emotions while trying to meet the needs of their parents. Emotions may include grief, frustration, helplessness, guilt, worry, appreciation/gratitude, acceptance of/resolved to the situation (Jessica), and stress. The caregiving experience may be very stressful for orchestrators. They may state, "I'd say it's extremely stressful" (Jessica). "To feel that depression, and that weight, and that stress has just been- it's enormous- it's like you can't even breathe" (Amy). Orchestrators may feel that the caregiving stress is cumulative, and "a little added M&M on the bowl of M&Ms of stress" (Sara). Stressors can include finances (e.g., travel costs and the cost of missing work to provide care), and missing phone calls from parents/caregivers. There is also stress while visiting parents, both from the physical care orchestrators might provide as well as the emotional stress of visiting. When visiting, "it's very much a whole nother world" (Kristen). "It's kind of intense caregiving when I'm out there ... [The] potential need is so enormous" (Sara). Orchestrators also have the "emotional and mental stress of just being there when he's anxious" (Sara). They also might not sleep well while visiting, as their parent may get up during the night and need assistance. Some describe visiting as a "more intensive experience of talking and being with

them, “(Fran) and sharing things with them like meals and walks. They may say that visiting is, “Just a very concentrated and intense experience of being with them for a few days. ... It’s just kind of the same [as being at a distance], but more so” (Fran). It is also difficult for orchestrators to see the parent’s decline in person. They may say, “I swear the last three years I don’t think I’ve gone out there and gone, ‘Oh that was a good visit,’ you know. I don’t. I don’t leave with that feeling so that’s really hard” (Amy). Such feelings and experiences may increase the stress an orchestrator feels.

Orchestrators all have their own way of dealing with the stresses the orchestrator role brings as they also try to live their own lives. Relying on faith or spirituality, maintaining a sense of humor (they may say, “If you can keep your sense of humor, and see it that way, I think you’re better off” -Michelle), getting away from phone or e-mail for a short time, engaging in leisure activities (e.g., sewing, gardening, running, playing violin, or going out with friends), getting massages, engaging in meditation, or getting away for a weekend with kids and spouses are some ways orchestrators may deal with the stress they experience.

Guilt is another emotion orchestrators can have. They may find it difficult to “give up ... the idea” (Scott) of doing more hands-on care for a parent, and letting someone else address those needs. Though they try to make sure health care providers know how to do things and work with the parent, orchestrators may say, “That was hard to pass off to somebody else” (Scott). This includes feeling “weird” (Scott) when caregiving becomes managing finances and visiting a parent. Such feelings may lead orchestrators to feel that they personally do not deserve to be happy when a parent is suffering, and that they do not want to leave after visiting, because

... as hard as it is to be with him, it's never gonna be as good as it is in this moment. You know, he's gonna continue to decline, and so I would like to be with him more. ... I wish I was spending more time with him. ... I really would like to do more than I do. (Sara)

Overall, orchestrators may feel guilt from not being with a parent more, and say "I think that I do feel guilty about not being more available" (Sara). "I feel guilty like I should move back there ... to take care of him, so it's hard, it's just very, very hard" (Amy). "I have had times where I felt really ... bad about being so far away and not being able to be there and help" (Fran).

Frustration.

Frustration seems to be another emotion orchestrators feel while trying to help their parents. Trying to locate and find care and resources for their parent can be a source of frustration for orchestrators. They may say,

It's just so frustrating, for some reason, trying to get anything done in their healthcare. ... I've been, every step of the way, telling my mother, 'Okay. Well, you have to call this one,' ... just figuring it out; (Fran)

or that,

We didn't even know about any resources. ... There was no respite of any kind, so I didn't know of resources and I didn't know who to call to find resources, either at a distance or up close. (Scott)

For some orchestrators, the process of trying to get a diagnosis for a parent is difficult (e.g., it can be difficult to locate the appropriate professionals, or a parent may initially be told by a health care professional that they have Alzheimer's disease, and then that they do not, and then be diagnosed again with Alzheimer's disease). It is also frustrating for orchestrators because they

may be dealing with “stuff that’s probably not fixable, and so that, that gets very hard” (Amy). For example, orchestrators may feel dementia/Alzheimer’s disease results in a different deterioration from other diseases, as you lose the “essence” (Fran) of who the person is/was. This can be frustrating and upsetting for orchestrators to experience in their parent. Furthermore, there is nothing you can do to stop the decline.

It is also very frustrating for orchestrators when they are not getting the information they want and need. This can result in them not knowing what is going on with their parent, and not knowing what the best thing to do may be (e.g., they may now know why a parent is getting a driving test after being told by a physician to stop driving or how to handle such a situation). Orchestrators might also become frustrated when parents and others do not follow through with things they were going to do, and when siblings do not help. They also may get frustrated at the responses they get from family members. For example, an orchestrator may send pictures of the loved one to family members who have not seen him/her in awhile, and receive negative feedback, such as, “Don’t send a picture like that, she looks so different, ...[or] When did her nose get like that?,” (Scott) when the orchestrator simply “wanted them [the family members] to see how well she’s [the parent] doing. So that kind of made me feel like ... I’m just gonna pretend they’re not around, just like they pretend she’s not around” (Scott). Orchestrators also may feel frustrated, and guilty, if they cannot physically help with certain tasks, such as moving a parent into a new home. “That I was not doing anything [when my parents were getting ready to move] ...was really hard” (Fran). The orchestrators may deal with this guilt by beginning to call their parents daily because “at least I could just offer emotional support” (Fran). Overall, orchestrators may feel that, “It’s been somewhat satisfying at times and then somewhat really feeling bad at times, that I am so far away and I can’t do more” (Fran). They may, however,

believe that it can be good at times to have distance between them and their parents, because “you just get so frustrated and full of guilt and so full of sadness that ... it’s good that there’s that distance” (Amy).

Helplessness.

In addition to frustration and sadness, orchestrators may feel helpless trying to meet the demands of the orchestrator role. This can include feeling like “there’s nothing I can do to change the situation,” (Jessica) or feeling like they are never doing enough, and a “real feeling of helplessness because ... you end up relying on people for reports” (Scott) and information. They may say,

I’ve done what I can even though it feels like a drop in the bucket. ... I’m pretty far away. We talk by phone, but ... I do feel bad that, you know, what I do feels like such a minuscule contribution ... I know it’s significant [in some ways], but it feels like the need is so enormous. (Sara)

Feelings of helplessness may correlate with feeling “clueless” (Bella) as orchestrators may not know what is true or what the best thing to do is. Orchestrators may say, “All I can do is what I know is good, what I think the best thing is right now. ... I have no idea if I’m doing this right. I’m just totally clueless” (Amy). Looking back at their caregiving journey, orchestrators might feel like, “I just didn’t know even where to start or what to do. ... I just was really clueless about what was happening, and just had to start figuring it out ...” (Bella).

Worry.

Feelings of helplessness also can lead to worry. Orchestrators may say, “You’re constantly worrying,” (Bella) the parent is an ongoing concern that gnaws at you. “It’s horrifying! It’s like can he reach me” (Amy)? Because orchestrators “can’t lay eyes on them,”

(Jessica) and be with their parents most of the time, they may not know what is going on with their parents and what situations and problems they must handle. This can increase their worry, and orchestrators may “feel like the shoe’s gonna to drop any moment, (Amy) because “things are dicey and at any point they [a parent with dementia/Alzheimer’s diseases] could need some major intervention” (Kristen). Orchestrators also may worry about how quickly they can get to their parent, geographically, if something happens, and worry that their parents are unhappy or frightened. As the orchestrator role is “a big deal,” (Jessica) they may worry about what they could or should be doing to help their parent. Orchestrators may report that

I tend to run over things in my head of what’s going on and what I should be doing, what I can do, what I shouldn’t do. ... I just worry more. ... I feel like there isn’t an answer.
(Michelle)

Orchestrators may often worry about the decisions they have to make, and wonder “Did I make the right decisions; did I not” (Rose)? Another worry for orchestrators, when they have both parents, is the spouse of the parent with Alzheimer’s disease/dementia. They want to make sure that both parents are being taken care of and not getting burned out or worn down. Orchestrators also may worry about “vultures” (Rose) taking advantage of their parents. For example, people might get their parents to sign over their trust or adjust their life insurance plan without alerting the orchestrator; or a parent living at a nursing home facility maybe charged for Depends diapers that are given to other nursing home residents. Orchestrators may say, “I think it’s because of the mind, I mean they can’t decide anything, they can’t do anything, they’re so vulnerable, on everything, could be taken advance of so easily ...” (Lisa). This worry is increased because the parent with dementia/Alzheimer’s disease may not able to find solutions to his problems like he/she was in the past. This can be “scary” (Rose) for orchestrators. Finally,

another concern of orchestrators may be that they talk about their parents and the orchestrator role too much with friends. They might say, “I always worry that I’m gonna ... overstep and ... I don’t want anyone to get tired of hearing about my situation” (Michelle).

Appreciation and gratitude.

Orchestrators can also have feelings of appreciation and gratitude. They may say

I appreciate the fact that we are doing something to contribute to his care [and help]. ... I do feel good ... cause I feel like I can do something, you know, like in some ways Alzheimer’s just feels so hopeless, you know, but I feel like ... I can do something and I can make a difference, even though it feels so small compared to, you know, to the massive nature of this disease, the sort of all-encompassing nature of the disease ...
(Sara)

Orchestrators also greatly appreciate and are grateful for everything the primary caregiver does. They can be “astounded at what she can do, it’s amazing” (Sara). Orchestrators may have similar sentiments for the work health care professionals do, and say that,

Everyone I’m coming into contact with are caring people that really want to do the best thing. ... It’s been a good experience as far as working with the professionals. ... They take very good care of him. (Michelle)

They may also report that, “People have been pretty good, they’ve been pretty understanding, and pretty helpful to my parents [once we got connected]” (Fran). It is encouraging to orchestrators when they see staff trying their best to care for their parents and others, and they understand that professionals do not “have time to think about every single person ... at length” (Michelle). Orchestrators respect, admire, and are grateful for the work healthcare professionals

do and their expertise. They tend to trust the judgment of health care professionals, and “understand how challenging it can be” (Sara) for professionals to do their job. Orchestrators may say, “I give them all the credit in the world. Much needed and much appreciated” (Michelle).

Worries about health care professionals.

While they can be a source of support and assistance, health care professionals may also be a source of worry and frustration for orchestrators. Orchestrators may worry and wonder “have they (the health care professionals) had enough training to know that that’s not the whole person” (Sara)? Orchestrators also might feel that staff need training in how to interact with clients who have dementia/Alzheimer’s disease, because “some people were really good with her, some people we didn’t feel so good about ...” (Scott). They also worry that staff does not get support themselves. This concerns orchestrators because “you can’t take care of someone else appropriately if you’re not taking care of yourself” (Sara). Staff inconsistency also worries orchestrators. Consistent staff is more likely to see changes in the parent as they better know what is “normal” (Lisa) for him/her. It is also easier on the parent, because “if you change people [the professional caregivers], it changes everything for them” (Michelle).

Orchestrators also may feel disappointed at times by health care professionals when “you trusted people to do their job and to tell you the things that need to be told and they didn’t” (Lisa). “It’s like people don’t necessarily do a really good job in what they’re supposed to be good at” (Scott). For example, the orchestrator may feel “very disappointed in ...the communication from those who have the ability to communicate information” (Lisa). Orchestrator’s unmet expectations may include care plans not being carried out (e.g., a loved one receiving food not prepared in the consistency it is supposed to be, because staff members are

too busy, and the parent chokes as a result), professionals not performing “astute” (Jessica) assessments of the parent, and by personal items being stolen or not being taken care of properly (e.g., a broken picture frame being left on a parent’s bedroom floor where someone could step on it). Some may even hear that residents where their loved one lives at are being abused by the staff. Orchestrators may ultimately feel that some staff get burned out and only do the job for a pay check. They also worry that facilities and organizations are business-oriented, only out for a profit, and trying to charge as much as they can. As a result, they fear that there is a benefit for such facilities/organizations to keep their loved one alive, despite family and patient wishes. Orchestrators feel that “it really needs to be client-centered ... [and focused on] really, what does this person need” (Scott)?

Fulfilling the demands of the orchestrator role can be an emotional experience for orchestrators. Trying to determine the best way to care for the parent, and seeing the parent decline, may be a frustrating and upsetting experience for them.

“You’re Trying to Continue with Your Own Life and Not ... Affect It in a Negative Way”

The orchestrator role can be a large responsibility and commitment. As a result, orchestrators may have to juggle many different things in their lives to meet the demands of the orchestrator role and take care of their own personal needs and relationships

Relationship adjustments.

For orchestrators, caregiving can be a strain on a relationship with a partner or spouse because “my parents always come first” (Rose). Orchestrators may feel that they need to do things for their parents that interfere with doing things for their partners/spouses (largely due to time constraints). An orchestrator may also find that

... the boyfriend, he sort of understands, you know, it's a problem, but ... I don't know, he's not really interested in it, or maybe a little fearful of even talking about it or something. And not really sure about it. So it's not a total supportive thing there. (Bella)

Orchestrators and their partners/spouses also may grieve differently as they experience the decline of the orchestrator's loved one, and find that communication lessens between them. Thus, orchestrators must try and balance meeting the needs of their parent with the requirements of sustaining a relationship with a partner/spouse.

Looking at friendships, some orchestrators may feel caregiving has had "a huge impact" (Jessica) on their relationships with friends. While trying to meet caregiving demands, orchestrators may find their dynamics with friends changing. They don't want to "dump" (Amy, Bella) on their friends, so orchestrators might not talk about the orchestrator role with friends. Some orchestrators lose friendships (including long-term relationships) as friends do not understand that the orchestrator does not have time to spend with them. An orchestrator may also feel that not all of his/her friends want to hear what's going on with a parent, or that friends worry the orchestrator will "lose it" (Amy). Some orchestrators may say that, "People get tired of hearing it when it goes on like this," (Jessica) and "you know who you can tell and who you can't ... give your story to" (Lisa). They may feel that "my true friends are still hanging in there with me. ... You find out who's going to stand beside you and who's gonna be there when it's done and willing to reengage" (Jessica). Overall, orchestrators may find it difficult to try and sustain relationships with friends while meeting the demands of the orchestrator role.

With siblings, "sibling things come up" (Fran) when trying to handle orchestrator demands. For example, past disputes (perhaps emanating from factors like family dynamics and

perceived “favorites”- Fran- among siblings) can reemerge and cause challenges between orchestrators and siblings. There may also be different levels of involvement and communication between siblings, the orchestrator, and their parents. Some siblings and orchestrators might become closer and work together in the best interest of their parents, setting aside historical issues and recognizing and respecting the contributions all can make. Other orchestrators may have a “rocky” (Bella) relationship with their siblings, where different values and personalities can cause disputes and misunderstandings (e.g., disputes may arise over who should have power of attorney) as they work together to help their parents. Some orchestrators report that “there’ve been difficulties in the family. ... So many misunderstandings happen when it’s long distance, you’re not sitting together, and you’re not seeing things” (Rose). This is partly because there often are limited opportunities for orchestrators and their siblings to sit down and talk about what is happening with their parents and their parents’ wishes. Some orchestrators may find that the siblings least involved raise the most disputes. A “chasm” (Rose) can be created among siblings when arguments arise, and siblings can personalize things that happen (e.g., an orchestrator’s sister and brother-in-law may become upset when a parent requests the assistance of the orchestrator over them). Thus, orchestrators may say, “It’s put some real strain on it [their relationship with siblings]” (Rose). The perceived guilt of siblings not as involved, as well as the resentment distance caregivers may feel at having to do the majority of caregiving tasks, also can affect relationships between siblings. The orchestrator may feel that a sibling could do more, yet say, “I also understand where he is” (Jessica) coming from, and feel that the sibling is “grateful for what I’m doing cause he couldn’t do it” (Jessica). As a result, orchestrators may find themselves trying to manage their parents’ care while dealing with sibling issues that come into play.

Facing resistance from siblings and parents.

Orchestrators may find that it is difficult “trying to win the support of people who are there,” (Bella) such as healthy parents or siblings. For example, family members may resist trying interventions the orchestrator feels would be beneficial for the parents, or resist reading information on the disease provided by the orchestrator. Even discussing the care a parent needs can be a sensitive issue. Orchestrators may find that parents and siblings

... didn’t want to talk about the details, or didn’t quite understand what was going on. ...

They don’t want to admit she’s got Alzheimer’s, because they weren’t told that directly.

... They’re choosing to believe that it’s just a lot little memory loss that comes with

aging. ... They were a little ... resentful or maybe just ... didn’t want to hear it. ...

They’re not wanting to grasp onto, hey, we have an issue, lets figure out how to make the

best of it or how to work around it. ... There’s still that denial that says no, I’m fine, so

they don’t want to participate in anything that might be even more valuable at this time to

help keep the optimum brain health. So that’s frustrating. ... It’s really hard to get them

to take action to do it. (Bella)

Parents and/or siblings may be in denial and not accepting or dealing with issues that arise, and they may not access available resources or follow up on recommendations. An orchestrator may find that the caregiving parent “doesn’t want me to push too much stuff on him,” (Bella) and that siblings are not “embracing” (Bella) the fact or idea that a parent has cognitive problems. Resistance to resources may also come from parents if the parents are suspicious of people coming to help, or if they have a negative stigma or feelings of embarrassment related to things like meals on wheels, senior centers, and other resources. Different values and ideas can also cause differences in opinion on what should be done,

potentially causing disputes between orchestrators, parents, and siblings (e.g., over comfort care issues vs. pursuing treatments or over placement issues and where a parent should live). Thus, orchestrators have the challenge of

... trying to ... influence them (family members) to help and do things with and for mom that I think could help her have a better quality of life. And there's only so much I can do. ... I've been kind of prodding him [her father] to do some things to get a little more proactive about mom's condition, but I think he's thinking, oh, it's just a little memory loss, it's not a problem ... (Bella)

While trying to deal with conflicts that might arise between their feelings and the feelings of their siblings or parents, orchestrators may try to pass on what they learned and give parents and siblings suggestions "in little steps" (Bella). Orchestrators may say, "I try not to make it some sort of zealous effort to harp on them all the time about it," (Bella) and they try to be sensitive to how their family members may feel. They do not want to make their parents or siblings feel guilty. Instead, orchestrators

... just try to, from the background, get that going with a lot of resistance. ... I'm trying to get out information to share with them, I'm not just trying to tell them here's what you've got to do, or here's what happening. And I think they're a little more open to that. (Bella)

Instead of "trying to pressure them, ... [orchestrators] encourage them to do as much as they can (Fran)."

Orchestrators seem to recognize that the different values and personalities among siblings can result in different ways of handling caregiving situations (e.g., a sibling may choose not to be

involved in caring for a parent, or may be in denial about a parent's cognitive/physical status). Some siblings engage in conference calls and e-mails with the orchestrator to keep updated on their parents and to offer assistance, while others may have no or limited involvement. Levels of involvement and communication can change between siblings and their parents over time. For example, a sibling may begin "recognizing that there was need there and taking the time to fill that" (Bella) (e.g., bringing over meals to parents), or siblings might have started "seeing what they needed to do and pitching in as well ..." (Bella). When there is limited sibling involvement, orchestrators may provide many reasons for the lack of engagement. Reasons could include feeling the sibling leads a stressful life, is too busy with work or his/her own children and spouse, that he/she does not know how to assist the parent, or that he/she has not dealt with a difficult past and upbringing. Orchestrators may state things like,

My brother's extremely sensitive, ... so for him to even see my parents the way they are now ... it just tears him up. I mean he cannot emotionally handle very well what's happening ... [so] it's easier for him to just let me do it all. (Jessica)

Such sentiments may result in orchestrators adjusting how they interact with their siblings. For example, some orchestrators may reduce their contact with siblings, while others gain a new appreciation for what their siblings can do to assist their parent and interact more frequently.

Children.

Orchestrators with children also may find themselves adjusting how they interact with their children. After taking on the caregiving role, the orchestrator may have a tendency to be protective of his/her children. Orchestrators don't want to "dump" (Amy) on their children, and they may withhold information from the children on how the loved one with dementia/Alzheimer's disease is truly doing. When visiting their parents, orchestrators may feel

the need to keep a closer eye on their children to make sure the interaction is going well (e.g., that the parent with dementia/Alzheimer's disease is not being overly harsh with the child, due to the parent's confusion/dementia). The orchestrator might try and include older children in the caregiving role. This could include asking children to call the loved one with dementia/Alzheimer's disease on a regular basis, or even having them check on the parent (if the child lives nearby) and assist as needed. Finally, some orchestrators use caregiving as an example to their children of how people and families support each other. For instance, orchestrators may discuss the type of care they are providing with their children and how it helps the orchestrator's parents.

Life adjustments.

While fulfilling the orchestrator role, orchestrators might have to make adjustments in their lives, largely because "it's a time thing" (Bella). The orchestrator may find himself/herself spending more time on the phone and the computer, monitoring and arranging the care of a parent; or taking more trips to see his/her parents. Orchestrators may have less time and energy for connecting with friends, so they do not see them as much, or they might not feel like doing leisure activities they usually enjoy. Some may state they "needed to create some space so I could get out there" (Kristen) to see their parents, and will adjust personal plans as needed (e.g., one may put work and school plans on hold to be with his/her parents and help as much as possible). Many orchestrators try to be more available for their parents. For example, they might answer phone calls at inconvenient times when ordinarily they would have ignored them. Orchestrators may say this is because,

It wasn't a high priority [in the past], and now ... I do [answer the phone] because, oh, it could be my dad, or it could be a caregiver ... so I try to be more cognizant. ... So it's on my mind that I might [need to] be available ... (Sara)

Many orchestrators will find a way to get to their parent "in a heartbeat" (Kristen) if they are needed.

The orchestrator might also find that vacations "revolve" (Michelle) around seeing his/her parents, which can be difficult. This can result in feeling like, "that's kind of getting old; I'd like to go do something else" (Michelle). "It's just kind of a given, when we go down there we do things to help ... that ... [is] a strain, cause it's kind of like, I'm tired. I want a vacation" (Rose)!

Career changes.

One's career might also be affected by taking on the orchestrator role. A career might be held up by having to frequently travel back and forth to assist parents, necessitating having a flexible job so the orchestrator can travel to see a parent when needed. This may prohibit the orchestrator from exploring promotions or job advancements, or from taking on additional projects at work. Other orchestrators might lighten their work-load. As a result of all this, they may say, "It's affecting my career choices. So, it's a big deal" (Jessica). Overall, life adjustments are felt to different degrees. Some say the orchestrator role has "been pervasive in my life, so it's not like it's been a change," (Scott) or "I haven't had to really adjust my life all that much. I am able to call them every day ...[with] cell phones ... you can always talk" (Fran). "I always have my cell phone, they can reach me if there's a problem and so I can still come and go and do everything the same way" (Michelle). Other orchestrators can feel that, "basically my life has

been put on hold. ... My life is not my own right now. ... That's just the way it is right now. I don't see anything else I can do differently" (Jessica).

Living their own lives.

Orchestrators ultimately must juggle meeting the demands of the caregiving role with other demands placed on them (e.g., work or parenting demands). They have their own life to run, in addition to performing caregiving tasks, and may feel like, "You're trying to continue with your own life and not ... affect it in a negative way" (Michelle). This can be challenging for orchestrators, who may report that "you don't take care of yourself," (Amy) partly because there is not enough time. They may say,

I'm so exhausted. ... I don't do the things that I know ... help me stay healthy because I'm too tired. I don't make regular meals because it's just too hard. ... There's only so much of me that I can spread around ... I have responsibilities to work and I have responsibilities to my parents, there's no time for me. I'd like to be dating. I'd like to be having a social life, and I can't. I can't. There's just no time. There's no time. (Jessica)

Some orchestrators feel that "it's a huge commitment, it's like your whole life is put on hold to be a caregiver" (Amy). One's physical health (e.g., due to not eating right or exercising) and lifestyle (e.g., going out with friends or engaging in leisure pursuits) also may be harmed. For example, orchestrators may say, "It has impacted my health. I don't sleep a lot of nights. I worry about them [my parents]" (Rose). Orchestrators might find they have more headaches, decreased sleep (e.g., they may say, "I was not getting a lot of rest cause I kept mulling everything over in my mind about what we can do to fix things"- Michelle), weight gain, or that they are continually worrying about their parents and what they could/should be doing to help their

parents. Thus, taking on the caregiving role may result in orchestrators not adequately fulfilling personal or professional roles.

Orchestrators also have tough decisions to make in their lives as they try to balance the multiple roles they have in life (e.g., that of spouse, friend, parent, or employee). These could include determining when to visit their parent, and making decisions regarding placement issues for the parent (e.g., when and where to move a parent). Orchestrators want to feel good about what they decide, but frequently discover that there are no easy answers. Some report the greatest challenge as a distance caregiver is dealing with

the decisions, the choices about how much to do, which for me is mostly how to plan my trips to go there and I am always feeling torn. ... I still have a hard time balancing out sort of, what's the right amount, how much. ... How do you decide how much to go out and visit? How does anybody decide that? I don't know, that to me is the main challenge.

(Fran)

Orchestrators may say, "I want to do the right thing for my parents, but there's no perfect solution, that's for sure"(Michelle). Factors in making decisions can include time (mostly the lack of it), other role demands (e.g., work), and finances and expenses. Finances can be a big issue for orchestrators. Some orchestrators can spend as much as \$10,000 in one year on various caregiving costs, including monitoring and managing care and travel expenses (including hotel, airfare/gas, and food costs). Orchestrators report trips may be more expensive if they are going on short notice (which might happen, for example, if a parent falls or is hospitalized), and they may not get paid time off from work to visit and help parents. Such constraints may limit how often an orchestrator can go out and visit. They may report, "I would do some additional visits,

probably, if money weren't a consideration" (Sara). Orchestrators also must take into account their own personal and emotional needs when determining when and how often to visit their parent. Based on what they decide, orchestrators must make life adjustments (e.g., going to visit a parent could mean less time at work or less time being a supportive spouse/partner).

Overall, it is difficult for orchestrators to try and run and maintain their own life and respect their parent's wishes when other crucial life events surround them (e.g., a sibling's terminal illness, a son's Bar Mitzvah, and marital problems). Orchestrators may say,

It's really difficult trying to navigate your parents through this part of their life ... they need your help and you're trying to do it the way they would want it and at the same time you're trying to continue with your own life and not ... affect it in a negative way.

(Michelle)

A new perspective.

While trying to meet the various demands placed on them, orchestrators may find they have a different perspective of their lives and the factors that comprise it, including work, material objects, and relationships. They may reprioritize their lives, and say "it is just the importance of whatever there is, or it's just today. Just live today and then we'll move on to tomorrow" (Lisa). Instead of becoming stressed and overwhelmed, they may say, "It is what it is. ... I'm not perfect and I don't know how to do this. ... I try to keep my eyes on what's good and do the best that I can" (Amy).

Moving the parent.

Trying to ensure that their parent is receiving the appropriate care while living hours away might become too challenging for orchestrators. This could be the result of poor communication with health care professionals, or it might become too time consuming or

expensive for the orchestrator to provide care from a distance. Other orchestrators may move their parents closer to them if the parent refuses necessary hired help, or if the family deems it unsafe for the parent to live alone. Therefore, some orchestrators may feel that moving their parent closer to them is the best option. They may say,

I ended up moving them out here [where I live] because of the fact that it was one, too expensive. I couldn't manage their care 2,000 miles away. Two, I had to lay eyes on them to know what was really going on, because what I would hear from my mother was real different from what I'd hear from staff or medical people. ... It wasn't workable, I couldn't do it. (Jessica)

Taking on the orchestrator role may mean numerous life adjustments for orchestrators, including changes at work and with personal relationships. The paths orchestrators choose may be directed by new perspectives they have on life, and how they can best meet the needs of their parents while still living their own lives.

Chapter Five: Discussion

The intent of this chapter is to summarize findings from my study, and to relate the findings to theory. Recommendations for future research are also discussed.

Summary of the Current Research Study

The current study was undertaken to better understand the lived experience of caregivers for people with dementia/Alzheimer's disease who live two or more hours away from the care receiver. There has been research conducted on caregivers of people with dementia/Alzheimer's disease, and on distance caregivers, but little has been explored on the specific caregiving population of distance caregivers for people with dementia/Alzheimer's disease. I chose a qualitative, phenomenological approach, which I deemed the most appropriate approach to explore the experiences of some members of this caregiving group. All 10 participants were caring for a parent with dementia or Alzheimer's disease, thus the transferability of results would apply only to children who are providing care from a distance for a parent(s) with Alzheimer's disease/dementia.

Participants in the current study reported that poor communication with health care professionals and/or family members can be a source of frustration for them. Lack of communication, or not being completely informed on how a parent is functioning, inhibited participants at times from adequately fulfilling caregiving demands. Participants also reported that they spend a great deal of time on the computer and phone, arranging and monitoring the care of their parents, and many participants found that they have grown closer to their parents (including healthy parents providing care) throughout the caregiving journey. Depending on sibling involvement and willingness to assist in meeting caregiving demands, siblings also were noted by participants to be a source of support and assistance in completing caregiving tasks, or a

source of frustration and resentment towards others (e.g., when the sibling does not help with caregiving tasks).

Many participants had to make adjustments in their personal and professional lives to fulfill the caregiving role, including decreasing work hours and spending less time with friends. Taking time to inform and educate health care professionals on the parent with dementia/Alzheimer's disease was also important for many participants. This included talking with the professionals about the activities and items the parent formally liked and enjoyed (e.g., the parent liked drinking Coke and enjoyed cooking), so professionals might be better prepared to understand and engage with the parent. Overall, the caregiving journey was an emotional one for participants. This included experiencing stress, frustration, worry, and guilt (these are similar to those emotions discussed by Dang et al., 2008, in their writing about distance caregivers). The caregiving experience led many participants to grow personally and professionally as they tried to assist their parents. For example, some participants reported they learned how strong they could be in difficult and challenging situations, and that they wanted to focus professionally on the dementia/Alzheimer's population. Thus, based on information from participants in the current study, the distance caregiver of someone with dementia/Alzheimer's disease appeared to have many demands placed on him/her that led to life adjustments, relationship changes, and personal growth.

Linking Theory and the Current Research Study

To thoroughly understand and interpret my research findings, it is necessary to critically consider how the results can be applied to current information in the literature and to the study's theoretical basis.

Role theory.

Goode's (1960) role theory was the theoretical basis used in my study. In my research, I explored how the fulfillment of the caregiving role, or the orchestrator in the background role as I have titled it, affected other roles this study's participants had. The role of employee was frequently altered as participants cut back on work hours, or had to turn down potential promotions and job advancements. Less time was devoted by some participants in fulfilling the role of spouse or romantic partner as they focused on providing care to their parent(s). For those with young children, the parenting role changed. For example, one participant stated she becomes more protective of her child when the child is around her father (who has dementia/Alzheimer's disease). Different approaches were taken by participants when discussing their loved one who has Alzheimer's disease/dementia with their children. This included withholding information regarding the child's grandparent who has dementia/Alzheimer's disease, or using the caregiving experience as a way to teach their child about helping others. The role of friend seemed to be the most altered role, as many participants reported having less time and energy to devote to their friends. Friendships were lost or the closeness decreased between participants and their friends, and many participants feared they spend too much time talking with friends about their parents and caregiving demands. Another changed role was that of self-care. Some participants felt they have no time to do things to support themselves, including engaging in leisure pursuits (which could include spending time with friends), exercising, getting adequate sleep, or eating properly.

Role theory assists in looking at the perceptions and attitudes people have towards their roles (Brookes et al., 2007). Many of the participants in the current study wanted to help and be of service to their parents. They wanted to give back to their parents and be there for them, reciprocating what their parents have given them in the past. Some participants also appeared to

feel a sense of obligation to provide care for their parent, whether it was to ease guilt or because no one else was available. Most participants deemed the caregiving role as demanding and challenging, but considered it to be an important role in their lives that has had some positive aspects. Things they gained included: a new perspective on what is or is not important in life (e.g., valuing relationships with others over material objects), a closer relationship with their parents, and increased personal strength and resourcefulness.

Role strain.

When I looked at role strain, which Fairbanks (2005) noted has been associated with role demand overload, it seemed to me that research participants who perceived having great demands placed on them felt more strain and stress from the role. Participants also reported role strain when they were unable to fulfill all the demands of the role in the manner they would like. For example, one participant reported she has tried to get her father to take her mother (who has dementia) to an exercise class at the gym. He declined to do so, and she felt stress and frustration that she is not with her mother and able to do such things herself. This is similar to what Goode (1960) mentioned, in that role strain can occur when one is unable to accomplish or is having difficulty accomplishing all of the demands various roles place on him/her. This also relates to role overload, when possibly the demands placed on someone exceed what he/she is able to do (Brookes et al., 2007; Fairbanks, 2005; Mui, 1992). This particular participant, living over 8 hours away, simply could not take her mother to gym class on a regular basis.

Many participants also mentioned that they would be able to do more, and visit more, if they had more time and resources like finances. Lack of time can be the result of other role obligations a person might have, such as having to be at work, that prevent him/her from assisting and visiting a parent more. Finances, in multiple ways, impacted how much assistance

participants provided. For example, the participant might have to be at work to get paid, and he/she might not be able to afford reducing work time to visit a parent or to take care of caregiving demands. There also are the financial costs involved with traveling, such as airfare and lodging, which must be considered.

Psychological conflict.

Psychological conflicts also might arise while fulfilling caregiving role demands. For example, conflict can occur in someone when behaving the socially anticipated way to fulfill one role conflicts with another role (Edwards et al., 2002; Mui, 1992). In this study, conflict occurred for some participants when fulfilling the demands of caregiving took time away from their time with friends and spouses/partners. In some cases, this resulted in conflict or distancing between participants and friends/partners/spouses. There also was psychological conflict between participants and healthy parents and siblings when ideas and suggestions the participant had were dismissed or not implemented by those family members. Participants may be torn between understanding that there is only so much they can do being at a distance, trying to respect what healthy parents and siblings are willing and able to do, and wanting the parent with dementia/Alzheimer's disease to have the best care possible. Finally, another conflict which participants had included wanting to help their parents out as much as possible, while desiring to take vacations, go out with friends, and spend time on other personal leisure pursuits and interests. In other words, they wanted to live their own lives too, and not have caregiving dominate their lives. Trying to balance that desire, while making sure their parents' needs are being met, was a difficult task. This related to Goode's scarcity hypothesis, which states that the limited resources available to a person (e.g., time, emotional resources, or physical resources) might not be sufficient to fulfill all of their role obligations. (Fairbanks, 2005, & Mui, 1992).

Thus, emotional, physical, vocational, social, and financial demands and stresses affected how participants fulfilled caregiving demands (Mui, 1992).

Personal expectations.

Participants also had expectations and ideas of how they were supposed to fulfill the caregiving role. For some, it meant calling their parents on a regular basis to check in and see how things were going. Other participants chose to take a more active role, including visiting their parents more often and conducting personal research on Alzheimer's disease/dementia and what they could do to help their parents. The path a participant took seemed to be based on how they personally viewed their role as the son or daughter of someone who has dementia/Alzheimer's disease, and their perspective of what taking on that role entailed. Those participants who took on a more active role appeared to put greater demands on themselves, and reported feeling more strain or pressure as a result of taking on the caregiving role. Participants might have felt strain when they were unable to fulfill the caregiving role to their satisfaction. Brookes et al. (2007) and Hogan et al. (2003) mentioned how an inability to perform a role in a matter that meets one's expectations, or society's expectations, can result in role strain and conflict. In terms of societal expectations, a few participants reported feeling pressure and strain from health care professionals and the expectations of health care professionals. Examples included being told that the parent needed to move in with the participant, and that the participant needed to reconsider the decision not to implement an expensive oral care regime. In these cases, the participants seemed to feel guilt and a sense of having been judged. In addition, some participants experienced role ambiguity. They were unsure of what exactly needed to be done, or how to fulfill their parents' needs, and did not feel they were getting enough information and support from health care professionals and/or family members. Brookes et al. (2007) discussed similar role ambiguity.

Role combinations.

The combination of roles each participant had also impacted how they met caregiving demands. The obligations various roles placed on them impacted the stress participants felt, an idea discussed by Goode (1960). For example, participants with flexible, part time jobs did not seem to feel that their career was impacted by the caregiver role, or that their career impacted their ability to provide care. Those with full time jobs seemed more likely to take their career into account when dealing with caregiving demands (e.g., when a participant needed to determine his/her ability to take time off work and go visit a parent), and more likely to feel that each role affected the other. For the role of the role of partner/spouse, those participants who appeared to have a strong relationship with a partner/spouse seemed to get support, advice, and reassurance from that person. Those who were single did not always have that support, and one participant reported having the desire to have such a relationship, but felt that she/he did not have the time due to providing care and work demands. Thus, the role of spouse/partner versus being single may positively or negatively impact a person's performance of his/her caregiving role. Marks and MacDermid (1996) discussed how roles can positively or negatively impact each other. Similarly, these factors can lead to the role stress and strain discussed in Goode's role theory, as discussed by Brookes et al. (2007). Goode (1960) noted that the choices a person makes after encountering role strain may enable him/her to function well or poorly overall, and that the overall collaboration of roles and role bargaining determines outcomes. Thus, the different values and ideas a person has regarding his/her roles and role obligations will affect the decisions he/she makes. This was reflected in the various ways participants fulfilled the caregiving role. Some seemed to place the role above all others, and did whatever caregiving task needed to be done. Other participants balanced the caregiving role more with other roles,

such as that of spouse or employee, and completed whatever role demands were most pressing or relevant at the time.

As Goode (1960) also noted, certain roles must be performed to fulfill the demands of other roles. To fulfill the caregiving role, most participants needed to work in order to have the financial resources to travel and visit/assist their parents, and they might have to personally pay for hired care or their parents' personal affects (e.g., clothing). Goode (1960) further noted that factors beyond a person's control also may direct or dictate that a person fulfill a role a certain way. In the context of this study, the distance factor appeared to be the main uncontrollable factor affecting the caregiving role. Participants were not able to provide the hands-on care they wished to provide, and, as a result, communication with others involved in the parent's care (e.g., the healthy parent, hired health care professionals, or siblings) became extremely important. Such communication was essential so the caregiver could understand what was going on with the parent and what needs the parent might have had.

Role bargaining.

The caregiver role requires various physical, mental, and emotional resources, as many roles do. Fulfilling such a role usually requires several actions and responses to take place (Goode, 1960). This was experienced by some participants. For example, one participant received a phone call from the nursing home facility of which her parent resided, stating that they wanted her mother to start physical therapy. This required the participant to talk to siblings, to talk to nurses/aides at the facility, and to do research on physical therapy and how it could potentially help her mother. Providing such care can take resources and energy away from fulfilling other roles (as Goode, 1960, mentions, meeting the demands of one role may result in being unable to fulfill the demands of other role). For example, the participant (or any distance caregiver) might have had less time to spend with her children or friends, or less time to devote

to work tasks as a result of fulfilling caregiver demands. According to Goode (1960), role bargaining will occur in such situations in an attempt to overcome role stress and strain. In role bargaining, one determines where to allocate his/her energy and resources to complete various role demands (Goode, 1960). In this study, participants used their resources to the best of their abilities to meet role demands and obligations as much as possible (a concept discussed by Goode, 1960). They did as much as they could to fulfill the caregiving role while trying to fulfill the other roles in their lives. According to Goode (1960), people react to the various demands placed on them with the ultimate goal of keeping role strain as low as possible. In the current research study, participants had various ways of adapting to meet role demands. For example, some participants tried to share or pass on caregiving demands to others, such as siblings, in an effort to ensure that their parent received quality care and that they (the participants) were not being overstretched. It was also apparent with some participants that, as their parent's health declined, more assistance was required of them, resulting in further adjustments that had to be made. For example, one participant mentioned during her follow-up interview that her mother had declined to the point that the family was now looking at nursing home options for the mother. As a result, she decided she was going to put all work related plans on hold and leave her summer open for assisting her mother with that transition.

Goode (1960) noted that situational factors can affect how one uses his/her energy and resources for role demands. In the current study, participants appeared to look at how their parent was currently functioning and provide care based on their assessment. For example, some visited more frequently, or arranged for more hired help for the parent, when the parent exhibited greater signs of confusion and difficulty functioning. Societal and organizational structures also impacted the type of care participants provided. For example, some participants that had parents

residing in a nursing home felt the need to provide more or less care based on the perceived quality of care provided at the facility (Goode, 1960, discussed how societal and organizational structures can impact role performance). Those who felt the care their parent was receiving was not as high quality as it could be seemed to check in on the parent more frequently, and some participants were in the process of exploring other placement options.

Personal norms and values.

Goode (1960) mentioned how norms and values placed on roles may direct a person to behave a certain way. This was possibly evidenced by participants in the current study defining their caregiver role as being a daughter/son, and by how they defined their role obligations (e.g., some felt they had to be extensively involved in monitoring/arranging the care of their parent, while others were not as involved). Some participants also reported that they grew up providing care to family members, and that caregiving had been an integral part of their lives. Such beliefs, values, and experiences may have impacted how participants viewed the caregiving role and the way in which the role is to be fulfilled. A few participants seemed to feel it was an honor and a privilege to give back to their parents, and they placed the role above other roles, such as employee or friend. Furthermore, most participants appeared to find the caregiving intrinsically motivating and/or valuable. This is consistent with the fact that, in general, people are more likely to perform roles that they find valuable or intrinsically motivating (Goode, 1960; Libbey & Carlson, 1973).

Family members and role allocation.

The impact of family members also affected how roles were allocated for participants (Goode, 1960, discussed how family members can affect role allocation). For example, some participants had siblings and/or a healthy parent that actively assisted with caregiving demands. This resulted in less caregiving work for those participants. While all participants had at least one

sibling, the siblings of some participants were not actively involved, or the spouse of the parent with dementia/Alzheimer's disease had passed away. This seemed to lead to increased caregiving demands for those participants. The impact of participants having a significant other/spouse and/or children also was evident during participant interviews. In most cases, the spouse/significant other was a source of support, and he/she frequently assisted the participant with caregiving demands, and/or with making caregiving decisions. As role obligations are usually linked to family members, systems, and subsystems (Libby & Carlson, 1973), the participant's immediate family (e.g., spouse/partner and children) also resulted in some participants having less time for fulfilling caregiving demands. For example, participants often had to stay home and take care of their young child instead of visiting their parents. Finally, Goode (1960) noted that family members are important to consider when looking at role strain because it is very difficult to formally withdraw from a family role like daughter, son, mother, or father. This may mean that some participants felt that they have no choice but to provide care, no matter what type of past they had with the parent (e.g., if the participant was physically/emotional abused by the parent), or what other demands they had placed on them. This may have increased the stress and strain they felt.

Dealing with role strain.

When looking at how people might deal with role strain, Goode's role theory (1960) discussed several options. The first possibility is compartmentalization. Compartmentalization includes setting aside a role demand based on the context and urgency of the demand and situation. Looking at participants in this study, the manner in which caregiving demands were met seemed to be based on what the current situation was. For example, when one participant heard that her mother fell and was in the hospital she set aside everything else and flew to be with her mother. Others saw caregiving as a "project" (participant "Bella's" word), and

incorporated it into their weekly routine as needed. It can be assumed that, if something more pressing comes up at work or in another area of that participant's life, the "project" will be put aside. On the flip side, caregiving will likely become the top priority for that participant if an unexpected accident or event occurs with the parent. Delegating role demands is another way in which people might deal with role strain. In this study, participants delegated roles by hiring professional assistance, or by requesting that a sibling become more involved or take over a certain aspect of the caregiving role. Role elimination, another method of dealing with role strain discussed by Goode (1960), was used to a small extent by participants in this study. While no participant appeared to outright surrender a role, some reduced their work hours so they could be more available to provide care to their parent. Others found their role of friend reduced (e.g., they were not able to spend as much time with friends), or that they were unable to pursue a romantic relationship due to limited time.

In conclusion, Goode's (1960) role theory applied well to my current research study. The theory served as a valuable guide while I interpreted my data from participants.

Surprises to the Researcher

I was surprised to learn how important supporting healthy parents providing care was to participants in my study. While I anticipated that discussing the caregiving journey would be emotional for participants, I was not expecting it to be as emotionally intense for them as it appeared to be. Many teared and cried during interviews. It also was a surprise to hear how important it was for participants to discuss with healthcare professionals what their parents were like before dementia set in. I also was not expecting to hear about such rapid decline in the participants' parents (and death in one case) between the initial and follow-up interviews. Such a finding seems to display how challenging the distance caregiving experience can be on multiple levels (e.g., it is difficult emotionally to see the parent decline and difficult to continually arrange

for more care). In addition, I was shocked when a few participants discussed how health care professionals made them feel guilty and “poured on” (participant “Lisa’s” word) the guilt. This was a sad and unexpected finding for me. I also did not expect to hear about the importance of quality of life over quantity of life as much as I did from participants. Many reported they do not want their parent with dementia/Alzheimer’s disease to live in their current state much longer. It even was mentioned by one participant that, after seeing what her parents have faced as they age, she is more afraid of living too long than dying too young. This was a completely new perspective for me. I have always been afraid of dying young, never of aging.

It also was interesting to observe the difficulty many participants had in talking about the hopes and fears they have for themselves. They had a much easier time talking about the hopes and fears they have for their parents, and frequently included those in their answer to the question “What hopes and fears do you have for yourself?” Furthermore, it was fascinating to me that, after being asked about the hopes and fears they have for themselves, some participants specifically said they fear getting Alzheimer’s disease while others stated they do not fear developing the disease. Finally, I had not anticipated how truly emotional it would be for me as the researcher to listen to the participants’ journeys and to analyze their data. I found myself (and continue to find myself) being able to relate to statements and revelations participants made whenever I think about my grandmother who has dementia/Alzheimer’s disease. Overall, my research journey educated me (as it hopefully will others) on how difficult being a distance caregiver to someone with dementia/Alzheimer’s disease can be, and on how health care professionals can better assist this population in providing care to their loved ones (e.g., initiating more communication with these caregivers and making sure good support and respite systems are in place).

Implications for Practice

The results of this study may assist health care professionals in providing more effective interventions to those with dementia/Alzheimer's disease. Based on data from the participants, health care professionals might want to take more time to work with family members of people with dementia/Alzheimer's disease. Family members can provide valuable information about the client with dementia/Alzheimer's disease to health care professionals, including that client's likes and dislikes and details about his/her past. Such information can better help health care professionals understand the needs of someone with dementia/Alzheimer's disease, and perhaps shed light on behaviors they may exhibit. For example, the person may have always taken baths in a tub, and may resist or fear taking a shower, as it is not what he/she is accustomed to doing. It is also important for health care professionals to take into account all family members- whether they live near the client with dementia/Alzheimer's disease, or on the other side of the country. Even at a distance, family members might be able to provide valuable assistance, support, and information to the health care professional and the person with dementia/Alzheimer's disease.

Many participants from the study also discussed quality of life issues. Health care professionals must discuss and respect family member's decisions regarding quality of life issues for their loved one, and what they believe their loved one with dementia/Alzheimer's disease would have wanted (e.g., quality of life, not quantity of life). Discussing such issues with all involved, as soon as possible, might make difficult decisions (e.g., whether or not to insert a feeding tube) easier down the line. This relates to another issue participants struggled with: respect. Health care professionals need to respect the decisions family members make, and not judge or question them. Participants also wanted to make sure health care professionals respect the loved with dementia, and treat them as a person. Health care professionals need to do whatever they can to respect those with dementia/Alzheimer's disease and their family members.

This includes understanding what family members are willing and able to do for their loved one, which is largely based on family members' personal lives and the demands placed on them.

Communication between health care professionals and family members is essential in order to have such an understanding develop. An important part of this communication can be the health care professionals educating family members/caregivers on resources and supports available (e.g., support groups or adaptive equipment). Health care professionals must communicate with distance caregivers, and anyone involved in the care of the person with dementia/Alzheimer's disease. Such communication can help prevent problems from occurring or escalating, and help ensure that the needs of the client with dementia/Alzheimer's disease and their family members are being met.

Transferability of the Findings & Ideas for Future Research

Readers need to keep in mind that this current study had only one male participant, and that all participants were sons or daughters providing care to a parent. All of the participants had siblings. Those who have no siblings, or whose siblings have passed away, may have a different perspective on their distance caregiving situation and may face unique challenges. For example, maybe adult children without siblings move their parent(s) closer since it is more likely no one else is involved in the parent's care. Such ideas were not explored in the current study.

Furthermore, the majority of participants worked in health care in some capacity (e.g., nurses, physical/occupational therapists, or psychologists). They likely viewed the caregiving experience differently than someone not working in healthcare would. For example, many participants reported they would not know what questions to ask health care professionals, or what signs of decline to look for in their parent, if they did not have a healthcare background. Furthermore, it is possible that those in the health care field have more altruistic tendencies and a stronger desire to help others when compared to the average person. Thus, they may be more likely to take on the

distance caregiver role and to have a better idea of how to support themselves and their parents when they take on the role. One of the primary methods of obtaining participants, that of contacting and speaking at support groups, also may have resulted in a unique set of caregivers who perhaps take a different approach to caregiving and have a different view on the caregiving situation when compared to those who do not attend them. This could perhaps limit the transferability of the findings, so that they may not be applicable to other distance caregivers, with other types of personalities and circumstances.

In addition, the stage of the disease the parent with dementia/Alzheimer's disease was in was not specifically taken into account in this study. This might be a further area to address, as those with parents towards the end stage of the disease might be facing more challenges while trying to provide care from a distance (e.g., having to arrange more care for the parent, and possibly having more psychological conflict at not being geographically closer to the parent). It also is important to note that the phenomenological, qualitative approach of this study limits generalizability. It can shed light, however, on the various challenges that this specific caregiving population may face. For example, given the nature of dementia/Alzheimer's disease, there is usually a consistent decline that may occur over an extended period of time. This may require the caregiver to increase consistently the amount of care they are providing (or to arrange for others to provide more care). It also is difficult for distance caregivers of people with dementia/Alzheimer's disease to know what is truly occurring due to the care receiver's cognitive deficits.

Overall, this study can be used as a stepping stone for future research exploring this caregiving population, and for possibly looking at how the current findings relate to distance caregivers of other populations (e.g., to those with Parkinson's disease). Another area to research

includes how the experience of distance caregivers of people with Alzheimer's disease/dementia differs, or is similar to, caregivers providing care locally to someone with dementia/Alzheimer's disease. Looking at the effectiveness of various communication methods (i.e., e-mail, phone calls, texting) between distance caregivers of people with dementia/Alzheimer's disease and health care professionals may also be of benefit. Furthermore, researching the benefits of having such caregivers fill out a life-history form on the care receiver could also be helpful. Having such a life-history form was recommended by a participant in this current study. The form could have information such as what the care receiver likes to eat and drink, what he/she did for a living, his/her preferred nickname, and the names/locations of family members (e.g., spouses, children, grandchildren, brothers/sisters, parents) with their contact information. Having such information could possibly help health care professionals provide more effective care and better understand the care receiver and how to relate to him/her, whether the care receiver lives at home or in a facility.

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Table 1

Participant Demographics

Age	Gender	Marital status	Employment status	Health care background	Distance in hours by car	Care receiver lives
51	Female	Married	Full time	Yes	>8	Home alone
56	Female	Married	Full time	Yes	Between 6.8 to 8	Assisted living
53	Female	Relationship	Part time	Yes	> 8	Home with spouse
57	Female	Married	Part time	No	> 8	Nursing home/assisted living
43	Female	Married	Part time	No	>8	Home with spouse
57	Female	Single	Full time	Yes	Local, Was >8	Nursing home (home alone at a distance)
53	Female	Relationship	Full time	No	>8	Home with spouse
53	Female	Married	Part time	Yes	>8	Nursing facility
54	Female	Married	Part time	Yes	>8	Home with spouse
57	Male	Married	Full time	Yes	Local, Was >8	Nursing home (home alone at a distance)

Length of time providing care	Approximate hours spent each month in caregiving role	Caring for
4 years	8	Father
6 years	20	Mother
2 years, 6 months	5	Mother
3 years	5-6	Father & mother
3 years	4	Father
1 year distance, 3 years local	48	Father & mother
2 years, 3 months	40	Mother
12 years	60	Father
2 years	12	Father
12 years	4-6	Mother

Table 2

Resources for Caregivers

Chart 1: Internet Resources for Alzheimer’s Disease and Related Dementia Caregivers

Administration on Aging	www.aoa.org
Alzheimer’s Association	ww.alz.org
Alzheimer’s Disease Education and Referral Center	www.alzheimers.org
America Association of Retired Persons	www.aaro.org
Area Agencies on Aging	www.aoa.dhhs.gov
Caregiving Online Community	www.caregiving.com
The Caregiver Zone	www.thecaregiverzone.com
Eldercare Locator	http://www.aoa.gov/naic/elderloc.html
Family Caregiver Alliance	www.caregiver.org
National Alliance for Caregiving	www.caregiving.org
National Council on Aging	www.ncoa.org
National Family Caregivers Association	http://www.nfecares.org
Well Spouse Association	www.wellspouse.org

Table 2 (continued)

Chart 2: Reference Books for Alzheimer's Disease and Related Dementia Caregivers

Callone, P., Kudlacek, C., Vasiloff, B., Manternach, J., & Brumback, R. (2006). <i>A caregiver's guide to Alzheimer's disease: 300 tips for making life easier</i> . New York: Demos Medical.
Cone, W. (2004). <i>Caregiver bible: Managing behavior problems in the elderly</i> . Pacific Palisades, CA: Matteson Books.
Lewis, Z. (2008). <i>I hope they know . . . The essential handbook on Alzheimer's disease and care</i> . College Station, TX: Virtualbookworm.com.
Loverde, J. (2000). <i>The complete eldercare planner 2nd edition: Where to start, which questions to ask, and how to find help</i> . New York: Three Rivers.
Mace, N., & Rabins, P. (2006). <i>The 36-hour day 4th edition- A family guide to caring for people with Alzheimer's disease, other dementias, and memory loss in later life</i> . Baltimore: The Johns Hopkins University.
Morris, V. (2004). <i>How to care for aging parents</i> . New York: Workman.
Schultz, R. (Ed.). <i>Handbook on dementia caregiving: Evidence-based interventions for family caregivers</i> . New York: Springer.

Appendix A

Letter for Locating Participants

July 13, 2009

Miss. Janet Aiken

Peachwood Inn Nursing Facility

511 Knobcone Dr.

Fort Collins, CO 80538

Dear Miss. Janet Aiken:

I am writing to inform you of my research study looking at caregivers of people with Alzheimer's disease or related dementia. My hope is to explore caregivers who are providing unpaid care, including those monitoring or arranging care, to someone with Alzheimer's disease or dementia from a distance. To be eligible, participants must live at least two hours or more away from the person they are providing care to and have been providing care of some type for at least 6 months. Participation in the study will involve 2 interviews, approximately 60 to 90 minutes each. Interviews will be done individually. Initial interviews will be done in person at a place chosen by the participant. Follow-up interviews will be done about a month after the initial interview and over the phone. Interviews will focus on the overall experience of distance caregiving for someone with Alzheimer's disease or dementia, including the challenges and struggles they have faced. I would like to provide you with a flyer detailing my study to display and pass out as you are able. It will have my contact information for potential participants to contact me. The results of my study may provide facilities like yours with ideas of how to best

Appendix A (continued)

help your residents and their families. Thank you so much for your time and consideration.

Please feel free to contact me if you have any questions or concerns. I look forward to speaking with you soon!

Sincerely,

Megan Edwards, M.S., OTR and Colorado State University, Ph.D. Candidate

(970) 420-7998

lomnic@aol.com

Appendix B

Phone Call Outline for Potential Participants

1. Explain the Purpose of the Study
 - a. To gain a better understanding of the lived experience of distance ADRD caregivers
2. Determine Participant Eligibility
 - a. Lives two hours or more away from care receiver
 - b. Has been providing unpaid care to someone with ADRD for 6 months or more
3. Determine Willingness and Ability of Potential Participant to Participate
 - a. Requires filling out a caregiver questionnaire
 - b. Requires an initial interview at a place of his/her choosing
 - i. Will likely be 60-120 minutes long
 - ii. Interview will be audio recorded
 - c. Requires a second interview to be done over the phone
 - i. Will likely be 30-60 minutes long
 - ii. Will be conducted about a month after the initial interview
 - iii. Interview will be audio recorded
 - d. Results will be published
 - i. Participant confidentiality will be maintained by using pseudonyms and information that could possibly identify the participant will not be used

If Willing to Participate

- Get participant's e-mail address or home address to send questionnaire
- Arrange location and time to meet for initial interview

Appendix B (continued)

In Unable to Participate

- Obtain reasons why he/she is unable to participate, if possible
- Thank him/her for their time

Appendix C

Caregiver Letter and Questionnaire

July 13, 2009

Ms. Jasmine Irvin

511 California

Fort Collins, CO 80528

Dear Ms. Jasmine Irvin:

Thank you very much for agreeing to participate in my study of distance Alzheimer's disease and dementia caregivers. Attached is a questionnaire regarding your background and the background of the person you are caring for (the care receiver). You can mail it back to me at your convenience in the return envelop provided, or bring it filled out when we meet for our first interview on ____ (date), ____ (time), at ____ (location). Please contact me if you have any questions or concerns. Thanks again!

Sincerely,

Megan Edwards, M.S. OTR and Colorado State University, Ph.D. Candidate

(970) 420-7998

lomnic@aol.com

Appendix C (continued)

Caregiver Questionnaire

Your Name: _____

Age in Years: _____

Your Gender: ___Male ___Female

Marital Status: Check Those That Apply

___Single

___Married

___Divorced

___Widowed

___In a Relationship

___Other (please specify) _____

Give the Ages of Your Children (if any): _____

Do You Have Children You are Caring For?

___Yes

___No

Check Your Current Working Status

___Working Part-Time (less than 40 hours per week)

___Working Full-Time (40 or more hours a week)

___Homemaker

___Retired

Care Receiver's Gender: ___Male ___Female

Appendix C (continued)

Care Receiver's Age in Years: _____

Your Relationship to the Care Receiver: _____

Hourly Distance (1 way) Between You and the Care Receiver by CAR:

Check the Most Accurate

___ 2-3.5 hours

___ More than 3.5 to 5

___ More than 5 to 6.5

___ More than 6.5 to 8

___ More than 8

Care Receiver Lives In:

___ Their Home Alone

___ Their Home with a Spouse

___ Assisted Living

___ Nursing Facility

___ Other (please specify) _____

Length of Time in Years and Months You Have Been Providing Care:

___ Years ___ Months

Average Time in Hours You Spend a Month Providing Direct Care:

___ Hours

Average Time in Hours You Spend a Month Arranging and/or Monitoring Care:

___ Hours

Appendix C (continued)

Stage of Alzheimer's Disease/Dementia Care Receiver is in: Check One

☐ Early ☐ Middle ☐ End ☐ Not Sure

How Do You Assist the Care Receiver (Please Circle All that Apply):

Bathing	Finances	Monitoring Care	Housekeeping
Dressing	Cooking	General Errands	Grocery Shopping
Toileting	Arranging Care	Medications	Laundry

Taking to Medical Appointments

Other (Please Specify) _____

Anything Else You Would Like the Researcher to Know:
