

THE EXPERIENCE OF TRANSITIONING TO THE CAREGIVING ROLE FOR A
FAMILY MEMBER WITH ALZHEIMER'S DISEASE OR A RELATED DEMENTIA

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THE EXPERIENCE OF TRANSITIONING TO THE CAREGIVING ROLE FOR A
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Duquesne University, 2007

Alzheimer's disease is a chronic, debilitating disease that currently affects approximately 5.1 million Americans (Alzheimer's Association 2007). The majority of these individuals are being cared for at home by family caregivers who are known to suffer from more depression and burden than any other group of caregivers. The purpose of this hermeneutic phenomenological study was to explore the lived experience of transitioning to the role of caregiver for a family member with Alzheimer's disease or a related dementia. The study followed purposeful sampling and eight women and two men with a mean age of 66.3 participated in the study. These caregivers reported being in the caregiving role for an average of 5 years. In depth semi-structured interviews along with observation field notes were the sources of data collection. Data were analyzed using the hermeneutic phenomenological approach based on the Utrecht School of Phenomenology (Cohen, Kahn, & Steeves, 2000). Seven themes were uncovered through data analysis including (a) something is wrong; (b) a journey to diagnosis: ambiguity and negative emotions; (c) shifting roles and relationships: losses and challenges; (d) seeking knowledge and support: solutions and frustrations; (d) adapting to the topsy-turvy world of caregiving: finding purpose; (e) preserving self without guilt; and (e) finding a way out. Findings have implications for nursing curricula and practice as participants expressed a need for opportunities for communication and access to resources. The findings also suggest

the need for health care planning early in the disease process. Policy implications include the need for public education on dementia and expanded coverage for family leave, respite care, and adult day programs. Further research is recommended to explore the experiences of caregivers during the early diagnosis period and the ethics and patterns of health care decision-making.

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DEDICATION

I dedicate this dissertation to my family who has been supportive in so many ways as I have pursued this doctoral degree. To my husband Rick, I thank you for your encouragement and understanding as I have followed a dream. To my children, Jill, Brian, Colleen, and Kevin, thank you for being you and giving me your support. I hope you too will continue to pursue your educational goals. To my parents Joan and Tom, who are forever proud of all of their family's accomplishments, I thank you as well.

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CHAPTER I

INTRODUCTION

Background

In 1906, a physician named Alois Alzheimer first reported on the symptomatology of a 51 year old woman he had treated in a mental health asylum (Alzheimer Society, 2004; Bird, 2005). She had exhibited progressive inability to care for herself up to five years prior to her death, with increasing confusion, disorientation, and trouble with reading and writing. Upon her death, an examination of her brain showed several important findings. First, her cerebral cortex was thinner than normal, but Alzheimer also noted two further abnormalities in the brain: senile plaque and neurofibrillar tangles. Senile plaque, a structure previously described in the brain of elderly people, was noted as well as neurofibrillar tangles, or nerve tangles. This was the first reporting of nerve tangling and it was mainly this abnormality that defined a new disease which was named after Dr. Alzheimer.

Alzheimer's disease (AD) is a chronic, debilitating disease that currently affects an estimated 5.1 million Americans, devastating their lives and that of their families (Alzheimer's Association, 2007). The number of cases of AD doubles in the population every five years after the age of 60. The implications of the disease are overwhelming when considering that the average life expectancy is 77 years. The prevalence of AD is expected to increase three-fold in the U.S. from an estimated 4.5 million in 2000 to 13.2 million by the year 2050 (Hebert, Scherr, Bienias, Bennett, & Evans, 2003).

Alzheimer's disease has been known to follow a course of about eight to ten years and progresses from a stage of mild cognitive impairment and memory loss to a

progressive decline in ability to perform activities of daily living (Alzheimer's Association, 2004; Bullock, 2004; Sadik & Wilcox, 2003). As the disease progresses, the individual may also have personality and behavioral changes.

Alzheimer's disease accounts for 50 to 70% of all cases of dementia in the United States; however, other conditions may occur alone or in combination with AD to cause dementia symptoms (Alzheimer's Association, 2007; Kawas, 2003). These conditions include: vascular dementia; frontotemporal dementia, also known as Pick's disease; and dementia with Lewy bodies. Table 1 shows the prevalence, causes, and symptoms associated with each of these conditions.

There is no single test used to diagnose AD; however, a diagnosis will usually involve a thorough workup of the person's physical and neurological status, history taking interviews with both the patient and a reliable informant, and the use of diagnostic criteria for dementia and AD (Alzheimer's Association, 2004; Kawas, 2003; Sadik & Wilcox, 2003). Since the early signs of AD may be gradual and subtle, the first symptoms can be confused with signs of normal aging, depression, stroke, and/or Parkinson's disease. The goal of the initial workup should be to determine if the symptoms may be related to a condition other than dementia.

Family caregivers often provide the majority of care for persons with dementia or AD (Hepburn, Tornature, Center, & Ostwald, 2001) as approximately 70% of those Americans affected live at home (Kantrowitz & Springen, 2007). Providing care for any ill or disabled loved one can be an overwhelming task; however, the patient with AD presents a unique challenge. The length of time actually spent in the caregiving role can be significantly long considering that Alzheimer's patients often live for an average of

Table 1

Conditions Other than Alzheimer's Disease Which May Cause Dementia

Condition	Percentage of Dementia Cases	Etiology	Signs and Symptoms
Vascular Dementia	10 - 20 % (Kawas, 2003)	Ischemic vascular disease related to hypertension/diabetes (Fladd, 2005)	Disorientation, confusion, behavioral changes, psychomotor slowness (Fladd, 2005)
Dementia with Lewy bodies (Parkinsonism)	10 – 15 % (Kawas, 2003)	Presence of Lewy bodies which are also present in Parkinson's disease (Smith & Buckwalter, 2005)	Fluctuating cognition, visual hallucinations, and motor deficits similar to Parkinsonism (Smith & Buckwalter, 2005)
Frontotemporal Dementia	5 – 15 % (Kawas, 2003)	Changes to the frontal and temporal lobes of the brain (Smith & Buckwalter, 2005)	Personality changes, disinhibition, and problems with language (Smith & Buckwalter, 2005)

eight years after the initial diagnosis and may go on to live for as long as 20 years after diagnosis (Prigerson, 2003). Those afflicted with AD are often not aware of their limitations; therefore, the caretaker may face the daunting task of providing care for a loved one who is unable to even recognize them. As the disease progresses, symptoms such as agitation and other behavioral problems reportedly occur in 70 to 99% of individuals and can be a major source of stress and burden for the caregiver (Logsdon et al., 1999).

The term “family caregiver” was first used in the 1980s to describe persons who were caring for elderly family members in their homes (Farran, 2002). Today that term can refer to any situation where care is being provided to persons dependent on others for care, in an informal or unpaid manner. It has been estimated that in almost one quarter of the households in the United States, care is being provided to persons 50 years of age and older. These numbers are only expected to increase as the average life expectancy increases and people with chronic diseases live even longer.

A profile of the American caregiver was reported in a national survey of 6,139 adults conducted in 2004 by the MetLife Foundation for the National Alliance for Caregiving (NAC) and the American Association of Retired Persons (AARP) (NAC & AARP, 2004). The results were based on 1,247 qualified caregiver respondents. The report estimates that there are 44.4 million caregivers in the U. S. providing unpaid care to adults. Approximately 59% of these persons are employed while providing care. Caregiving responsibilities impacted their work life in that they either were reporting late to work or were forced to give up work completely. The survey also found that caregivers typically needed information and education about their caregiving responsibilities. A

profile of the representative caregiver emerged as a female that is approximately 46 years old who was typically caring for a woman age 50 or older and widowed. Almost one in five caregivers (17%) reported providing 40 or more hours of care per week.

Additional analysis that was conducted from this survey by the Alzheimer's Association and the NAC (2004) indicated that 227 persons identified themselves as caregivers of persons 50 years or older with AD or some type of dementia/confusion. They also analyzed the responses of these caregivers using the original survey questions and compared them to non-Alzheimer's caregivers. Their findings revealed that AD caregivers carried a heavier burden when compared to other caregivers. This role involved sacrificing personal time, careers, and, in some cases, their personal health in order to meet the care demands of their care recipient. AD caregivers also expressed needing more personal support, acquiring information on providing care, and obtaining accessible services.

A fundamental need for AD caregivers is recognizing and managing problem behaviors. Caregivers must gain an understanding that the disease processes of AD are the cause of problem behaviors. These are not intentional acts by the care recipient aimed at causing distress for the caregiver. Smith and Buckwalter (2005) note that problem behaviors are often related to the inability of persons with dementia to express themselves. For example, agitation may just be the result of the need to urinate, or the inability to express pain or fear.

In addition, the typical Alzheimer's patient is at an advanced age and is often cared for by another elderly person. In many cases, the caregiver is the patient's spouse who also has age-related health impairments. The strain of caregiving can then be

magnified due to age and debilitated status (Prigerson, 2003). Caregivers may experience a variety of symptoms as a direct result of the caregiving role which includes fatigue, frustration, anger, and depression (White & Dorman, 2000).

Hills (1998) portrayed caregivers as hidden team members and suggested that they must also be seen as hidden patients needing attention focused on their needs. While caregiving is known to include physical care, Hills (1998) also identified anticipatory activities, planning of activities, and protective caregiving as a major portion of dementia caregiving. For many caregivers, the most stressful aspect of caregiving can be trying to manage problem behaviors such as paranoia, delusions, hallucinations, aggression, and problems with activities of daily living (ADLs) (Robinson, Adkisson, & Weinrich, 2001).

Schulz and Beach (1999) studied a cohort of caregivers drawn from the Caregiver Health Effects Study (CHES) to prospectively investigate the relationship between caregiving demands among older spouse caregivers and mortality. The study results indicated that caregivers who reported caregiving strain are 63% more likely to die within four years than noncaregivers.

The importance of the role of caregiver has also been documented as an essential component of maintaining the health of the Alzheimer patient and keeping the patient in the community. Brodaty, Green, and Koschera, (2003) stress this importance because “when there is no caregiver or the caregiver is stressed, the likelihood of nursing home admission rises sharply” (p. 657). Although home-based care is financially more cost effective than institutional care, the increased reliance on family members exposes them to high levels of chronic stress and contributes to the physical and psychological morbidity of caregivers. Aggressive patient behaviors may burden the caregiver and have

been connected with a loss of freedom of choice for the caregiver (Burgener, Bakas, Murray, Dunahee, & Tossey, 1998). Once the demands of care surpass resources, caregivers are faced with what they consider is the only option left to them such as an assisted living facility or nursing home (Farran, 2002).

In a prospective study of 134 persons with AD, Andrieu et al., (2002) evaluated the frequency and predictive factors that would lead to acute hospitalization for the patient with AD. Twenty four percent of the patients had at least one hospitalization during the one year period of the study with predictive factors that included a greater dependency for ADLs and bathing. Other predictive variables included caregiver reports of a greater frequency of problem behaviors, and lower levels of education. The authors suggested that interventions to help patients and caregivers manage the loss of ADLs may reduce the need for hospital admissions.

The Caregiving Career

The concept of caregiving as a trajectory which spans across three stages was described by Aneshensel, Pearlin, Mullen, Zarit, and Whitlatch (1995) in their book, *Profiles in Caregiving: The Unexpected Career*. The authors described a career that is not driven by professional ambitions, but by the pathogenesis of a disease such as dementia. They portray the role of family caregiving as an informal status that lacks the rights and privileges of a formal career status and one in which entry into the role is unplanned. As stated by Dyck (2004), "...living with or caring for someone with dementia is never part of anyone's life plans" (p. 298).

Aneshensel et al. (1995) conveyed a career that begins with the role acquisition stage and for many caregivers, the entry into this role occurs long before they apply the

label of caregiver to themselves. Since the onset of AD is often imperceptible, symptom recognition may not occur immediately, but sometime after the true onset of the disease. Difficulties with household tasks such as managing financial responsibilities may start to become apparent to family members (Kearney, Shaw, & Gitlin, 2005). Up until this point, family members may have been adapting to changes in their relative's memory and behavior before recognizing that these changes are abnormal (Aneshensel et al., 1995). Ready, Ott, and Grace (2004) found that informants who lived with persons with memory impairments were able to more accurately report about their loved ones' cognitive abilities. As an informant, the family member is aware of previous abilities of their care recipient and is able to report on changes in cognitive aptitude (Jorm, 2003). The caregiving role shifts in this stage from that of informant to caregiver.

In the early stages of the disease, caregivers may initially need to take over only higher level functions, such as finances and medication administration; over time and as the disease progresses, the responsibilities increase. No longer is it just a part time role, but also one that involves full time care (Haley, 1997). Early symptoms can often be confused with signs of normal aging and since the onset is gradual, the actual diagnosis may be delayed. This delay may mean the caregiver has not been offered appropriate education until later in the disease process (Sadik & Wilcox, 2003).

According to Aneshensel et al. (1995) caregiving then evolves to the role enactment stage which involves care in the home as well as institutional care. Finally, caregiving develops into the role disengagement stage which is most often precipitated by the death of the care recipient. The distinguishing feature of the caregiving career is the uncertainty of the timing and duration of each stage.

Purpose of the Study

The purpose of this study is to explore the lived experience of transitioning to the role of caregiver for a family member with Alzheimer's disease or a related dementia (ADRD). The specific aims of this study are to: 1). Describe the meaning that caregivers attribute to their experience; 2). Gain an understanding of the experience of transitioning to the role of caregiver for a family member with ADRD; and 3). Gain an understanding of strategies that caregivers identify as effective in enabling them to transition to the role of caregiver.

Definition of Concepts

Alzheimer's Disease and Related Dementias (ADRD)

The Alzheimer's Association defines AD as a "progressive brain disorder that gradually destroys a person's memory and ability to learn, reason, make judgments, communicate and carry out daily activities" (Alzheimer's Association, 2004, ¶ 1). In addition, the person with AD may experience "changes in personality and behavior, such as anxiety, suspiciousness or agitation, as well as delusions or hallucinations" (Alzheimer's Association, 2004, ¶ 1).

Alzheimer's disease is known as the most common form of dementia, and the World Health Organization (WHO) (2004) has defined dementia as "a loss of multiple components of intellectual function" (¶ 5). Furthermore, the WHO notes that the most common form of dementia is AD, which accounts for 50-70 percent of all dementias worldwide (WHO, 2004).

For the purposes of this study, the terms Alzheimer's disease and related dementias (ADRD) will be used to describe dementias from all causes. A care recipient

with ADRD will be identified as such by the caregivers who volunteer to participate in the study. The caregivers will be asked if their care recipient has been diagnosed with dementia by their physician.

Family Caregivers

Using a modified version of the definition from the *Caring for Persons with Alzheimer's: 2004 National Survey* (Alzheimer's Association & NAC, 2004), and the Family Caregiver Alliance (2001), the term “family caregiver” will be used to describe an individual who is 21 years of age or older who is living with, and providing unpaid care, to a family member, friend, or neighbor with ADRD to help them take care of themselves. This care includes such activities as helping with personal care and activities of daily living.

Aneshensel et al. (1995) described the caregiving role in this manner:

Caregiving is not merely a set of tasks; instead, it is a career that can envelope one's very being over a considerable span of time, often continuing its effects long after the death of the care recipient. Caregiving involves not so much an array of responsibilities as a recurrent redirection and reorganizations of one's life.....At each turn and twist of their career trajectories, caregivers are faced with new circumstances calling forth different behaviors and modes of adaptation (p. 349).

Transitioning to the Role of Caregiver

Due to the subtle nature of the onset of ADRD, caregivers often assume the role of caregiving even before they identify themselves as caregivers (Aneshensel et al.,

1995). By the time a physician has been consulted, there have been signs and symptoms of disease in the care recipient without a confirmed diagnosis.

In their study of 1480 caregivers of persons diagnosed with AD, Knopman, Donohue, and Gutterman (2000) found that the lag time from observation of first symptom to initial physician visit was at least 1.6 years; many of the patients did not necessarily receive a diagnosis of AD at the first physician visit. Consequently, the authors suggest that caregivers were not prepared to handle the personality and behavioral changes often seen in AD or to obtain referrals for supportive care.

Leifer (2003) noted that the tendency for physicians to dismiss memory complaints as a normal sign of aging must be replaced by an awareness of the need to assess early, and, if needed, intervene. Early intervention offers the opportunity to preserve patient function for a longer period of time and, ultimately, to delay institutionalization. Caregivers who are given early education about the disease and its implications have time to adjust and adapt in due course. A barrier to early education may be a limited knowledge of ADRD among the health care professionals with whom caregivers are coming into contact.

In this study, caregivers were asked to reflect on the experience of transitioning or entering into the role of caregiver for a family member with ADRD.

Assumptions

The assumptions for this study were: 1). The research method was appropriate, and the data obtained through the phenomenological approach represented a valid strategy to begin to understand the process of transitioning to the role of caregiver

for a family member with ADRD; and 2). Participant's stories reflected a narration of their actual lived experiences.

Limitations

Limitations for this study were: 1). Participant selection was based on purposeful sampling, which is not reflective of a larger population. Transferability of the findings, however, is enhanced through rich and thorough descriptions of the data (Polit, Beck, & Hungler, 2001); 2). Participants may at times have had difficulty in recalling their experiences of transitioning to the role of caregiver because of the length of time between the transition to caregiving and subsequent recall.

Significance to Nursing

The statistics are overwhelming and point to a significant percentage of the U.S. population being affected by ADRD. Nurses interact with both these persons with ADRD and their caregivers in a multitude of settings. According to the John A. Hartford Foundation Institute for Geriatric Nursing (American Association of Colleges of Nursing, 2005), adults over the age of 65 are using a large percentage of hospital days (48%) and home care visits (69%), and comprise a majority of the nursing facility residents (83%). In recognition of these statistics, the Hartford Foundation Institute for Geriatric Nursing seeks to improve the care of older Americans through the promotion of geriatric nursing in education, practice, research, and policy. They note that less than 1% of U.S nurses are certified in geriatrics, and 58% of baccalaureate nursing programs have no fulltime faculty who are certified in geriatrics.

Alzheimer's disease caregivers are known to suffer from more depression and burden than any other group of caregivers (Alzheimer's Association & NAC, 2004);

therefore, a study focusing on these caregivers can serve as a model of care for any other diseases with a slow decline and these as well. For those clinicians who work with dementia patients and their caregivers, the role of educator is especially important as the caregivers are faced with assuming a role for which they have usually have had little preparation. In her mentoring tool for AD caregivers, Kehoe (2003) notes that AD caregivers cannot draw on the skills they learned as a child from their parents and then later reinforced when parenting children. Parenting builds on the assumption that the child's brain can learn new information and store it; in a person with AD, the damage to the nerve pathways in the brain impairs that ability. While AD is not curable, there is evidence to suggest that there are strategies that can improve the quality of life for both the caregiver and care recipient. An example may be to provide caregivers with education on the disease process, physical activity, safety measures, environmental modification, problem solving, and stress reduction (Gitlin et al., 2003; Smith & Buckwalter, 2005; Tackenberg, 1992). The caregivers in this study offered an important perspective as they shared their stories.

Toth-Cohen et al.(2001) also noted that the caregiver's beliefs and values can affect how they perceive their role and thus, attention must be paid to the factors of, "race, ethnicity, education, socioeconomic status, family relationships, gender, and religion" (p. 25). Since the goal of educational and supportive interventions often is to delay care recipient institutionalization and increase well-being among caregivers (Mittelman, Roth, Haley, & Zarit, 2004), health care professionals and, most especially nurses need to learn from caregivers about their perspective on the transition to the role of caregiver.

Hasselkus (1988) recommends that health care professionals view caregivers as “lay practitioners” (p. 686) or partners in the caregiving role. This view respects the personal knowledge and history of the care recipient that caregivers can offer in providing care.

Currently, the evidence base for education in dementia care is lacking (Hirst, Blake, & Lane, 2003) and a study such as this can contribute to the body of knowledge that describes for nurses the experiences of caregivers as they transition to the role of caregiver for a family member with ADRD. For practicing nurses, there is also a need for continuing education that focuses on care that is appropriate and based on the current evidence (Gitlin et al., 2002). For future nurses, faculty must be competent in geriatrics and incorporate content and skills specific to the care of persons with ADRD into nursing curriculum (Hirst et al., 2003; The John A. Hartford Foundation Institute for Geriatric Nursing, 2005). Personal recollections from caregivers as to how they are experiencing this role transition to caregiving for persons with ADRD can help to develop the role of the nurse in the early stages of the disease. This is a period of caregiving for which little to no interventions have been carefully developed and tested.

CHAPTER II

REVIEW OF THE LITERATURE

Introduction

A review of the literature was conducted to search for studies on Alzheimer's disease and related dementias (ADRD) and caregiving. Based on this review, it was determined that there has been a wealth of studies focused on caregiving, burden, and interventions to address this burden. However, only two studies addressed the experience of transitioning to caregiving, one from the perspective of the experience of diagnosis of dementia (Teel & Carson, 2003) and the other from the outlook of embarking on the caregiving role (Adams, 2006).

Several databases were systematically searched and included the following: Medline 1966-2007; ERIC 1966-2007; and CINAHL 1982-2007. A manual search of information available on the web, in current library journals, and reference lists of selected studies was also conducted in order to retrieve the most up to date materials. The search was limited to English language studies. Research articles were chosen based on their ability to provide new and different information with a focus on more current research. The articles were further divided into categories based on the focal concepts presented in the articles. The categories that will be presented include: uncertainty and the diagnosis of ADRD; transition to caregiving; the experience of caring for a family member with ADRD; ethnic/racial, cultural, and gender influences on family caregiving, ADRD and caregiver burden; interventions to reduce caregiver burden; and education and AD.

Uncertainty and the Diagnosis of Alzheimer's Disease and Related Dementias

Several studies are presented that highlight the uncertainty that surrounds the dementia diagnosis for both health care professionals and caregivers. Beisecker, Chrisman, and Wright (1997) conducted telephone interviews with 104 family caregivers of AD patients in order to examine their perceptions of the changes that occur in patient-caregiver and physician interactions when the diagnosis of AD is made, and as the disease progressed. The authors found that physicians often withdrew from elderly patients with dementia, and attributed this withdrawal to false beliefs or negative attitudes about aging, and their uncertainty about dementia and the prognosis of the disease. Physicians also tended to communicate more with caregivers and less with patients as the disease progressed. Caregivers requested that physicians be up front with them from the time of diagnosis with more information about the disease process and prognosis, financial/legal issues, available services, research, and their own personal needs.

Boise, Camicioli, Morgan, Rose, and Congleton (1999) used focus groups with 78 physicians in three geographic areas to assess barriers to dementia diagnosis in the primary care setting. Results from 18 focus group sessions identified the barriers of; failure to recognize and respond to symptoms, perceived lack of a need to determine a diagnosis, time constraints, and negative attitudes towards the value of assessment and diagnosis. Family members were important factors in the diagnostic process, from reporting symptoms, to advocating for a comprehensive workup to determine a diagnosis. The authors noted that families had an influence on which tests were ordered, whether specialists were consulted, and the actual terms used to name the diagnosis. Additionally, a finding in this study was that some of the physicians perceived that nothing could be

done for the patients, so a diagnosis was of limited value and that a stigma was associated with the term Alzheimer's disease. Boise et al. (1999) noted that diagnosis can serve as an entry point for support services, a basis for communicating with others about the disease, and can lead to planning for future financial and health care needs.

Wackerbarth and Johnson (2002) surveyed 528 family caregivers who had been through a diagnostic assessment for their loved one at a memory disorders clinic. Their goal was to study the benefits and barriers of this assessment. On average, study participants had delayed seeking evaluation of their family member for 22.4 months after noticing symptoms. A majority of the respondents indicated that they received benefits that included a "confirmation of medical condition, access to treatment, and help preparing for the caregiving role" (p. 218). Information about understanding the care recipient's limitations especially in regards to decision-making, how to be more patient, and to make the most of the present were some of the lessons learned. Fewer caregivers reported receiving information on community and social support services, and availability of research studies. Wackerbarth and Johnson (2002) suggested that early access to treatment offers the possibility of reversing conditions, delaying progression, and diminishing behavioral problems.

Teel and Carson (2003) conducted a descriptive, qualitative study to describe the experiences of families of persons with dementia as they sought a diagnosis and treatment. The authors were also searching for barriers and challenges that led to a delay in diagnosis and information from the caregivers about what they wanted primary care providers to know about their experiences. The sample consisted of 14 caregivers recruited from support groups in Kansas. All participants were Caucasian and 50% of

them lived with their care recipient. Themes that emerged from the interviews included: uncertainty in the diagnostic process; loneliness as they provided dementia care; and a need to feel support from health care professionals. Participants found that the process of diagnosis was delayed as they experienced hesitancy on the part of their primary care providers in making the actual diagnosis. The deterioration of their care recipient occurred over several years and the caregivers ultimately had to see multiple primary care doctors and specialists before a diagnosis was made. The caregivers also expressed challenges in learning about dementia care and found a lack of knowledge among health care providers. They reported the unrelenting stress of the role and that their best source of information about caregiving was the support groups. As noted previously, all caregivers were recruited from support groups. Teel and Carson (2003) suggested that the delays in diagnosis postponed pharmacological treatment, which has been shown to offer some benefit in delaying disease progression. Also, the authors recommended that future research is needed in the area of nursing practices that can support patients and families in this early period of diagnosis and caregiving. In this study, Teel and Carson (2003) found that descriptions of interactions with staff or advanced practice nurses during the process of the dementia diagnosis were notably absent.

In a cross sectional study looking to determine what information was provided to dementia patients and their caregivers by health care professionals, Vernooij-Dassen, Van Hout, Hund, and Grol (2003) found that most often only basic information was given to caregivers and patients. The authors studied 51 elderly dementia patients who were living at home with their caregivers and attending an outpatient memory clinic. They found that specific information about care was given more often in situations where patients had

more cognitive, behavioral, or instrumental activities of daily living (IADL) problems and when caregivers reported lower levels of competence in these areas. The authors found that there was not always congruency between what the caregivers saw as a need and what the health professionals identified as a need. The researchers found that education should include not only information about issues that appear to be relevant by the clinicians, but what the caregivers and patients identify as their needs. Further research in the area of how and what information should be given and to whom was recommended.

Wald, Fahy, Walker, and Livingston (2003) developed their “rule of threes” (p. 313) from the results of a survey of 100 caregivers of persons with dementia recruited from community mental health teams and a memory clinic. The “rule of threes” referred to information that should be provided to primary caregivers at the time of the dementia diagnosis. Caregivers were asked questions regarding how much information they wanted to know about dementia, at what stage of the illness, and in what medium did they want the information presented. Their results indicated that caregivers generally would have wanted information at the time of diagnosis about the definition of dementia, medications available for treatment, and behavioral and psychological symptoms of dementia. Most caregivers preferred that this information be provided verbally by health professionals and supplemented by written materials. The authors note that since this was a retrospective study, the caregivers may not have expressed the same desires at the time of diagnosis.

Kazui et al (2004) developed a clinical pathway for the treatment of patients newly diagnosed with dementia in a special ward for dementia in a hospital in Japan.

The clinical pathway identified protocols for the diagnosis, treatment, establishment of a care system, and caregiver education over a three week period. The clinical pathway was used with 23 patients diagnosed with dementia, and then 20 controls used conventional medical practice. The authors compared length of hospital stay, hospital costs, and comments from the treatment team and caregivers about their impressions of the clinical pathway. The results indicated that the use of the clinical pathway significantly shortened the hospital length of stay and reduced hospital costs. The results of the survey also suggested that caregivers felt the clinical pathway gave them a deeper understanding of the medical practices, treatment methods, and methods for coping with the disease.

In a study examining the attitudes of caregivers and physicians towards the assessment and diagnosis of dementia, Connell, Boise, Stuckey, Holmes, and Hudson (2004) conducted focus group interviews with 52 caregivers and 39 physicians. Caregivers were asked to describe the first symptoms they initially noted in their family member, how the physician they first contacted responded, and how would they have liked to have been given the information and/or diagnosis. The physician interview focused on the diagnosis disclosure process. Physicians were asked about the terminology they used, who was given the information, what was the reaction of patients and family members, and how they responded to the caregivers. Physicians were also asked about suggestions they would offer for making the diagnosis process less stressful for all involved. Caregivers described negative emotional responses to the diagnosis. However, many physicians reported that caregivers handled the information well. Many caregivers expressed regret in not obtaining a diagnosis of dementia sooner and requested information about the disease and referral to community based services. In some cases,

caregivers were disappointed by the fact that the physician did not even suggest a return visit to them after the diagnosis had been made.

Caregivers' preferences for how the diagnosis should have been made varied from a direct approach to being eased into the diagnosis in a gentler manner (Connell et al., 2004). Physician responses included: pressure to make a diagnosis, challenges to providing up to date information and referrals, a need for a specific diagnostic protocol for dementia, and increased time available to spend with patients and family members. The authors suggested that physicians need to consult with family members to learn about their preferences when it comes to this devastating diagnosis.

Milne, Hamilton-West, and Hatzidimitriadou (2005) reported on a comparative analysis of general practitioners' (GPs) attitudes toward early diagnosis of dementia. The two studies were conducted four years apart, in 1997 and 2001, in the same geographic region in the United Kingdom. Questionnaire responses related to early diagnoses as well as responses to open-ended questions were analyzed. One hundred eighty-two GPs participated in the first study, and 93 in the second. Their results showed a significantly greater commitment to early diagnosis at Time 2 compared to Time 1, fewer GPs viewed early diagnosis as having negative consequences. The qualitative data derived from the study indicated that GPs considered early diagnosis as an important opportunity to offer treatment when it can be most effective. Early diagnosis also facilitated the ability of patients and caregivers to make future plans. GPs moreover cited additional numbers of psychiatric colleagues, increased investment in support services, and policies which emphasize early diagnosis as contributing to their attitudinal shift. The authors in addition noted that memory clinics and anticholinesterase inhibitors were only mentioned by

participants in Study 2, most likely because these interventions only received national support sometime after the completion of the first study.

van Hout, Vernooij-Dassen, Jansen, and Stalman (2006) conducted a prospective observational study with 64 general practitioners (GPs) in the Netherlands. The GPs were instructed to use the Dutch national dementia guideline on patients newly suspected of dementia. Participants were then referred to a memory clinic team that served as the diagnostic standard. One hundred and seven possible cases of dementia were reported. After assessment, dementia was believed to be present in 69 persons, absent in 29 and uncertain in nine. In most of the cases, the GPs were considered correct in their diagnosis. Of the 69 patients diagnosed with dementia, the GPs told 42% of the patients and 82.3% of the caregivers. Less than half of the caregivers were advised of any common communication or behavioral issues. The authors suggested further research to determine the best practice in dementia diagnosis.

Vernooij-Dassen, Derksen, Scheltens, and Moniz-Cook (2006) examined the impact of receiving a dementia diagnosis in a qualitative study with 18 pairs of individuals, one of whom was diagnosed with dementia at a memory clinic in the Netherlands. The couples were interviewed at two weeks post diagnosis and at 12 weeks. The authors identified the themes of “changes in awareness” (p. 402), “changes in partnership” (p. 402), and “changes in social relationships” (p. 403). For the caregivers, many saw the diagnosis as a confirmation of what they had been suspecting and the point of diagnosis was a trigger to make plans about the future. Even at two weeks after diagnosis, family members were starting to identify themselves as caregivers, and some had made decisions about their future. Couples also had reported that friends and family

members were not surprised by the diagnosis. Interestingly, the authors noted that none of the participants expressed any episodes of devastation. This was attributed to the sensitive disclosure process at the memory clinic and subsequent support they received as far as planning and setting up of goals.

Summary

The studies presented highlighted the fact that caregivers want information and support at the time of the diagnosis of dementia (Beisecker et al., 1997; Connell et al., 2004; Kazui et al., 2004; Teel & Carson, 2003; Vernooij-Dassen et al., 2003; Wald et al., 2003). Caregivers need to know what to expect during the disease progression as well as referrals to appropriate services. This necessitates open communication. Health care professionals must be competent in dementia diagnosis, care, and management in order to provide caregivers with the tools they need to take on the caregiving role, and to understand the experience from the perspective of the caregiver (Boise et al. 1999; Connell et al., 2004; Kazui et al., 2004; Milne et al., 2005; Teel & Carson, 2003; van Hout et al. 2006; Wackerbarth & Johnson, 2002; Wald et al., 2003).

Transition to Caregiving

The actual transition to caregiving can be a gradual one as in the case of persons with ADRD, but what these transitions are and how they affect caregivers becomes important to consider when designing interventions for their care.

Seltzer and Li (1996) reported on the first wave of a three wave longitudinal study of wives and daughters of care recipients 60 years of age and older. A probability sample was drawn from noninstitutionalized elderly residing in Wisconsin and receiving care from a family member. The resulting sample consisted of 121 wife and 147 daughter

caregivers. Reasons for the need for care for the care recipients included dementia, heart disease, and stroke. The authors focused on two indicators of the sequential trajectory of caregiving: duration of caregiving and the perception of caregiving as a role that is new, ongoing, or one that will end soon. For the daughters that perceived themselves to be in the later stages of caregiving, their relationship with the care recipient was more distant and they reported more subjective burden than daughters in earlier stages. Seltzer and Li (1996) attributed this to the “wear and tear” (p. 624) effect of caregiving and that other roles in their lives may compete with the caregiving role. Conversely, for the wives who reported an abrupt onset of the caregiving role, a longer duration of care was predictive of lower levels of burden and greater degrees of closeness in their relationship with their spouse. This is suggestive, according to Seltzer and Li (1996), of an “adaptational” (p. 624) pattern of caregiving. This adaptational pattern may be reflective of the fact that the caregiving role for older wives comes at a period when other roles are diminished due to retirement and health restrictions.

In a prospective study designed to examine the types of caregiving transitions experienced by wives and daughters, Seltzer and Li (2000) reported on the analysis of data taken from wave one and wave three of their longitudinal study. The probability sample of wives and daughters providing care to a relative aged 60 or above were compared to noncaregivers who had a husband or parent aged 60 or above who were not in need of any care. During the course of the three year period of the study, one third of those who were caregivers exited the role because of the death of the care recipient. Additionally, 10% of the daughters who were initially providing care placed their parent in a group or nursing home; however none of the wives placed their husband during this

period. Of those daughters who were not caregivers at the beginning of the study period, one third entered the caregiving role during the study compared to 10% of the wives. Daughters experienced fewer changes in their social, familial, and psychological well-being measures as they entered or exited the caregiving role compared with wives who showed declines in well being after entering the caregiving role but improvement after exiting the role. Seltzer and Li (2000) proposed that entry into the caregiving role for wives affects their leisurely pursuits and relationships with family and spouse, whereas for daughters, the social and psychological effects of entry into the caregiving role come at a time when they are experiencing demands from multiple family roles which may act as a buffer. Seltzer and Li (2000) recommended further research to track caregivers over a longer period of time to examine the impact of the transitions.

Lawton, Moss, Hoffman, and Perkinsin (2000) conducted a prospective, longitudinal study during two transition periods with daughters and daughters-in-law of unmarried elders to test their hypothesis that becoming a caregiver was associated with negative effects on their physical and mental health. The first transition compared women who were not caregivers at baseline but became caregivers one year later (n=33), with continuing non caregivers (n=56), and veteran caregivers (n=78) who had been providing care for greater than 12 months. In the second transition, new caregivers, identified from the Time I measurement, who became new veteran caregivers (n=69) were compared with old veteran caregivers (n=189). Study measures addressed characteristics of the care recipient, amount of care provided by the caregiver, the caregivers' appraisal and attitudes towards the caregiving situation, and caregiver health.

Lawton et al. (2000) found that the transition into the caregiving role was discernable by a significant decrease in the competence of the care recipient, and a significant increase in the amount of help received when compared to continuing non caregivers or veteran caregivers. Significant changes were not seen, however, in the caregivers' quality of life measurements. The authors suggest that further research is warranted before implying that caregiving does not erode mental health.

Shue, Byers, and Graham (2005) used a retrospective interview technique with 38 caregivers of persons with AD to obtain descriptions about critical incidents that occurred during the progression of their care recipient's disease and how they responded to them. Critical incidents were defined as "significant events or occurrences that capture an image of change at specific points in time" (p. 235). The researchers were looking to determine the types of incidents that families would report during the progression of AD and the nature of the communication that emerged during these critical incidents. Nine critical incident categories were derived from the 304 critical incidents identified by the participants. The most frequently reported critical incident category was identified as "small problems" (n = 74, 24% of all critical incidents reported) (p. 235) and generally occurred before the diagnosis of dementia. In the early stages of dementia, the participants reported that their care recipient had difficulty with retaining information, although they were still able to participate in interactions with others; often repeated ideas; and had problems in keeping up with the pace of conversations. These small problems became more meaningful for caregivers after the diagnosis of AD.

The second most frequently reported critical incident was "relocation" (n = 55, 18%) (Shue et al., 2005, p. 237) and involved family members moving in with care

recipients, or the move into assisted living facilities or nursing homes for the person with AD. Communication patterns in this area focused on measures to increase understanding among the care recipients on why the relocation was occurring. The category of “health-related events” (n = 41, 13%) (Shue et al., 2005, p. 237) concerned attempts to seek information from the care recipient regarding health problems and medical needs. The “darkside” (n = 40, 13%) (Shue et al., 2005, p. 238) category revolved around behaviors that may occur during various stages of the disease such as paranoia and hallucinations. Communication during this period was often stressful for caregivers and they described using calming, appeasing, and soothing measures to decrease the volatility of the situation. “Loss of independence” (n = 26, 9%) (Shue et al., 2005, p. 238) consisted of events that related to the losses of the rights of adulthood such as work, driving, and participating in social events.

The critical incident of “realization moments” (n = 25, 8%) (Shue et al., 2005, p.239) focused on the caregiver and included the recognition of the nature of the disease, acceptance of the condition, diagnosis, and discussion with family members on what was to happen in the future. While some participants shared that they were aware something was wrong, the actual diagnosis forced them to discuss with family members how they were going to address present and future needs of the care recipient.

Shue et al. (2005) identified the remaining critical incident categories as: “togetherness moments” (n = 20, 7%) (p. 239), ways in which the caregivers strived for connection and quality time with the care recipient; “assisting events” (n = 12, 4%) (p. 239) which focused on measures to maintain independence for the person with AD for as long as possible; and “moments of clarity” (n = 11, 4%) (p. 240) as events that offered an

indication of past care recipient competencies. Shue et al. (2005) also present suggested strategies gleaned from these caregivers that could be used during these critical incident periods and recommended further research in the area of effective strategies especially in the area of communication.

Adams (2006) conducted a phenomenological study with 20 caregivers of persons with early to mild dementia or mild cognitive impairment about their transition into the caregiving role. Participants were recruited from a research registry of a memory and aging center in Cleveland. The sample consisted of spouses (n=16) and adult daughters (n=4) who participated in a one time semi-structured interview. The mean time since onset of memory loss was 3.8 years. The questions focused on the following: the early cognitive changes noted, their relationship with the care recipient during this transition, their understanding of the caregiver role and its effect on them, and present and future concerns. Themes that emerged included: family member tasks, changes in the relationship, negative emotions, and thoughts of the future.

Caregivers reported struggles with taking on responsibilities that their loved one had traditionally handled, such as household chores and finances, and with how much they should continue to involve their care recipient in these tasks. Safety issues also arose as a concern especially in relation to driving. Caregivers also spoke to taking on the role of “emotional cheerleader or coach” (Adams, 2006, p.13). Caregivers expressed a loss of important elements in their relationship and a loss of a confidante. Of the 20 caregivers, 19 reported some negative effect that included anger, frustration and impatience. Most of the caregivers were able to identify at least one outside source of support; however some caregivers were reluctant to burden others such as their children. Only seven of the

caregivers were using some type of service which included; Adult Day Care, a support group and a continuing care community. The others expressed some reluctance with accessing formal services. Adams (2006) suggested that while the sample is small and mostly white, the findings indicate that attention must be paid to the early stages of dementia when caregivers are vulnerable and possibly reluctant to seek out help.

Summary

The studies presented offer support that the transition period from informant to caregiver to veteran caregiver can have effects on both the physical and mental health of the caregivers; however, evidence provided did not show consistent effects. A gradual versus abrupt onset into the caregiving role (Seltzer & Li, 1996), and the role relationship (Lawton et al., 2000; Seltzer & Li, 1996, 2000) were seen to factor into the challenges of transition. For some caregivers, “critical incidents” (Shue et al., 2005) provided defining moments regarding the progression of the disease. How caregivers are experiencing the transition in a new role should also be considered when planning support services (Adams, 2006).

The Experience of Caring for a Person with Alzheimer’s Disease

Several studies described the experience of caring for a relative with ADRD. Perry and Olshansky (1996) conducted ten in depth interviews over the course of 18 months with several members of a family in which one member had AD. This study was unique in that it focused on how various members of one family came to terms with changes that occurred in the person with Alzheimer’s disease. The authors used grounded theory techniques to guide their data analysis and noted that although the sample was small (n=5) and insufficient to produce a grounded theory, the data showed that each

family member experienced a similar process as they came to terms with the changes in their family member with AD. Three stages were identified: “identifying how the person with AD was the same as he was before, as well as how he was different; redefining the identity of the person with AD; and rewriting one’s relationship with the person with AD” (p. 12). The authors suggested that further research with families of persons with AD would contribute to the understanding of the how this experience impacts the family system.

Butcher, Holkup, and Buckwalter (2001) conducted a phenomenological study to describe the experience of caring for a family member with AD at home. The study involved secondary analysis of in-depth interviews with a sample of 103 caregivers who had participated in a four year longitudinal study to evaluate the effectiveness of a psychoeducational nursing intervention. From the analysis, the authors identified eight essential elements or themes: “enduring stress and frustration, immersed in caregiving, finding meaning and joy, integrating ADRD into our lives, moving with continuous change, preserving integrity, and gathering support” (p. 43). The authors noted, consistent with other qualitative studies, that respondents described the stress, frustration, and difficulties with day to day care. Many caregivers also seemed to find the positive aspects of caregiving and that brought meaning to the experience.

Mahoney (2003) conducted a qualitative study of caregivers of persons with AD participating in an online discussion board. Data were collected from a review of the postings from the caregivers over a 12 month period. The electronic mailing list for the group had 370 subscribers. Mahoney (2003) had special interest in the messages related to caregiving issues and from an analysis of the 566 messages that met the criterion

related to caregiving concerns, themes emerged. Caregivers in the early stages were often seeking information, while those caregivers in the middle stages addressed concerns about managing behaviors. For those in the later stages of caregiving, anxiety about institutionalization emerged. From the analysis, Mahoney (2003) described the concept of vigilance as one that emerged throughout all of the stages and operationalized the term as “supervising and being there (on duty)” (p. 28). For caregivers of persons with AD, this entailed overseeing the care recipient’s activities, and intervening when necessary. These findings supported the caregivers’ perceptions of the 24 hour responsibility that is involved with ADRD caregiving.

Paton, Johnston, Katona, and Livingston (2004) conducted a qualitative study using a semi-structured interview with 205 caregivers of persons with AD. The purpose of the study was to gain an understanding of the caregivers’ perceptions of the causes of problem behaviors. Their findings indicated that the majority of caregivers did not attribute problem behaviors to AD even though they were well aware of the diagnosis of AD. Many felt the care recipients had control over those behaviors and some believed their loved one would improve. Behaviors such as aggression, apathy, delusions, hallucinations, and anxiety were identified as problem behaviors; but in the case of aggression, it was rarely attributed to AD. The authors suggested that education on the disease process of AD is essential for caregivers, along with a focus on the caregivers’ understanding of the disease and attribution of the symptoms. Recognizing that a symptom may be beyond the control of the care recipient will enable the caregiver to plan for and implement more effective care.

Summary

Studies which address the caregiving role from the perspective of the caregiver help to identify those experiences that have meaning for the caregiver. Concepts such as: vigilance (Mahoney, 2003); the burdens of everyday care of the person with dementia (Butcher et al., 2001); and perceptions of problem behaviors (Paton et al., 2004) emerged as part of the experience of caregiving. Studies suggest that strategies should be designed to speak to those experiences.

Ethnic/Racial, Cultural and Gender Influences on Family Caregiving

Several studies have examined the caregiving experience from a cultural perspective. The history, traditions, beliefs, social roles, and customs that are part of any family can also be reflected in the caregiving role. Those values may determine who enters the caregiving role and how that role is perceived (Corcoran, Vause Earland, Lipsitt, & Toth-Cohen, 2005). In order to provide services for caregivers, there is a need for attention to be focused on how racial, ethnic, cultural, and gender variations may impact the experience.

Reviews and Analyses of Studies Focusing on Ethnicity and Culture

Connell and Gibson (1997) reviewed twelve studies published between 1985 and 1995 that examined the differences in the dementia caregiving experience between subgroups based on racial, cultural, or ethnic variations. Ten of the studies selected for the review compared Black with White caregivers (Cox, 1993, 1995; Cox & Monk, 1990; Haley et al., 1995; Hinrichsen & Ramirez, 1992; Lawton, Rajagopal, Brody, & Kleban, 1992; Macera et al., 1992; Miller, Campbell, Farran, Kaufman, & Davis, 1995; Morycz, Malloy, Bozich, & Martz, 1987; Wood & Parham, 1990; Wykle & Segall, 1991); one

compared Black and Hispanic caregivers (Cox & Monk, 1990); and one study compared White and Hispanic caregivers (Mintzer et al., 1992). Several consistent findings emerged in the comparison of White and Black caregivers. Black caregivers often were an adult child, friend or family member, while White caregivers often were a spouse, older, had more education, and higher incomes than Black caregivers. In several studies, White caregivers experienced higher levels of caregiver burden, depression, and lower level of satisfaction with caregiving than non-White caregivers. Regarding coping strategies, White caregivers were more likely to use professional help and support groups, whereas Black caregivers relied more on prayer or religion as a coping strategy. White caregivers indicated a greater desire to institutionalize care recipients than Blacks.

Significant findings were also reported by Connell and Gibson (1997) in studies comparing Black and Hispanic, and White and Hispanic caregivers. White and Hispanic caregivers had higher levels of depression compared to Black caregivers, and both Black and Hispanic caregivers tended to rely more on informal support, such as assistance from family and friends, than White caregivers. While the authors cited limitations in the reported studies regarding sample size, selection methods, and representativeness, they proposed that more research in the area of racial, ethnic, and cultural differences among groups was warranted.

Janevic and Connell (2001) built on this review and examined 21 studies published between 1996 and 2000 that compared two or more racial, ethnic, or cultural groups related to the caregiving experience. The purpose of the review was to substantiate the conclusions drawn from the Connell and Gibson (1997) review and to identify new directions for future research. The studies selected compared the following

groups of caregivers: African Americans; Chinese; Chinese Americans; Koreans; Korean Americans; Latinos; Whites; and residents of 14 eastern European countries.

As was found in earlier studies, White caregivers were more likely to be spouses when compared with other groups; White caregivers also reported higher levels of depression and stress related to the caregiving experience than African American caregivers. Janevic and Connell (2001) reported mixed findings in their review regarding the availability of extensive social networks for African American caregivers and suggested that minority groups may not necessarily have more available support than White caregivers. The authors noted that the lack of use of formal networks should not lead program planners to assume that minority caregivers receive sufficient support from informal networks. Rather, research should be directed towards understanding the barriers that minorities may encounter in accessing care.

Janevic and Connell (2001) note that the lack of control groups in all but two of the studies presents a methodological issue and that further research should also consider more than just the inclusion of the primary caregiver. They also suggest that the inclusion of individuals from the entire family system may demonstrate the impact of the disruption of the caregiving experience on the family system across cultures.

Pinquart and Sorensen (2005) used a meta-analysis to integrate the findings of 116 studies published between 1983 and 2004 that compared ethnic differences among caregivers. Caregivers included in these studies were not limited to dementia caregivers, 50% of the studies focused on dementia caregiving; 6% focused on caring for physically impaired older adults; and 44% included both dementia and other caregivers. The studies in the sample compared caregivers of various ethnic/racial/cultural backgrounds: African

American and White caregivers (n=63); Hispanic and non-Hispanic white caregivers (n=23); Asian American and White caregivers (n=10); and Native American and White caregivers (n=1).

Pinquart and Sorensen (2005) investigated a variety of variables related to caregivers that included: background; objectives stressors; filial obligation beliefs; psychological and social resources; coping; and mental and physical health. Among the caregiver variables, they found that ethnic minority caregivers were younger than White caregivers, less likely to be a spouse, and less likely to be married. White caregivers reported higher levels of education and income than the minority caregivers. Ethnic minority caregivers were more likely to provide greater number of hours of care, but used more informal support networks and more cognitive coping skills, such as seeking the positive aspects of the caregiving experience. African American caregivers exhibited an advantage in psychological health, but Asian American caregivers displayed poorer psychological health than White caregivers. Physical health for minority caregivers was found to be worse than for White caregivers.

Pinquart and Sorensen (2005) proposed that some of the factors contributing to poorer health may be independent of the caregiving experience and may include decreased access to health care, lower levels of insurance, and effects of discrimination. They recommended that future studies should compare the factors of motivation for caregiving, processes used for coping, and emotional strengths of various ethnic groups. Interventions for White caregivers have traditionally focused on decreasing the negative effects of caregiving. Learning from ethnic minority groups about how the positive aspects of caregiving can increase well-being may benefit White caregivers.

Comparing White and African American Dementia Caregivers

Using participants from several of the National Institute of Health Resources for Enhancing Alzheimer's Care Health (REACH) study sites, Roff et al. (2004) explored the differences among African American and Caucasian caregivers regarding their positive feelings about the Alzheimer's disease caregiving experience. African American (n=275) and Caucasian (n=343) caregivers responded to an instrument called the Positive Aspects of Caregiving (PAC) scale that assessed for positive aspects related to caregiving in an in-home interview. African American caregivers scored significantly higher on the scale than their Caucasian counterparts. Factors that emerged as possible explanations for this finding included: lower socioeconomic status; lower bother or upset with problem behaviors in the care recipient; lower anxiety; and greater religiosity among African Americans as compared to Caucasians. No significance was found between the two groups related to the variables of depression, social support or educational levels.

Roff et al. (2004) suggest that those caregivers of a lower socioeconomic status may use past experiences with adversity as a means of adjusting to difficult situations. The importance of religious practice among African American caregivers was also supported and was seen as a mediator in the caregiving relationship. The authors suggest that interventions for African American caregivers should, for example, provide respite so that these caregivers can attend religious services. Further research in the area of potential mediators between race and positive aspects of caregiving was suggested.

Using a phenomenological approach, Paun (2004) explored the experience of caregiving with fourteen older women (age 60-82) caring for their spouse with AD. Five of the women were African American and nine were Caucasian. Although only one

interview question targeted spirituality or religious beliefs, the participants shared the theme of spirituality and religion as essential aspects of their caregiving role. Spirituality was reflected in the themes that emerged from the interviews that included: taking charge; adjusting/coping; making sense of the situation; and looking into the future. In taking charge, the participants shared their experiences of keeping their spouse engaged in some aspect of their religious practice. Religious services and prayer were identified as strategies for coping and most caregivers identified beliefs and philosophies of life that led them to make sense of the situation. The African American women relied wholly on their faith in making sense of the situation and in their trust in God to guide them through the experience. The Caucasian women, however, were more varied on how they made sense of the situation and looked to the future. The authors proposed that nurses must consider a holistic approach in providing interventions for caregivers and include an assessment of their religious practices, identification of spiritual conflicts or crises, and recognition of the varied ways that caregivers may use spirituality and religion to construct meaning in the caregiving experience.

Dilworth-Anderson et al. (2005) conducted a study designed to explore the effects of caregivers' characteristics on cultural reasons for providing care to family members with AD. A sample of 48 African American and 121 White caregivers of a spouse or parent with AD completed the *Cultural Justification for Caregiving Scale (CJCS)*. This is a ten item instrument designed by the authors to measure caregivers' cultural reasons and expectations in providing care. Scores range from ten to 40 and higher scores indicate stronger cultural reasons for providing care. The African American caregivers scored significantly higher than the White caregivers on the scale. The authors suggest that

expected reciprocity among African American family members and the interdependence of family and community contribute to a “collectivist way of thinking” (Dilworth-Anderson et al., 2005, p. 260) about caregiving. Among both groups, there was an inverse relationship between CJCS scores and caregivers’ educational level. Those caregivers with higher levels of education tended to score lower on the CJCS; the authors proposed that higher educational levels may change the way caregivers think of their role in the caregiving process. There also were differences in CJCS by gender and age. Compared to females, African American males had lower CJCS scores and White males had higher scores. Also, younger White males had higher scores when compared to older White caregivers. Some of these differences were attributed to the fact that the majority of White males in the study were husbands rather than adult sons and may have perceived the caregiving role as an extension of their spousal role. Women in the study were more likely to be providing more hands on care than males. The authors recommended further studies investigating the relationship of culture to the process of socialization into the caregiving role.

African American Dementia Caregivers

Clutterbuck and Mahoney (2003) conducted focus group interviews with seven African American caregivers of persons with dementia. The purpose was to explore their experiences and perspectives as they obtained a dementia diagnosis, and to examine the barriers and facilitators in that process. The main theme of “respect” emerged; caregivers shared the importance of maintaining respect for the care recipient’s independence and wishes for as long as possible. Caregivers also encountered feelings of a lack of respect when they felt their concerns or observations were not being listened to by health care

providers. The caregivers also reported that early signs and symptoms of the disease were not recognized as anything more than normal signs of aging; for some caregivers, it took a crisis for them to realize that something was wrong. Informal networking was identified as the facilitator to obtaining a diagnosis. Conversations with friends from church and the workplace, who happened to also be caregivers of persons with dementia, were the factors that encouraged caregivers to seek a diagnosis. The authors identified that the cultural strength of tolerance of cognitive and behavioral changes in the elderly among African American caregivers was also a weakness. This acceptance of changes in the care recipients' cognition and behavior ultimately led to a delay in seeking evaluation and treatment.

Clark et al. (2005) studied early patterns of care in a group of African American patients with AD and their caregivers in a suburban and an inner city memory clinic. The caregivers (n=79) were questioned about the delay from symptom recognition to problem recognition until first physician visit. For both groups, the lag time between noticing AD symptoms and recognizing that there was a problem was as long as six to seven years; and the time between problem recognition and a physician visit was as long as four to seven years. More than half of the caregivers attributed delays to the fact that they thought the changes were normal aging; were not sure of the severity of the problem; and had difficulty in discussing the problem with the patient. Those participants who attended the suburban clinic were more likely to have seen an MD but no more likely to have received a diagnosis of AD. Due to the higher prevalence of AD among African Americans, Clark et al.(2005) proposed that efforts are needed which connect African American families with physicians to obtain a more timely diagnosis. This earlier

diagnosis will allow for interventions to educate them on the disease, plan for safety for the patient, and make plans for the future.

Comparing White and Hispanic/Latino Caregivers

Depp et al. (2005) examined caregiving self-efficacy among 238 Hispanic/Latino and Caucasian adult daughter and wife caregivers who participated in the Resources for Enhancing Alzheimer's Caregiver Health (REACH) intervention program in California. REACH was a national research program that tested different types of interventions for caregivers of persons with dementia. Self-efficacy was investigated in the following domains: obtaining respite; responding to disruptive behaviors; and controlling upsetting thoughts. Depp et al. (2005) reported that the concept of self-efficacy is important in dementia caregiving because beliefs about an individual's ability to respond to a given situation can be behaviorally modified and a higher sense of self-efficacy has been associated with less depression, burden, anxiety, and anger. Among the REACH participants, Depp et al. (2005) found that Hispanic/Latinos reported higher levels of self-efficacy in the areas of responding to disruptive behaviors and in controlling negative thoughts. The authors concluded that the higher self-efficacy among the Hispanic/Latino caregivers may relate to the cultural value attributed towards caregiving; that it is an honor and an expected role for the eldest daughter in the family. Even when caregiving situations were more challenging among the Hispanic/Latino caregivers, they were less likely to describe the situation as burdensome. Daughters (mean age = 51.35, Caucasian; 48.03, Hispanic/Latino) reported higher self-efficacy on all three of the scales when compared with spousal caregivers (mean age= 70.68, Caucasian; 65.29, Hispanic/Latino). For wives, reduced mastery in performing caregiving tasks and a lack of availability of

social support were cited as possible explanations for the lower self-efficacy ratings. Cognitive interventions that focus on restructuring the view of the role of the caregiver were recommended for spouse and Caucasian caregivers, while skill acquisition strategies were recommended for Hispanic/Latinos and daughters.

Comparing White, African American, and Hispanic/Latino Caregivers

Belle et al (2006), in their second phase of the REACH randomized controlled trial, implemented an intervention designed to address specific quality of life areas for the individual caregivers of persons with dementia. This project was a six year multisite study which looked to test various interventions for family caregivers. Caregivers were assigned to an intervention group which received 12 in-home and telephone sessions over six months, or a control group which received two check-in phone calls over the six months. The researchers hypothesized that caregivers in the intervention group would score better on scales measuring depression, burden, self care, social support, and care recipient problem behaviors. Hispanic and Latino caregivers were also expected to show the greatest improvement in these measures. All intervention materials were translated into Spanish for Hispanic and Latino participants, and bilingual staff was used for this population. Their results showed that the caregiver intervention led to statistically greater improvement in the quality of life measures for white and Hispanic or Latino caregivers compared to the control group participants, but not for African-American caregivers. African American spouse caregivers' quality of life measures however, did improve significantly. Belle et al. (2006) suggested that an intervention adapted to individuals can improve quality of life for ethnically diverse caregivers.

Italian Caregivers

In a phenomenological study with 26 Italian caregivers, Vellone, Sansoni, and Cohen, (2002) explored the experiences of family members caring for a person with AD. The authors noted that caregiving for persons with AD had been widely studied in other countries, most notably the U. S.; however, little knowledge of the topic existed in Italy which has the second highest prevalence of AD in the world, behind Japan. Six themes were identified which included: changes in relationships, changes in lifestyle, difficulties in caring, lack of support and knowledge, hopes and fears for the future, family duty, and respectful treatment. Themes which the authors reported and attributed to the Italian culture included a desire to limit family involvement in caring so as not to burden adult children with their own families, little assistance with home care and respite services from the national health system, and a general lack of knowledge about the illness. The participants also described their faith in God's help and their duty to provide care for their loved one. The authors noted that this information offered nurses in Italy ways that they could effectively improve the quality of life for Italian caregivers.

Auglia et al. (2004) surveyed 236 Italian caregivers of persons with AD with the intent of describing these caregivers and assessing their level of stress. The typical caregiver was a female, either a wife or daughter, approximately 60 years old, and, on average, devoted three-quarters of their day to the care recipient. As functional dependency increased, so did the level of need for care and supervision of the family member with AD. Often, the demands of care necessitated that the caregiver must either reduce or leave their place of employment in order to provide the care needed. The

authors recommended that these findings support the need for community services that will help to alleviate the burden associated with this demanding care.

Sansoni, Vellone, and Piras (2004) conducted a study with 34 female Italian caregivers living with a care recipient with AD. The purpose of this descriptive, correlational, repeated measures design study was to investigate levels of anxiety and depression among these caregivers. The authors also examined the correlations among anxiety and depression scores and sociodemographic variables, caregiver requirements, and physician ratings of mental impairment among the care recipients. The study found that the hours spent in caregiving were positively correlated with depression and anxiety; that is, those caregivers who spent more hours per day in providing care, scored higher on the anxiety and depression scale. Also, a significant finding was that caregivers with increased level of education had a decreased incidence of depression. The authors proposed that education may be a protective factor that assists caregivers in dealing with depression. The major limitation of this study was the sample size and the fact that only women were enrolled, but the authors suggest that the findings demonstrate the need to provide Italian AD caregivers education and support as they are in the caregiving role.

Chinese American Caregivers

Zhan (2004) conducted interviews with four Chinese American caregivers about the experience of caring for family members with AD. The purpose of the study was to identify factors that hindered or facilitated Chinese American caregivers in obtaining a diagnosis of dementia and in receiving services. Zhan (2004) found that there are strong stigmas attached to a diagnosis of AD because it is seen as an indication of a mental illness which is considered shameful. These stigmas were identified as barriers to

accessing services, as well as a lack of family and community support, negative interactions with health care providers, language difficulties, and a lack of culturally specific AD services. Factors which facilitated appropriate care included the resources of the Alzheimer's Association, the cultural belief of valuing care for older adults, and resources of home care services offered through Medicaid.

Gender Variations in Caregiving

In order to gain insight into the world of the male caregivers, Harris (1993) conducted an exploratory study with 15 husbands caring for their wives with AD. In-depth interviews were conducted and later transcribed. Common themes that emerged from the interviews included: "commitment; social isolation/loss of companionship; coping strategies such as control; a structured routine combined with respite care, a problem solving approach, and outside activities; a sense of accomplishment; the need for specialized services for men; and limited expectations of help from their children" (p. 553).

Harris (1993) was also able to identify a typology of male caregivers through the analysis of the transcribed interview. The "worker" (n=3) was one who modeled the caregiving role after their work role. The caregiving role became for them a new work identity. The "labor of love" role (n=4) was motivated by their devotion for their wife. The men with "a sense of duty" (n=5) felt an overwhelming sense of responsibility to care for their wife and those men described as "at the crossroads" (n=3) were the newer caregivers who had not yet oriented to the caregiving role and expressed the most stress. While the implications of the study were limited due to the nonrandom, purposeful

sample, the authors suggested attention to gender specific needs when working with caregivers. The authors also recommended that caregivers who are at the “crossroads” may need to be targeted first for education and service interventions. Some of the caregivers discussed the benefits of having a nurse explain how to care for their wife, and expressed a need to speak with more experienced male caregivers (Harris, 1993).

Yee and Schulz (2000) reviewed research reports published between 1985 through 1998 that studied gender differences in psychiatric morbidity among caregivers of frail elders, physically ill adults, and/or demented adults. Their goal was to determine if there was greater psychiatric morbidity among female caregivers and if this morbidity was attributable to the caregiving situation. Most of the studies reviewed showed that female caregivers had higher levels of depression, anxiety, and general psychiatric symptoms when compared with men as well as lower levels of life satisfaction. When compared with non caregiving samples, the larger differences in depression scores among female caregivers pointed out that it was at least in part due to the caregiving experience.

Yee and Schulz (2000) then used a stress process framework to evaluate the factors that may contribute to excess psychiatric morbidity among female caregivers. Most of the studies reviewed highlighted that women spent more time involved in caregiving tasks than men; however, there were inconsistent results on the number of actual caregiving tasks performed by each group. In the area of housework related responsibilities, adult daughters were more likely to perform these tasks when compared with sons; however, results were less conclusive for spouse caregivers. Generally, female adult children and spouses provided more assistance with personal care yet no differences

were found between men and women in terms of care management tasks that involved such things as shopping and transportation between men and women. Overall, women reported higher levels of burden or strain, more interference with work and social life, and used less coping resources when compared with men. Men were more likely to relinquish the caregiving role as the care recipient became increasingly disabled and were more likely to obtain assistance with caregiving.

Based on these findings, Yee and Schulz (2000) recommend that “at risk” women must be targeted early in the caregiving process with strategies to reduce the psychiatric morbidity. This can include such things as the use of adult day care and respite programs, counseling and support programs, and training in skills and preventive health measures. Policy recommendations included research in the area of reducing the severity of conditions that require long term care such as AD and other conditions that impair the functional ability of older adults. Also recommended were policies to increase options for caregivers such as family responsive workplaces to meet the demands of caregiving, and policies that could encourage men to take on the caregiving role such as employer subsidized elder care.

In an exploratory study of 30 primary caregivers of persons with ADRD, Robinson et al. (2001) measured the frequency of problem behaviors in the care recipient and the caregiver reaction to these behaviors. The authors found a significant relationship between the frequency of problem behaviors and social and personal restrictions on the caregiver’s life. Also significant was the caregiver’s perception of the severity of the problem behavior rather than the actual frequency of occurrence of the behavior. Females also experienced a greater reaction to problem behaviors. The authors concluded that

caregivers, especially females, needed to receive individualized, specific education, and training on how to understand and manage disruptive behaviors in persons with ADRD.

Pinquart and Sorensen (2006a) used a meta-analysis to examine the gender differences in caregiver outcomes. The meta-analysis included 229 studies of which 46% focused on dementia caregiving, 15% on caring for the physically frail older adult, and 39% included both dementia and non dementia caregivers. The authors found that caregiving women reported higher levels of burden, depression, lower levels of physical health and subjective well-being than men. Caregiving women also described more problem behaviors in the care recipient, more hours devoted to caregiving, as well as more caregiving tasks. No significant differences were found for use of formal support, or use and availability of informal support. Interventions designed to address women's level of stressors were recommended.

Summary

The studies presented demonstrate that culture and gender have an effect on the caregiving role. These factors may also influence who transitions into the caregiving role and their response to that role. Any interventions to support caregivers must take into account the effect of beliefs, customs, traditions, and differences based on ethnicity, culture, and gender.

Alzheimer's Disease and Caregiver Burden

The concept of burden commonly appears in the literature as an effect of the caregiving role (Kinney, 1989; Morimoto et al., 2003; Novak, & Guest, 1989; Vitaliano et al., 1991; Zarit et al., 1980). This concept of burden becomes an important phenomenon to understand in beginning to understand the role of the caregiver.

Novak and Guest (1989) developed the *Caregiver Burden Inventory (CBI)*, a multidimensional measure of caregiver burden. According to the authors, previous tools had not distinguished between dimensions of burden and its ultimate impact on caregivers. The CBI is a 24 item tool which categorizes burden related to five factors. These factors included restrictions on the caregivers' time, developmental stage, physical health, social roles, and emotions. Time dependence referred to restriction on caregiver's time related to assisting with ADLs, feelings of increased responsibility, and a need for vigilance due to disease progression in the care recipient. Developmental burden was described as the feeling of being unable to follow a predictable life course. Other components of burden were described as the affect on physical health and feelings of fatigue (physical burden), role conflict (social burden), and feelings of guilt, resentment and anger (emotional burden). Often the authors found that the caregivers' perception of caregiving and availability of support systems affected their sense of burden.

In a study comparing the stress and psychological morbidity among caregivers of elderly with dementia versus those without dementia, Gonzalez-Salvador, Arango, Lyketsos, and Barba (1999) found that caregivers of persons with AD experienced increased levels of stress and psychological morbidity. A cross-sectional, case control design was used with 58 caregivers of persons with AD and compared to 32 caregivers of chronically ill persons without dementia. Compared to the controls, stress was found to be higher among the AD caregivers and related to behavioral symptoms in the care recipient as well as impaired capabilities with activities of daily living. Psychological morbidity was also higher in this group and correlated with the length of time providing care. The authors suggested that attention needs to be paid to the treatment and

management of both behavioral and functional symptoms in the AD patient along with education and coping skills for the caregiver.

In a qualitative, reflective study, Juozapavicius and Weber (2001) interviewed 20 former caregivers of AD patients who had died. The authors reported that one of the biggest problems that caregivers identified were a lack of reciprocity in the caregiving situation. In other types of caregiving, the loved one may be able to attempt to express gratitude for the care received; however, by the middle and late stages of the disease, when caregiving needs are greatest, the care recipient is no longer able to express appreciation for that assistance.

Meuser and Marwit (2001) in their study with 87 spouse and adult child caregivers of persons with dementia; found that anticipatory grief was common among caregivers. The authors used a both a questionnaire and focus groups to collect the data from participants recruited through the Memory and Aging Project (MAP) at Washington University School of Medicine. Based on their findings, Meuser and Marwit (2001) suggest that interventions should be targeted to the demands of care and expectations. Suggestions included providing adult-child caregivers precise information on the early stages when they may be in denial, and services such as support groups for spouse caregivers who appeared more knowledgeable and realistic in the early stages. As time progressed to the moderate stages; anger management strategies appeared to be needed for adult children, however the spouses were typically experiencing extreme sadness at this time.

A triangulated study was conducted by Narayan, Lewis, Tornature, Hepburn, and Corcoran-Perry (2001) to examine the relationships between spouse caregivers' positive

and negative subjective responses to caregiving, and to understand the experience of being a spouse caregiver for a person with dementia. The sample of 50 spouse caregivers completed quantitative measures of positive and negative responses to caregiving, as well as interviews about their caregiving experiences. The authors found that spouse caregivers experienced caregiving as self-fulfilling and affirming while at the same time experiencing loss and hardship. Those caregivers that believed that caregiving had enriched their lives saw themselves as competent and confident caregivers. Those who suffered from a loss of their intimate relationship were more likely to feel trapped in the caregiving role. These findings suggest that clinicians need to recognize that both negative and positive feelings can be present in the caregiver. The positive aspects of caregiving may help to reaffirm the caregiving experience. The negative responses indicate the need for support, such as working through the grieving process for those spouses that express the loss of an intimate relationship.

Markowitz, Gutterman, Sadik, and Papadopoulos (2003) surveyed 2477 caregivers of patients with AD to investigate the relationship of caregivers' health related quality of life (HRQOL) to the burden of caregiving. Support, perceived quality of patient medical care, fewer hours of caregiving, and fewer patient behavioral problems were significantly correlated with increased caregiver mental functioning. Disruptive patient behaviors were associated with both poorer mental and physical functioning of the caregivers. However, depressive symptoms among the patients were associated only with poorer mental functioning of the caregiver. The authors noted that timely diagnosis and the use of both pharmacological and nonpharmacological interventions can contribute to improved patient outcomes with a positive effect on caregiver HRQOL.

Adams and Sanders (2004) surveyed 99 caregivers associated with an urban Alzheimer's Association chapter about their losses, grief reaction, and depressive symptoms. The caregivers self-identified their care recipients' condition as either early, middle or late stage dementia. The authors found that caregivers in the early stages were concerned with missing activities they once shared with their loved one and losses that they anticipated happening such as the loss of plans and goals. Caregivers in the middle stages reported losses related to personal changes within themselves such as a loss of time and freedom. Those caregivers in the later stages were grieving the loss of the relationship with their loved one.

Gaugler et al. (2004) described the phenomenon of "unmet need" as a condition that exists when the caregiving demands exceed the resources of the caregivers or create some deficit in the caregivers' life. In an exploratory study of 694 caregivers of persons suffering from dementia, the authors examined the relationship of unmet need and subjective stress at three points of time for caregivers: those caring for the care recipient at home, following placement of the care recipient in an institution, and following the death of the care recipient. Their findings suggested that the unmet need of a formal or informal support system had a significant relationship to emotional distress for caregivers in all circumstances. Subjective distress was described as "role overload, role captivity and loss of intimate exchange" (p. 375). These findings suggested that programs looking to assist caregivers across all settings should incorporate the assessment of unmet needs in order to provide more effective interventions for the caregivers' holistic needs (Gaugler et al., 2004).

Summary

In summary, the selected studies addressing caregiver burden in those caring for a person with ADRD supported the need for caregiver education and support. Caregivers reported burden and stress as the dependency of the care recipient increased, and problem behaviors presented (Gaugler et al., 2004; Gonzalez-Salvador et al., 1999; Markowitz et al., 2003; Narayan et al., 2001; Novak & Guest, 1989). Further research on interventions to decrease caregiver burden (Gaugler et al., 2004; Gonzalez-Salvador et al., 1999; Novak & Guest, 1989), effective models for community services (Markowitz et al., 2003), and the positive aspects of caregiving (Mahoney, 2003) are warranted.

Interventions to Reduce Caregiver Burden

Meta-analyses and Reviews of intervention Studies

Over the past 20 years, a wealth of studies has been conducted in the area of interventions to reduce caregiver burden. Several studies have looked at educational programs as a means of providing caregivers with skills and information to be effective and satisfied; however, the results on the most effective educational strategies are inconclusive.

Acton and Kang (2001) conducted an analysis of the literature from 1966 to 1999 on the effect of interventions on caregiver burden in persons caring for family members with dementia. A variety of caregiver interventions were examined: support groups; education; psychoeducation, which included education along with supportive interventions; respite; and counseling. The authors found inconclusive evidence of the effect of interventions on caregiver burden and proposed that researchers should consider focusing on exploring measures to affect the positive outcomes of caregiving which

included finding meaning in the experience, and increasing both well-being and life satisfaction. These positive outcomes may be more amenable to change.

Schulz et al. (2002) conducted an analysis of 50 articles published from 1996 to 2001 reporting on 43 intervention studies with caregivers of dementia patients. In their review, they found that no single intervention was found to be consistently effective in achieving significant success in caregiver outcomes; however, most studies reported some level of success.

Bower, McCullough, and Pille (2002) conducted a review of studies published between 1994 and 2002 on the topic of education of family and staff caregivers of people with AD. Their intent was to describe the interventions that have been attempted as well as what interventions have been successful, and what further research was needed. The authors noted that while studies have been done that focused on education for caregivers and health care professionals, more studies were needed that focused on the specific content that needs to be delivered, educational approaches that are considered successful, how programs can be effective over time, and how nurses can help to educate the public about AD.

Sorensen, Pinquart, and Duberstein (2002) used a meta-analysis to determine the effectiveness of 78 intervention studies for family caregivers of older adults. More than half of the studies chosen focused on caregivers of persons with dementia (61%) while the remaining studies included both dementia and non dementia caregivers. The intervention studies were divided into two major groups, those that aimed to reduce the objective amount of care provided by the caregivers and those interventions whose goal was to increase well-being and coping skills in the caregivers. The outcome variables

being measured in the meta-analysis were: caregiver burden; depression; subjective well-being; uplifts of caregiving; knowledge and coping abilities; and care receiver symptoms and caregiver outcomes.

Overall, Sorensen et al. (2002) found that the interventions had a small to moderate effect on the outcome variables. Interventions which included a psychotherapeutic or psychoeducational component showed the most consistent effects on the variables of caregiver burden and depression, well being, and in increasing caregiver ability and knowledge. Based on the findings from the analysis, Sorensen et al. (2002) recommended that the length of the intervention should be matched to the program goals. For example, an intervention which includes seven to nine sessions, the average among the studies included, should be effective in increasing caregiver ability and knowledge, but not necessarily in improving caregiver depression. Spousal caregivers were also seen to benefit less from the interventions compared to adult children. Factors which may influence this included advanced age with possibly comorbid health problems, smaller social networks and decreased income. Dementia caregivers, when compared to non dementia caregivers and those in mixed samples, also benefited less from the interventions.

Sorensen et al (2002) proposed that interventions for dementia caregivers should combine respite, such as daycare, and training in coping skills and managing problem behaviors. Those interventions that were individually focused had more effect on caregiver well-being compared to group interventions which were shown to improve care receiver symptoms. The authors recommended that interventions be chosen based on the

goals, and in some cases, combining both individual and group interventions might be the best solution.

Brodaty, Green, and Koshera (2003) conducted a meta-analysis of published studies reporting on interventions for caregivers of persons with dementia. Thirty studies published from 1985 to 2001 were included in the meta-analysis. The primary outcome measures for the studies chosen were psychological morbidity and burden. From the analyses, the authors noted that the only significant factor that emerged was involvement of the patient in addition to the caregiver in a structured program. Interventions which were evaluated as unsuccessful included short educational programs, support groups alone, single interviews, and brief interventions which did not include long term contact.

Pinquart and Sorensen (2006b) expanded upon their previous meta-analysis (Sorensen, Pinquart, & Duberstein, 2002) to integrate that results of 127 intervention studies with dementia caregivers published or presented between 1982 and 2005. Studies which were included compared an intervention to a control group. Focus was on the effects of interventions on the caregiver variables of; burden, depression, indicators of subjective well-being, ability and knowledge, as well as the symptoms of care recipients, and risk of institutionalization. Pinquart and Sorensen (2006b) also compared the effects of various types of interventions and group versus individualized interventions. Similar to the Brodaty et al. (2003) meta-analysis, Pinquart and Sorensen (2006b) found a small to medium effect size for caregiver knowledge, abilities, and psychological health among larger samples. Only multicomponent interventions reduced the risk for institutionalization. A significant, although small, effect was found on caregiver burden. This effect, Pinquart and Sorensen (2006b) reported, is contrary to the findings of the

Acton and Kang (2001) and Brodaty et al. (2003) meta-analyses. The inclusion of more recent and improved studies was suggested as the rationale for this finding.

Pinquart and Sorensen (2006b) reported that psychoeducational interventions which involved active participation of the participants had the broadest effects. An example of active participation is role playing. Interventions such as; cognitive-behavioral therapy, support, counseling, daycare, training of the care recipient, and multi-component interventions had significant but small effects but were domain specific. Pinquart and Sorensen (2006b) recommended that interventions should be tailored to the individual needs of the caregivers in order to provide the most benefit. Suggestions for future research included; interventions which are more structured and intensive with inclusion of active participation, determination of the appropriate combination of effective interventions, mediators of intervention effects, individual differences in responses to interventions, more long term follow up on effects of interventions, and the short and long term effects of interventions with ethnic minority caregivers.

Selected Intervention Studies

Hepburn, Tornature, Center, and Ostwald (2001) conducted an experimental study to test role training as an intervention to help family caregivers appreciate and assume a more clinical belief set about caregiving. Ninety four caregiver/care recipient dyads were randomized to a training intervention group or to a control group assigned to receive the intervention five to six months later. Significant improvement occurred with the treatment group caregivers on measures of beliefs about caregiving, and reaction to behaviors, with improvement seen in measures of burden and depression.

Gitlin, Corcoran, Winter, Boyce, and Hauck (2001) researched the short term effects of a home environmental intervention on self-efficacy and upset in caregivers of persons with dementia, and on the daily function of the dementia patients. The authors also looked to determine if the treatment effect varied by caregiver gender, race, and relationship to the patient. Families of dementia patients were randomized to an intervention group (n=93) or to a usual care group (n=78). A small, but statistically significant, effect was found among caregivers in the intervention group who reported fewer declines in instrumental activities of daily living (IADL), less decline in self-care, and fewer behavioral problems in their care recipient. Intervention spouses also reported reduced upset with behaviors, women reported enhanced self-efficacy in managing behaviors, and minorities reported enhanced self-efficacy in managing functional dependency. The authors concluded that further research is warranted to evaluate a more intense and long term intervention involving home environmental strategies and the subsequent impact of improved self-efficacy on caregiver psychological and physical health.

Wright, Litaker, Laraia, and DeAndrade (2001) studied the effect of a year long nurse educational and counseling program offered to caregivers of persons with AD. Participants were recruited from an inpatient setting where their care recipient had received treatment for agitation. The researchers used a block sampling technique to maximize the number of participants who could receive the intervention, so 68 participants were assigned to an intervention group and 25 to a control group. The caregivers in the experimental group received two home visits and three phone calls from a nurse over the course of a year. The intervention consisted of educating caregivers on

strategies to manage problem behaviors in the care recipient, medication monitoring, and counseling. Caregivers were also referred to home care agencies, support groups, and AD programs as needed. The caregivers in the control group received five phone calls over the course of the year for the purpose of data collection only. Variables measured included: agitation and level of functional and cognitive impairment in the care recipient, caregiver depression, stress, and physical health. There were no significant treatment effects on agitation in the care recipient, caregiver stress, depression or physical health, or rates of institutionalization between the groups. The trends noted were that agitation in the care recipient rose over time in the control group participants, but declined for those in the experimental group. Caregiver depression rose for control group participants, but declined for those in the experimental group. Physical health in the caregiver declined in the control group; however, physical health was maintained for those in the experimental group. The authors noted that the block sampling method resulting in unequal groups may have been responsible for a Type II error and that control group participants may have viewed the phone calls from the nurse for data collection purposes as support. The authors recommend future studies with larger numbers of subjects, more frequent contacts by the nurse, and consideration of a different method of data collection for the control group participants.

Gitlin et al. (2003) examined the effects of a skill building program offered to 89 family caregivers of persons with ADRD. This randomized, clinical trial was implemented as part of the National Institute of Health initiative called REACH. The Philadelphia site tested a home-based environmental intervention called the Environmental Skill-Building Program (ESP). As part of the study, 89 caregivers were

enrolled in the intervention group who received five home contacts and one telephone contact from an occupational therapist who offered education, training on problem solving methods, and adaptive equipment. One hundred and one caregivers were assigned to a usual care group. Caregivers in the intervention group reported statistically significant improvement in three areas: objective burden, subjective burden, and affective well-being over a six month period as compared to the controls. More specifically, spouses in the intervention groups reported less upset with disruptive behaviors, women reported less need for help from others, and men reported less time spent in doing things for the care recipient or vigilance. Women in the experimental group also showed significant improvement in overall well-being, ability to manage caregiving, and enhanced affect, as compared to controls. The authors recommended that their findings indicated that such an intervention should be incorporated into community based services for families.

Hebert, R. et al. (2003) conducted an experimental study with 158 caregivers to test the efficacy of a psychoeducative group program for informal caregivers of persons with dementia. Caregivers were randomized to a control group receiving traditional support groups (n=79) or an intervention group which received 15 two hour sessions focusing on stress appraisal and coping (n=79). In the intervention group, significant findings included a decrease in the caregivers' reactions to behavioral problems in the care recipient and the frequency of behavioral problems decreased in the study group. This was one of the first studies to show a significant effect from this type of intervention on caregivers of persons with dementia.

Paun, Farran, Perraud, and Loukissa, (2004) conducted a descriptive study using the content analysis from an ongoing clinical trial testing the effectiveness of a caregiver skill building intervention. Data were collected from the six and twelve month follow up sessions. The authors found that the change in knowledge was insufficient to foster skill development. Caregivers who were successful combined the information and knowledge learned with emotional acceptance that they had a loved one suffering from an incurable disease. The authors suggest that clinicians must become aware of and assess for the complex process of learning, emotional acceptance, and behavior changes that require practice.

Kuhn and Fulton (2004) researched the effectiveness of an AD Knowledge Building Program designed for caregivers of relatives with early stage AD. The authors noted that educational programs frequent target caregivers of persons who are in the middle to late stages of the disease. The AD Knowledge Building program focused on the medical, legal, financial and psychosocial aspects of caregiving and consisted of five weekly sessions. The goal was to increase the participant's sense of self-efficacy, knowledge, coping skills, and to improve levels of depression. Forty-five caregivers participated in the intervention which was found to significantly increase caregivers' knowledge about AD, improve their self-efficacy and decrease their level of upset with problem behaviors in their care recipient. The intervention did not affect the level of depressive symptoms among the caregivers or the frequency of problem behaviors among the care recipients. While the sample size was small and did not include a control group, Kuhn and Fulton (2004) suggested that the intervention had value and further research is warranted to explore the nature of caregiving in the early stages of AD.

Kuzu et al. (2005) investigated the effectiveness of a comprehensive educational program reinforced by an individualized component (CEPRIC) on reported problems of caregivers. These problems included; depression, anxiety, and diminished quality of life. Thirty-two pairs of caregivers and their care recipients participated in the intervention. The program consisted of an educational session led by a nurse trained in AD, an educational booklet, and a follow up one-on-one session designed to allow the caregivers to discuss individual concerns. At the conclusion of the intervention, caregivers reported an increase in quality of life scores, and a decrease in depression and anxiety scores. Kuzu et al. (2005) also collected qualitative data which suggested that learning about effective strategies to address care recipient problems was helpful because they had not previously received sufficient information or felt burdened by it. Caregivers in addition reported losing social contact due to caregiving responsibilities.

Drentea, Clay, Roth, and Mittelman (2006) analyzed the effectiveness of a multi-component intervention designed to improve caregiving skills and social support for spouse caregivers of persons with AD. Ninety-four caregivers in the intervention group received individual and family counseling in the first four months of the study and at the end of this period were required to join support groups that met monthly. Caregivers also had counselors who were available to discuss any problems while they were enrolled in the study. Those caregivers in the control group (n=89) received information and referrals on request, but no formal counseling sessions. Caregivers were followed for five years. As Drentea et al. (2006) hypothesized, those caregivers in the treatment group reported higher levels of satisfaction with their social support network than those in the control group. These caregivers were better able to foster the emotional resources they needed

and to socialize more which predicted support network satisfaction. Drentea et al. (2006) were surprised to find that the amount of physical, financial, and informational support were not necessarily predictors of satisfaction. More likely it was an effective social network which included a number of people to whom the caregivers felt close and the amount of emotional support they received. The authors suggested that for those elder spouse caregivers who find themselves isolated, a close circle of friends and family may be what is of real importance.

Summary

The benefits of various interventions with caregivers have shown to be effective in reducing caregiver burden; however, there is inconclusive evidence on the most successful methods. Strategies to address the needs for ADRD caregivers included a combination of education, support, and counseling over time (Brodaty et al., 2003; Drentea et al., 2006; Gitlin et al., 2001; Gitlin et al., 2003; Hebert et al., 2003b; Hepburn et al., 2001; Kuhn & Fulton, 2004; Kuzu et al., 2005; Paun et al., 2004; Pinqart, & Sorensen, 2006b, Sorensen et al., 2002; Wright et al., 2001).

Education and Alzheimer's Disease

Several researchers have investigated how caregivers of persons with ADRD learn the responsibilities that entail caring for a loved one with ADRD. In order to investigate the process of learning to become a caregiver, it is imperative to examine what the literature offers on this phenomenon.

Graham, Ballard, and Sham (1997) surveyed 136 caregivers from three different categories about their knowledge and concerns about dementia. The categories included: caregivers who had not had any contact with mental health services for the elderly; those

who had contact with mental health professionals; and caregivers who had been in contact with an AD support group. The most knowledgeable caregivers were found to be those in the support groups. The authors attributed this to the fact that caregivers who participated in support groups had access to both written and verbal educational materials about the various aspects of dementia. No significant difference was found between the groups related to contact with mental health professionals. These study findings highlighted the need for accurate, well presented information tailored to individual caregiver's needs.

Werner (2001) conducted a study to assess the level of knowledge among family caregivers about AD among 220 caregivers of persons with dementia. Participants were recruited from four memory clinics and a questionnaire was used to determine the knowledge of the disease, symptoms, treatments, and services available. The study results indicated that levels of knowledge were low overall, especially in relation to the prevalence, causes, and symptoms of AD. Caregivers with a low level of education, less than 12 years, were reported as the most vulnerable and correlated low levels of knowledge about AD. These caregivers, Werner (2001) proposed, may have had less access to support groups which are often attended by highly educated caregivers and where information about AD is often shared. Also, children caring for their parents had significantly higher levels of knowledge than spouses. Werner (2001) proposed that understanding the correlates associated with the levels of knowledge among AD caregivers may help to identify the sketch of the caregiver who is in need of education and training.

Educating caregivers on simple communication techniques often can be an effective technique to assist in the management of activities of daily living for the care recipient. Small, Gutman, Makela, and Hillhouse (2003) investigated the effectiveness of recommended communication strategies with 18 persons diagnosed with AD and their spouses. Caregivers first identified the frequency and success with which they used 10 commonly recommended communication strategies and then they were assessed in their homes using wireless audio-recording on the use of these strategies. Based on both the caregivers' report and researchers' assessment, the communication techniques of eliminating distractions, using simple sentences, and yes/no questions were validated as effective techniques. While the sample size was small, such information can benefit the caregivers in the beginning stages of the disease as they begin to learn how to adapt to the disease and caregiving.

Education and Health Care Professionals

Several studies addressed the level of knowledge about ADRD among health care professionals. In a phenomenological study examining the experiences of nursing students caring for cognitively impaired elderly, Beck (1996) asked 37 undergraduate nursing students to describe in writing an experience they had while caring for a cognitively impaired elderly person. Themes that emerged from the analysis included innumerable emotions, such as frustration, sadness, fear and empathy. The care of these persons presented difficult challenges, multiple approaches were used to deliver care, and some students expressed negative consequences as a result of the experience. The authors concluded that the students were inadequately prepared to care for these patients and the recommendation was made that more content about AD needed to be taught in nursing

schools such as information about ageing, and therapeutic and coping strategies to use when caring for cognitively impaired elders.

In a study evaluating the level of knowledge among general practitioners about dementia, Turner et al. (2004) surveyed 127 physicians who had volunteered to participate in a randomized controlled trial of educational interventions about dementia. The researchers found that the study participants in general showed a poor awareness of the epidemiology of dementia and a lack of confidence in their ability to manage behaviors and other common problems in the dementia patient. The general practitioners reported difficulties in talking to patients about the dementia diagnosis, responding to problem behaviors, and being able to coordinate support services. Since early diagnosis and institution of support services may subsequently decrease stress in the caregiver and delay the need for institutionalization of the care recipient, the authors stressed the need for educational support for general practitioners.

Summary

The studies chosen which focused on education on ADRD for the caregivers supported the need for accurate and timely information on the disease process, problem behaviors, and communication techniques (Graham et al., 1997; Small et al., 2003; Werner, 2001). The deficiencies noted in medical and nursing education on ADRD content means that in general, health care professionals are not adequately trained to offer the education from which caregivers could benefit (Beck, 1996; Turner et al., 2004).

Summary and Conclusion

Challenges exist for caregivers of persons with ADRD along their care trajectory. From the beginning stages of uncertainty and diagnosis to the bereavement stage, the

research has shown the need for education and support. The goal of early diagnosis that leads to early treatment has implications for all health care providers. Education for ADRD caregivers on the disease process, progression, and treatments has been well documented as an effective means of maintaining the care recipient in the home and also in reducing burden for the caregiver (Hepburn et al., 2001; Paton et al., 2004; Robinson et al., 2001; Tackenberg, 1992). The evidence also reveals that caregivers need this support from the earliest stage of diagnosis when symptoms of ADRD are just beginning to emerge (Beisecker et al., 1997; Connell et al., 2004; Kazui et al., 2004; Teel & Carson, 2003; Vernooij-Dassen et al., 2003; Wald et al., 2003).

It is this stage, when caregivers are transitioning into a role for which they may be unprepared, that needs further exploration.

Teel and Carson's (2003) study of the experiences of families as they sought a dementia diagnosis provided a glimpse of challenges of the early period of caregiving. Only one study was found that focused on the lived experience of the caregiver as they transitioned into this role (Adams, 2006). This area constituted a gap in the literature and provided support for the study. While evidence suggests that support and education may be effective during this transition period, the perspective of the experience from the caregiver needs to be heard. Only caregivers can share the meaning of the impact of the dementia diagnosis and the new role of caregiving.

Using a phenomenological approach with caregivers about their experience of transitioning to care for a family member with dementia, this research study intended to contribute to the knowledge of the significance of that transition and implications for practice. The results of this study provide an understanding of the experience from the

perspective of the caregiver. This information can guide practice for nurses in the early stages of ADRD.

CHAPTER III

METHOD

This chapter summarizes the philosophical underpinnings of the phenomenological movement. It describes the study design, sample and setting, and the methods of data collection and analysis. The procedures for protection of human subjects and the criteria for assuring trustworthiness of the data are also included.

Philosophical Underpinning

Carper (1978) identified four fundamental patterns of knowing in nursing; “empirics, the science of nursing; aesthetics, the art of nursing; personal knowledge in nursing; and ethics, the component of moral knowledge in nursing” (p.14) as essential in the teaching and learning of nursing. Traditional quantitative research methods have contributed to the development of nursing science or empirics; however, beginning in the late 1970s and early 1980s, nurse researchers questioned whether these quantitative methods were adequate to study human life experiences. It became evident that science alone would not answer the important questions in the discipline of nursing and phenomenology was identified as a research method that could provide an understanding of the person and the human experience (Van der Zalm & Bergum, 2000). The results of a phenomenological inquiry allow nurses to gain an understanding of that which is meaningful and important to the individuals they care for. This information enlightens nursing practice, and contributes to moral, aesthetic, and personal knowledge development and a holistic approach to the care that is delivered.

Phenomenology is both a philosophy and research method of inquiry that is used to determine “what an experience means for the persons who have had the experience and

are able to provide a comprehensive description of it” (Creswell, 1998, p. 53).

Phenomenology offers the possibility of studying human experience in the context of the informants’ world which includes not only their physical and social environment, but also their history, concerns, and aspirations. Through this process, meanings are developed and shared (Madjar & Walton, 1999). The assumption of this method is that, in sharing experiences, the individual contributes to knowledge of the phenomena being studied (Crowe, 1998).

Phenomenology first appeared as a method of inquiry in the latter half of the 19th century with the work of a philosopher, Franz Brentano (1838-1917) and his colleague Carl Stumpf (1848-1936) (Cohen, Kahn, & Steeves, 2000). This period was known as the preparatory phase of the phenomenological movement and the goal for these philosophers was to provide answers that religion could no longer supply and to make psychology truly scientific by basing it on descriptive psychology (Cohen, 1987; Cohen et al., 2000; Parse, Coyne, & Smith, 1985).

The German phase of the Phenomenological movement followed and was dominated by Edward Husserl (1859-1938), a German philosopher and mathematician, and Martin Heidegger (1889-1976) (Cohen et al., 2000). Husserl strived to gain a logical understanding of the nature of the lived experience and introduced the idea of eidetic reduction or bracketing as the reduction from particular facts to “general essences” (Cohen et al., 2000, p. 7). Husserl’s thought was that in setting aside preconceived notions, the researcher would be able to objectively describe a phenomenon under study; he assumed that people are able to separate personal knowledge from life experiences (Byrne, 2001). Heidegger was a junior colleague of Husserl, and developed this

perspective further as he focused on the meaning that individuals attribute to an experience and thus how phenomena are interpreted. Heidegger did not believe it was possible to bracket out assumptions of the world, but rather saw individuals' life experiences, background, and the world in which they lived as the context in which experiences should be interpreted (Byrne, 2001; Cohen, 1987; Cohen et al., 2000).

The practice of phenomenology moved from Germany to France and since World War II has been the dominant philosophy there. The central figures in this phase were Gabriel Marcel (1889-1973), Jean-Paul Sartre (1905-1980), and Maurice Merleau-Ponty (1908-1961) (Cohen, 1987; Cohen et al., 2000).

The phenomenological movement gave rise to three different schools of phenomenology; descriptive phenomenology, hermeneutics, and the Dutch school of phenomenology (Dowling, 2004). Descriptive or eidetic phenomenology is based on the work of Husserl and is also known as objective hermeneutics. The goal is to maintain objectivity regarding the phenomenon under study and uses bracketing or phenomenological reduction by the researcher as a means to accomplish this (Dowling, 2004). In this process, the researcher must identify and suspend all beliefs, assumptions and biases about the phenomenon under study so that they do not bring their preconceived ideas into the description of the experience (Speziale & Carpenter, 2007). The Duquesne school of phenomenology was based on this philosophy (Cohen et al., 2000).

Hermeneutic or interpretive phenomenology is guided by Heidegger (Dowling, 2004). Using Heidegger's approach, the researcher seeks to understand "...the meaning of being" (Mackey, 2005, p.181) and how individuals interpret experiences (Cohen et al.,

2000). A major difference between hermeneutic phenomenology and descriptive phenomenology is that the researcher is not required to bracket out preconceptions of theories during the process (Speziale & Carpenter, 2007).

Phenomenological research in nursing has been most influenced by the work of Husserl, Heidegger and the Dutch phenomenology of the Utrecht school. The Dutch phenomenological approach combines both descriptive elements which can be attributed to Husserl and interpretative elements which can be attributed to Heidegger. Known as the hermeneutic phenomenological approach, the goal is to both describe the experience under study as well as to understand the meaning that the individual ascribes to the experience (Van der Zalm & Bergum, 2000).

Design

The study design was based on the hermeneutic phenomenological approach which offers the premise that individuals seek to make sense of their experiences. Cohen et al. (2000) describe this process further:

The understanding people have of their world and life situation and the meaning they have made of this is usually contained in the narratives or stories they tell, first to themselves to make sense of their own experiences, and then to family, friends and other social actors in their lives, and finally to any social scientists who come asking. (pp. 59-60)

The hermeneutic phenomenological tradition holds that in the act of turning experiences into stories, the informants have already interpreted the meaning of those experiences (Cohen et al., 2000). Van der Zalm and Bergum (2000) described the results of a phenomenological inquiry as “a life-world account of a phenomena upon which we

can reflect, and say ‘so that is what it is like’” (p. 214). Beginning to understand a situation affects the way in which individuals respond to and find meaning in similar situations.

The course of analysis is a circle of interpretation that begins with a naïve understanding and emerges to an explicit understanding (Speziale & Carpenter, 2007). The framework of hermeneutic phenomenology acknowledges that persons are unavoidably bound together in their worlds. The researcher’s role is to acknowledge any assumptions that could influence their conduct of interviews, observations, and interpretation as much as possible. As a circular process of analysis, the narratives and interpretations are examined simultaneously so as not to lose sight of each individual participant’s story and context (Crist & Tanner, 2003). The hermeneutic circle is a metaphor that “guides the process of inquiry on several levels” (Cohen et al., 2000, p.72). The researcher needs to uncover the meaning of the smallest statements in relation to the larger unit of data and vice versa. Also important is that the researcher must consider the context of all experiences (Cohen et al., 2000).

The hermeneutic phenomenological method can be used when investigating questions of meaning and to understand the experience from the perspective of those who are having it. An advantage of the phenomenological approach is that it gives nurses an understanding of patients’ experiences, which in turn allows them to interact in ways that are different than those nurses who lack that understanding. “The meanings that patients attribute to their experiences help create the needs they have and how those needs can best be met” (Cohen et al., 2000, p.4). It can also be a useful method when studying a new topic or one that needs a fresh perspective.

The focus on feelings with the phenomenological method made it the most suitable method for the study as the literature review has revealed only two studies reflecting on the caregivers' experiences in this time of transition. Listening to caregivers describe the experience of transitioning to the role of caregiver for a family member with ADRD and the meaning they ascribe to the experience can help nurses understand the caregiver's perspective as they assume this important role. This understanding of the human experience of transitioning to caregiving also will help to develop a model of care for nurses interacting with new caregivers of persons with ADRD on the basis of that understanding.

Sample and Setting

Sample

Study participants were drawn from the research database for Project ACT (Advanced Caregiving Techniques) from the Center for Applied Research on Aging and Health at Thomas Jefferson University. Project ACT (#R01 AG22254) is a large randomized controlled trial funded by the National Institute of Aging (NIA) and the National Institute of Nursing Research (NINR). The researchers are currently testing the efficacy of a home-based intervention designed to reduce the occurrence of troublesome behaviors in persons with ADRD. The researcher serves as the Nurse Interventionist on this study and received permission from the Primary Investigator to access the database of participants from both the control and experimental groups, once they completed all study measures. There was a potential pool of approximately 140 eligible participants that could be accessed from this group and on average; they have been in the role of caregiver for four years.

The caregivers recruited from this site are considered “veteran” caregivers in that they have already been providing care for a loved one with ADRD and were asked to reflect back on the experience of their role transition to caregiver. They can also be seen as “expert” caregivers who, in recreating the experience of transitioning, have familiarity with health care professionals, possibly use pharmacologic therapy for their care recipient, and possess knowledge of services and information that would have been helpful during their transition.

Sampling Method

Purposeful sampling was used in this study. In purposive sampling, participants who have experienced the phenomenon being studied are recruited (Cohen et al., 2000), which is in this case, transitioning to the role of caregiver for a family member with ADRD. With this method, participants are added until the needed data requirements are met, usually to a maximum of ten participants (Kleiman, 2004). The exact number of participants can not be predetermined since the goal is to continue data collection until “saturation” is achieved. Morse and Richards (2002) describe saturation of the data as the time when the investigator “has the sense of having heard or seen it all” (p. 174). At this point, the data are being replicated in several cases and with replication comes verification of the phenomenon.

The sample was considered adequate in this study when the researcher noted redundancy of statements regarding the phenomenon under study (the experience of transitioning to the role of caregiver for a family member with ADRD) and no new findings were revealed with additional informants (Crist & Tanner, 2003; Parse et al., 1985). Evidence from the literature indicates that meaningful data were obtained in

similar qualitative studies using five to twenty-six informants (Harris, 1993; Paun, 2004; Perry & Olshansky, 1996; Vellone et al., 2002).

Inclusion/Exclusion Criteria

Inclusion criteria for the participants included family caregivers who: 1) identified themselves as the primary, unpaid caretaker of a community dwelling person diagnosed with ADRD by their physician; 2) were 21 years of age or older; 3) were English speaking; 4) were responsible for the physical, emotional, and/or spiritual care for their family member with ADRD; 5) agreed to share experiences and participate in the study; and 6) were available for two interviews over approximately a two month period.

Exclusion criteria for participants were those caregivers who: 1) stated that they were not able to reflect back on their transition to a caregiving role for a person with ADRD; or 2) those that did not meet the inclusion criteria.

Recruitment Strategies and Techniques

The researcher, with permission of the Principal Investigator of Project ACT, coordinated a mailing from the Center for Applied Research on Aging and Health at Thomas Jefferson University to the pool of completed participants from Project ACT who agreed to be contacted per the requirements of the Health Insurance Portability and Accountability Act (HIPAA). The Principal Investigator provided a letter of introduction informing them of the proposed study, and that the researcher would be contacting them to invite them to participate in the study (Appendix A). Letters were sent out in waves so that interested caregivers would not be turned down and to meet the goal of saturation of the data.

Participants were offered a ten dollar gift certificate from their choice of a local convenience store or one of three local pharmacies, after each interview to thank them for their participation. This approach had been shown to be well received by the current participants in Project ACT, and the researcher had received funding from the Summer Exploration fund at Thomas Jefferson University to support this expense. The amount of ten dollars was also not considered excessive and would not be used as a measure to coerce participation (American Psychological Association, 2005). All of the participants had met the researcher once through their participation in Project ACT. This familiarity may have served as a further incentive to participate in the study.

Setting

The participants were asked to take part in the interviews either in their home or in a private setting of their choice. The choice of setting was offered to allow the participants the opportunity to share their experiences in a comfortable environment without the concern of having to travel or arrange care for their relative with ADRD. All participants chose to meet in their home and either their care recipient was at an Adult Day Program or if home, was in another part of the home.

Data Collection and Analysis

Methods of Data Collection

The primary methods for data collection were interviews, conducted by the researcher in the participants' homes, and field notes. Participants who contacted the researcher either by phone or mail were screened via a follow up telephone call to determine their eligibility for the study based on the inclusion criteria established. This telephone call also served as a means of describing the study for the participants and

answering questions. Once the participant agreed to participate in the study, the researcher set up a meeting date, time and place.

Interviews.

Two interviews were conducted for data collection purposes. At the first interview, the researcher reviewed the consent form with the informant, allowed time for questions, and then asked the participant to sign the consent form (See Protection of Human Subjects). The researcher also collected demographic data for the purposes of describing the sample (Appendix B). This tool was developed by the researcher and contained 17 questions about both the caregiver and the person with ADRD such as: age, marital status, gender, highest level of education, occupation, and culture/ethnicity of the caregiver and care recipient. The caregivers were also asked about the length of time in the caregiving role, average amount of hours spent per day caring for their family member with ADRD, and if they attend a support group. Alzheimer's disease has been known to follow a course of approximately eight to ten years (Bullock, 2004), and those questions served to gain an understanding of where the participants are in the care trajectory, early vs. late stages. Since researchers have noted that the most knowledgeable caregivers tend to be those who attend support groups (Graham et al., 1997), a question regarding involvement in support groups was also included.

When using a hermeneutic phenomenological method to solicit narratives for a retrospective reflection of a phenomenon, interview questions that turn the informant to the experience must be developed (Cohen et al., 2000). These open-ended questions were used as a guide to encourage participants to talk freely about their experience of transitioning to caregiving. In the first interview the researcher started with the question

“Tell me about the day you learned about your family member’s ADRD diagnosis.” Additional follow-up questions such as “Tell me about key events that led up to the diagnosis.”, “Did your life change from the time of diagnosis?”, if yes “Tell me more about those changes”, “How did you know what to do for your family member?”, “Tell me what would have been helpful to you during this time of diagnosis and early caregiving”, “Can you describe anything that made this time of diagnosis and early caregiving more difficult?” were used to elicit further explanation. The interview was guided by the informant. Appendix C includes other open-ended probes that were used to further explore the experience of transitioning to the role of caregiver. The goal was to offer the participants the opportunity to provide a rich, detailed accounting of their experience (Polit & Beck, 2004).

The first interview varied between 60 and 90 minutes and ended when the caregivers had nothing more to add. All sessions were audiotape recorded. After each session, the tapes were transcribed verbatim by a transcriptionist and the transcripts were verified for accuracy by the researcher.

The second interviews occurred three to five weeks after the first interview and were for the purpose of confirming and clarifying the preliminary analysis of the data, and to serve as a conversation that offered the informant another opportunity to share more narratives about their experience. Questions such as “Have you thought of any other information since I last spoke to you”, and “Is this what you meant?” were used. Cohen et al. (2000) note that participants often reflect on their experiences after the first interview and can offer enriched data during a second interview. Crist and Tanner (2003) also note that a subsequent interview with informants allows the researcher the opportunity to

“gain informant’s reflection of the interpretations derived from the previous narratives, and any new lines of inquiry” (p. 203). All of the participants completed a second interview and these interviews varied between 45 to 60 minutes.

Field notes.

The researcher also took notations, otherwise known as field notes, as the second method of data collection, to record aspects of the interview that were not be available from the transcript of the tape. The fieldnotes can also be a very useful source of validation of important points made by the participants and in providing emphasis on developing themes (Speziale & Carpenter, 2007). These notes included descriptions of such things as participants’ facial expressions, body language, intonation, distractions in the environment, and observations related to the setting/environment (Cohen et al., 2000). The fieldnotes were transcribed into the narrative text as soon as possible by the researcher. Cohen et al. (2000) note that “both fieldnotes and documents are invaluable in writing about the context of the findings allowing detailed description of the circumstances surrounding the specific lived experiences studied” (p. 68).

Data Analysis

Data analysis was accomplished using the phenomenological methods described by Barritt, Beekman, Bleeker, and Mulderij (1984) and Cohen et al. (2000) according to the Dutch phenomenology of the Utrecht School. The process was as follows:

1. The researcher read through the data several times in order to become immersed in the data. Through this process, the researcher identified essential characteristics or common themes. Using the language of the informants, the

researcher extracted important elements that described the experience of learning to become a caregiver.

2. The researcher transformed or reduced the data in the second stage. This process is also known as editing and involves reorganizing the interviews to place similar topics together and eliminating information that is not considered relevant without changing the character of the interview (Cohen et al., 2000).
3. Then the researcher analyzed themes. The goal for this part of the analysis was to find common or shared themes and language that captures these themes. In this step, the researcher read through the transcripts with fresh eyes and selected from it phrases that seemed to be at the center of the event for the informant. Themes were labeled and passages that had similar themes were extracted. A continual process of moving back and forth from the text to theme statements allowed for identification of unique as well as shared themes. Informants were asked to clarify, as needed, this analysis in the second interview.
4. The researcher analyzed the fieldnotes to contextualize and clarify themes from the interview data.
5. The researcher in the next step attempted to put the experience in a different context, known as “phenomenological variation” (Barritt et al., 1984). The purpose here is to give a sharper picture of the shared aspects of the lived experience by seeing whether the themes identified may have been experienced by the participants in a different context.

6. The researcher then completed the descriptions using materials from sources such as the literature, observations, and interviews. Cohen et al. (2000) note that “when informants mention specific literature that they have read and that has affected their experience, that literature should be collected and studied” (p. 69). The goal here is to include only what can be useful in giving an adequate picture of the lived experience. Books that caregivers found particularly useful will be described in Chapters IV and V.
7. The researcher asked participants to comment on the accuracy of the preliminary analysis at the second interview.

Data were managed using the computer software program NVivo (QSR International, 2003). This program edits, codes, and labels the text allowing for easier retrieval of themes, eliminating the need for the manual cutting of data (Cohen et al., 2000). The researcher attended a training program for the use of this software in April 2006.

Procedure for Protection of Human Subjects

The proposed research was submitted to the Institutional Review Boards (IRB) of both Duquesne University and Thomas Jefferson University. Approval was received by both prior to beginning the study (Appendix D and E).

Each participant was asked to sign a consent form after receiving a verbal and written description of the study which included the following: purpose of the study, type of data that will be collected, procedures that will be used to collect the data, the nature of their commitment, the fact that participants may withdraw from the study at any time. The consent also included the information that the risk of participating in the study is

minimal, and that all information will be kept confidential. Once each participant orally agreed to participate and had sufficient opportunity to ask questions, he/she was asked to sign the consent form (Appendix F). The researcher also signed the consent form and both the participant and the researcher each kept a copy.

The researcher informed each participant that there was the possibility that he/she may become upset as he/she shared their experiences of transitioning to the role of caregiver. In the event that the informant became distressed at any time during the interview, it was planned that the researcher would alert him/her that they could stop and rest for a while or that he/she could continue with the interview at another time. If needed, the researcher was prepared to refer the caregiver to the Alzheimer's Association 24 Hour Helpline. This helpline provides guidance, decision-making support, crisis assistance, education, and referrals to local community programs, services, and ongoing support (Alzheimer's Association, 2005). All caregivers were left with information on the Alzheimer's Association Helpline.

A number was used to identify each informant on the tape and interview transcript. Only the researcher has access to the list that links the code number and name of the informant. This master list is being kept in a locked cabinet in the researcher's office until all data analysis and presentations are completed.

The transcriptionists hired for the study also signed a consent form of confidentiality in which they promised to adhere to confidentiality in dealing with the tape-recorded material for the study (Appendix G). Data will be kept in a locked cabinet in the researcher's office until the study, presentations, and publications are completed.

Trustworthiness of the Data

Rigor in qualitative research is demonstrated through accurate representation of the participants' experiences (Speziale & Carpenter, 2007). An indicator of the trustworthiness of the data is the ability to follow the decision or audit trail related to the theoretic, methodological, and analytic choices used by the researcher (Whitehead, 2004). Using the criteria identified by Guba and Lincoln (1989), this researcher followed certain procedures to ensure trustworthiness or credibility of the data. Guba and Lincoln (1989) describe the process of credibility as "establishing the match between the constructed realities of the respondents, and those realities as represented by the evaluator and attributed to various stakeholders" (p. 237). Techniques to accomplish this include prolonged engagement, persistent observation, peer debriefing, and member checking (Guba & Lincoln, 1989).

Each of these primary elements of trustworthiness will be presented along with the measures used in the study to ensure credibility.

Decision/Audit Trail

The decision/audit trail is a means of demonstrating to the reader how the researcher analyzed the data and came to the conclusions or interpretations reported. Parts of the audit trail include; the raw sources of data (transcribed interviews, field notes, and any related documents), the products of data reduction and analysis (codes, concepts, themes and clusters), and the findings. This record attests to the fact that the data have gone through a process of analysis, reduction and synthesis (Wolf, 2003). During the course of the study, all materials, including audiotapes and raw data were stored in a

locked cabinet in the researcher's office. All materials will be destroyed when all activities related to the research are completed.

Prolonged Engagement

Prolonged engagement requires that the researcher invests sufficient time in the process of data collection in order to gain a thorough understanding of the individual and phenomenon being studied. This technique is also a necessary step to build rapport and trust which will lead to the sharing of accurate and rich information (Polit, Beck, & Hungler, 2001; Polit & Beck, 2004). In this study, prolonged engagement was accomplished through interviews in the informant's homes which were conducive to the development of rapport between the researcher and participant. Once the consent form was signed, the researcher used the demographic questionnaire as an opening to the first interview, and a lead in to the open ended questions. The second interview was also another opportunity to gain further observations and correct any misinterpretations. Finally, the verbatim transcripts of the audio-taped interviews were read and reread to immerse the researcher into the data.

Persistent Observation

According to Lincoln and Guba (1985), "If prolonged engagement provides scope, persistent observation provides depth" (p. 304). The technique of persistent observation refers to the researcher's focus on aspects relevant to the experience under study (Polit & Beck, 2004). The home allowed for opportunities for persistent observation of relevant findings recorded in the form of field notes related to the topic of transitioning to the role of caregiver for a family member with ADRD. The field notes

were another method of data collection and method triangulation, or the use of multiple means of data collection (Polit & Beck, 2004), enhances credibility as well.

Peer Debriefing

Peer debriefing is the use of an external expert to reflect on the accuracy of the interpretations of the data. This process exposes the researcher to questions related to the themes identified, evidence of bias, possible omissions, and errors of fact or interpretation (DePoy & Gitlin, 2005; Polit & Beck, 2004). Peer debriefing strengthens the legitimacy of the findings and was done with an expert in the phenomenological method for the purpose of checking preliminary findings, conclusions, and tentative analysis. This process involved analysis of the first three interviews separately, followed by a comparison analysis with an expert in the phenomenological method. Periodic checks on the analysis also continued throughout the study.

Member Checking

Member checking is the most crucial technique for establishing credibility according to Guba and Lincoln (1989), and involves verification of the data and analysis with the informants. The researcher returned for a second interview three to five weeks after the initial interview in all of the cases. During this interview, the participants were asked to confirm the preliminary analysis of the data, and clarify any questions that the researcher may have. This interview offered the informant another opportunity to share more narratives about their experiences that they may have reflected on since the first interview. An important part of this technique was that the participants were able to correct misinterpretations since they are considered the experts of their experience (Cohen et al., 2000; DePoy & Gitlin, 2005).

Conclusion

This chapter has provided the specifics of the hermeneutic phenomenological method that was used for the study. This approach lent itself well to studying the transition to the caregiving role since it focused on understanding the impact on the individual who experienced this transition.

Caregiving presents a special challenge for anyone, but in the case of caregivers of persons with ADRD, there are unique challenges. In order that caregivers are able to maintain their loved ones in their homes, support must be given from the very beginning of the disease process. The review of literature revealed a wealth of studies related to ADRD caregiving but only two studies on the experience of transitioning to the caregiving role. This hermeneutic phenomenological study, using the Utrecht method, gave caregivers the opportunity to share the meaning of that transition. It is not only to gain an understanding of the phenomena, but to understand how the transition was interpreted by the caregivers. Through their voices, nurses, and health care professionals can begin to respond to themes that are common to caregivers. These themes will provide a basis for effective interventions that can truly meet the needs of caregivers as they transition into an unknown territory. This information has implications for all practicing nurses but also educators as future generations of nurses enter practice in an environment with greater numbers of elderly patients with a variety of needs.

CHAPTER IV

FINDINGS

The findings of this phenomenological study illustrate the lived experience of ten caregivers as they described the transition into the role of a caregiver for a loved one with Alzheimer's disease or a related dementia. This chapter describes the sample, lists the thematic findings of the study, and gathers the participants' descriptions and interpretations into thematic categories with supportive verbatim excerpts from the interviews.

Description of the Sample

Following the tenets of phenomenology and saturation, the sample consisted of ten purposively selected caregivers of persons with Alzheimer's disease or a related dementia. The participants were purposively selected according to the study inclusion criteria detailed in Chapter 3.

Ten participants were included in the study: eight women and two men. Their ages ranged between 37 and 84 years with a mean age of 66.3 years. Length of time in the caregiving role varied between one and thirteen years with a mean of five years. The ages of their care recipients ranged from 58 to 92 years, averaging 77.1 years.

One care recipient died within the last year. His caregiver responded to the invitation to participate in the study by indicating she had valuable experience to offer regarding the transition to caregiving. After conferring with my dissertation committee, I elected to include her interviews, as she was able to share her experiences about the very beginning of her caregiving career.

Seven caregivers reported caring for their spouses, one participant cared for her female partner, one cared for her mother-in-law, and one cared for her father. The caregivers reported an average of 16 hours per day spent caring for the loved one with ADRD. Seven of the caregivers reported that they had participated in a support group at some point during their caregiving experience. Nine of the ten caregivers were married or had been married at some point in time, one caregiver was widowed, and one was a partner to the care recipient. The ethnic backgrounds of the caregivers were as follows: Caucasian (n=7), African American (n=2), and Indian (n=1). The educational backgrounds for the caregivers varied among secondary education (n=2), some college (n=3), bachelor's degree (n=4), and graduate degree (n=1). Table 2 reflects characteristics of the sample of informants.

The interviews began with the question: "Tell me about the day you learned about the dementia diagnosis", a time period that ranged from one to thirteen years ago for the respondents. Caregivers also recalled events that preceded the diagnosis, the process of obtaining an actual dementia diagnosis and their reaction to this diagnosis. As the interviews proceeded, planned probes were used in an effort to keep the participants in the experience of transitioning. As the caregivers shared their stories, descriptions of the experience and the meaning that they ascribed to their experiences unfolded.

Table 2

Characteristics of Sample (N=10)

Caregiver (Pseudonym)	Age	Relationship to CR	Years caregiving	Age of CR at diagnosis
Mrs. Decker	76	Spouse	6	86
Ruth	49	Partner	1	57
Mr. Adler	82	Spouse	3	79
Mrs. Lang	84	Spouse	3.5	84
Mrs. Cohen	65	Spouse	2	77
Mr. Jaffar	71	Spouse	3	68
Mrs. Weiss	70	Spouse	10	63
Tonya	59	Daughter	7	86
Mrs. Jackson	70	Spouse	13	48
Lisa	37	Daughter-in-law	1.5	67

Note. Pseudonyms based on the convention of how the caregivers preferred to be addressed.

Thematic Findings

Based on the principles of the Utrecht School of Phenomenology, a list of themes was created (Barritt et al., 1984; Cohen et al., 2000). These themes reflect essential descriptions and interpretations mentioned by the participants and provide a depiction of the experience of transitioning to caregiving for these participants. The themes are illustrated in Table 3.

Table 3

Identified Themes

Theme 1: Something is Wrong

Theme 2: A Journey to Diagnosis: Ambiguity and Negative Emotions

Theme 3: Shifting Roles and Relationships: Losses and Challenges

Theme 4: Seeking Knowledge and Support: Solutions and Frustrations

Theme 5: Adapting to the Topsy-Turvy World of Caregiving:

Finding Purpose

Theme 6: Preserving Self without Guilt

Theme 7: Finding a Way Out

Descriptions and Interpretations

In this section, each theme is presented with examples in the form of direct quotations and summarized text. Field notes are also incorporated into the text as well as demographic data reported by the participants. Pseudonyms were used to protect the identity of the caregivers.

Theme 1: Something is Wrong

Although the interviews began with the question: “Tell me about the day you learned about the dementia diagnosis,” all of the caregivers began with a recall of events that preceded the actual diagnosis. For eight of the participants small incidents began to coalesce, signaling that something other than old age or mere forgetfulness was responsible for these events; for two of the caregivers, a medical incident precipitated the diagnosis.

Compiling evidence.

Caregivers described occurrences which in and of themselves did not initially cause alarm, but taken together over time began to cause apprehension. These events varied among the care recipients, and included memory lapses; inability to complete routine tasks; disorientation to time and place; incidents which reflected impaired judgment; difficulty with communication; and inability to retain new information. Common among the caregivers was the fact that these abnormal behaviors occurred over a long period of time, in some cases years. One of the most salient characteristics in this early pre-diagnosis stage was fear. Once the dementia was diagnosed, however, the meaning of these episodes became more significant to the caregivers.

Mrs. Decker is a 76-year old woman caring for her 92-year old husband, who was diagnosed six years earlier with Alzheimer’s disease. She recalled signs which indicated that something out of the ordinary was occurring with her husband, especially as she compared past with present behaviors. Initially, she noticed the lists he placed throughout the house and his inability to learn new tasks. She described these events as follows:

He used to make lists all over the place, that's a sure sign...[of AD]. Lists of everything...he had a to-do list on the back of that door, just everything was listed. With the computer he had a lot of lists....I didn't realize what he was doing there, but he would forget. His big computer crashed and his kids bought him a new one, and he could never use it.

Another warning sign indicating for Mrs. Decker that something was wrong was that her husband was experiencing periods of becoming lost and difficulty in fulfilling his role as a volunteer for a community organization. She said:

He was a very active person. He used to be a recruiter for [a community organization]. He would recruit people to help out at the different blood drives. He got in a little trouble there because he missed meetings and they weren't very nice about it. I was really upset. I told them he was having problems and I don't think they believed me. I think they thought I was just a jealous wife who didn't want him going away.

As she shared this story, it was evident that Mrs. Decker had begun at this point to implement strategies to protect her husband. Her awareness of her husband's aberrant behaviors was mounting; however, she had not yet sought medical attention. She shared her upset that in trying to protect him she was seen as getting in the way.

For Mrs. Lang, an 84-year old woman caring for her 87-year old husband, his becoming lost in familiar environments indicated to her that something was awry. She described these scenarios:

[He was] getting lost in familiar places where we were living. Going to a friend's house...forgetting not only how to get there, but when we were ready to come home he didn't know how to get home; he'd go the wrong way.

Mrs. Lang, like Mrs. Decker, was compiling evidence of a series of incidents that indicated something was wrong. Even though these events happened over three years ago, her memories were vivid of the fear she experienced as she imagined the possible consequences of her husband's reckless behavior. She shared her story with distress as though it had just recently happened:

The driving was making me a nervous wreck. Tearing across the country on the superhighways and I'm in charge of when we do whatever. The map is in my lap...and he suddenly would take off and I mean the hair would stand straight up...and everyone is tooting horns and things like that....once I remember he was coming to an incline...over an overpass, and he went in the left lane and you couldn't see what was coming the other way. I can think of these things in the middle of the night.

The intensity of these memories seemed to bring Mrs. Lang right back to those harrowing driving experiences and continues to frighten her to this day.

Likewise, Tonya, a 59-year old female caring for her 88-year old father with dementia, observed situations prior to the actual diagnosis similar to those mentioned above: forgetfulness, lots of notes around the house, and concerns related to her father's driving. Her home lies in a small valley and accessing this main road requires a cautious approach due to the busy traffic. As Tonya shared this story, it was easy to envision her father pulling heedlessly out of her driveway. She stated:

I knew something was wrong; I just didn't know what it was....I would watch him going out the driveway and his judgment was going because people would blow [horns] as he was going out, or when he was stopping to come in people were blowing [horns]. I could hear and I would say, "Well something different is going on here."

Ruth is a 49-year old female caring for her 58-year old partner, Jane, who has been diagnosed with early onset dementia. She remembers her partner's "loss of common sense" and difficulties in the workplace as signals of something definitely amiss. Jane, who was employed as a bookkeeper, began complaining to Ruth about additional responsibilities and new projects that were being demanded of her. Ruth has this to say about the time prior to the actual dementia diagnosis:

You know those scenarios, "They take advantage of me; they work me so hard; they want me to do this." New projects, anything new or a different way of doing the same job...threw her [Jane] for a loop because she knew certain programs and that's what she wanted to do.

As a condition of her employment, Jane was required to successfully complete a certification exam for radon testing. After two unsuccessful attempts to pass the examination, Ruth offered to help Jane study at home. It was during this process that Ruth realized that something was wrong beyond frustration with increased workload. She described:

I was helping her study....she was consistently wrong on certain questions, even though they were all multiple choice. As we were going back after we completed

the test...there was a pattern that was coming up. I could just see that she wasn't retaining new information.

Jane's inability to learn new information was now the clue that something more was wrong.

Mrs. Weiss, a 70-year old widow, had cared for her husband for 10 years but was able to reflect on events that preceded his dementia diagnosis. She recalled times when her husband became lost, forgot appointments, and had difficulty handling financial responsibilities. These incidents caused Mrs. Weiss little concern until her daughter, who worked in her father's dental office, confronted her with the seriousness of the problem. Mrs. Weiss had this to say:

The beginning of the problem...I didn't notice too much, but my daughter who works as the hygienist in the office, really knew more. When [her husband] used to call me to meet him at lunch at one of the restaurants in Marlton...I'd go there and he never showed up. I waited an hour once. When I came home he was here, and he said, "Where were you, I was waiting for you for lunch?" I said, "You just called me to meet you", and he said, "No, I didn't." But then he just went on about regular business...seemed okay. Then...my daughter came home and said, "You know, dad's doing things that he was doing when he was in dental school. The way he was putting in fillings is how he learned how to do it; he's not using the newer equipment." I just pooh-poohed her because nobody in the family ever had any kind of dementia.

Mrs. Weiss once believed that her husband wanted a divorce because he "was forgetting things...not paying our income tax, I mean really serious things." She recalled

a time when she broke down and cried at the kitchen table, asking, “Are you trying to just tell me to leave?” Her husband’s reaction, she shared, was one of shock and disbelief as he had no idea to what she was referring. For Mrs. Weiss, the escalating evidence had yet to become significant.

Mr. Adler is an 82-year old man who has been caring for his 82-year old wife for three years. He too initially became aware that something was out of the ordinary. Mr. Adler recollected that the first signs of a problem occurred when his wife began to have difficulty remembering names. He said:

I noticed in our conversation that my wife was not recalling certain things, especially people’s names. She was always a Hollywood hobbyist who knew all the actors’ and actresses’ names and...movies that they played in. I noticed that she wasn’t able to pick that up whereas I still remember some of the movies that we went to back in the 40’s and 50’s. So...as that started I was alerted to it but I didn’t do anything about it, quite frankly. I just, you know, you talk to people and they say, “I have that same problem.” Really they don’t have that same problem, they have different problems.

His wife’s behavior during a trip to visit their granddaughter in college alerted Mr. Adler to the fact that something serious was happening. He had this to say about that trip:

We stopped off at a pit stop...and my wife appeared to be lethargic. She would take care of the toll ticket that you would get on the turnpike; she would get the toll. I would be in the back seat, my daughter would be driving, and I’d give her the exact change. She never had a problem figuring out where we were getting

off. This particular day, it was a Friday; she was having trouble on the correct exit. As we got out of this pit stop, my daughter kind of got my attention and said, “She’s acting funny.” I said, “I know, maybe she didn’t sleep well last night because of going away today.” My granddaughter saw her and said to her mother, “She’s changed. She sort of changed both in her personality and her kidding around.”

This event finally alerted Mr. Adler that something was wrong with his wife.

Mrs. Cohen, a 65-year old woman caring for her 83-year old husband with dementia, recalled imperceptible changes, especially related to communication, which occurred over time. She too looked back upon the mounting evidence that something was wrong as she stated:

I remember like ten years ago...when we’d go on a cruise; he would sit at the table and not say a word, like with his head down. The waitress...would say, “How come you’re not talking Mr. [Cohen]?” He’d just...look around, kind of blank. I just figured, he’d been such a high-powered engineer all of his life and such an outgoing, social man, maybe his mind or whatever just needed a rest. Then I saw lack of interest. If he’d look at a newspaper there’s nothing here, he wouldn’t look at it. He couldn’t concentrate on a television program. He used to love reading war stories or Tom Clancy books. He wouldn’t do anything. He wasn’t able to.

Mrs. Cohen initially however, had been able to rationalize her husband’s unusual behavior to be a consequence of a demanding career.

Lisa is a 37-year old female who is caring for her 72-year old mother-in-law. She shared a vivid memory of behavior that occurred four years prior to the actual dementia diagnosis. It took place at Thanksgiving dinner at her in-laws' home. Lisa stated that her mother-in-law, "who always prided herself on being a homemaker and a cook, was really struggling to get Thanksgiving dinner on the table". Her accounting of the story follows:

We realized that the turkey was actually incredibly underdone and it was very tough to navigate. Nobody was willing to say anything...that we really could die from eating this turkey. My husband had an older brother.....he and his wife...looked over at me like, "We're going to die!" It was also very strange. She had put some kind of cereal...in a bowl on the table. She had made eggplant parmesan, things that normally wouldn't be on her Thanksgiving table or any American Thanksgiving table [laughing]. It was a very surreal moment.

Because Lisa and her husband were not living with her in-laws and only saw them sporadically, she realizes now that they were unaware of the scope of the problem. They would attribute an unfamiliar situation, such as visiting her in-laws' and finding a dirty house, to a possible depression. It wasn't until her father-in law passed away, when Lisa and her husband took on her mother-in-law's care, that they were faced with the reality of the disease.

For these caregivers, the pre-diagnosis stage encompassed observation of changes in behaviors and interpretive hypothesizing of the causes. As the frequency and seriousness of these episodes increased, the caregivers began to realize that something more was going on.

Sentinel events.

For two of the caregivers, a medical event preceded the dementia diagnosis. For these caregivers, dementia was not an expected outcome of the surgical procedures.

Mr. Jaffar is a 71-year old gentleman who is caring for his 71-year old wife. He noticed changes in his wife's memory while she was recovering from complications from surgery to remove a meningioma of the brain. He described those changes:

We thought she would recover and that she would get her memory back, but then the short term memory was completely gone. She needed a lot of care because she couldn't walk steadily, she couldn't bathe by herself, and she needed to be reminded to go to the bathroom a lot.

Mrs. Jackson, a 70-year old woman caring for her 61-year old husband, described a "bleed in his head" as the origins of his dementia. She shares: "They put a shunt in.... He has a shunt leading from his head to the stomach, and from then his memory started waning". During this time her husband was hospitalized, the doctors told Mrs. Jackson that he would need a blood transfusion. Mrs. Jackson is a practicing Jehovah's Witness, and even though her husband is not, she refused the procedure. Nevertheless, her husband received the transfusion, and to this day, Mrs. Jackson believes the transfusion has changed her husband. She said: "I think the life forces [are] in the blood, and so characteristics are in the blood. Sometimes other people's characteristics flow out onto you...go into you. So I think he picked up a lot."

While the origins of dementia for these care recipients could be traced to sentinel events, the caregivers were also compiling evidence of deficits before an actual dementia diagnosis was rendered.

Theme 2: A Journey to Diagnosis: Ambiguity and Negative Emotions

As they realized that something was not quite right, all of the caregivers described their efforts to obtain answers from health care professionals. Their emotions ranged from self-doubt, as their concerns were not being recognized by their health care providers, to frustration and dissatisfaction.

Experiences of seeking a diagnosis.

Seven of the caregivers expressed frustration with the exceedingly slow process of diagnosis and the fact that their concerns were not being heard. They felt the physicians were ignoring valuable information they had to offer as first-hand observers of their charges' behaviors. Initial explanations offered for their loved ones' problems included hearing problems, depression, and fatigue. Mrs. Decker recalled:

When it first began it was very, very frustrating because I knew something was wrong, and I couldn't get his doctor to admit it. He [the doctor] kept saying that it was his hearing and I knew it wasn't his hearing. Only the person who lives with him really recognizes it.

Ruth also expressed dissatisfaction with the long delay in obtaining an accurate diagnosis. Initially her partner was treated for depression; however, after enduring months of no improvement and worsening symptoms, Ruth was forced to change physicians in order to be heard. She expressed her frustration when she shared:

The doctor said, "Well, you've [Jane] been going through a lot of changes recently, you're probably depressed. [I'll] put you on antidepressants, come back in a month." We came back in a month; I think she failed the test [certification exam] again. She was...still depressed and stressed out with work. The doctor

changed the antidepressant. And so, this was just going on. It was in December when the company...she worked for closed. By March we were starting to go to the doctor and she was being treated for depression. They changed the treatment. [We] kept going back, told the doctor about memory. She [the physician] said that...Jane looked good. She was really getting annoyed with me.

Ruth realized that she needed to change physicians when “she [physician] did send her for an MRI and she wrote on the MRI, ‘headache’ as opposed to dementia or memory problems”. Ruth could only rationalize that “even the doctors were in denial that someone could be in dementia at that age”. Ruth, however, was beginning to consider that Jane’s family history of early onset dementia accounted for the memory changes and difficulty with learning new tasks.

Tonya, too, found that “depression” was initially diagnosed as the source of her father’s difficulties. Since her mother had recently died, depression seemed to be a logical cause for her father’s deficiencies. As Tonya looked back though, she shared:

I really think we could have diagnosed earlier, because I was giving them all of the information and he [the physician] was just prolonging it, saying that it was depression.....So I said something else was going on and he [the physician] says, “Well it’s the depression.” Thinking back on the situation, he was probably already in the Alzheimer’s because, prior to my mother passing, we saw a lot of signs. ...but he [the doctor] had never put it together. The medicine he’d been given for depression wasn’t helping. So there were a lot of things...we could have done this a little sooner.

Responses to a diagnosis.

Caregivers were asked to speak to the day they first received the dementia diagnosis. The memory of this time evoked strong emotions for some caregivers who became tearful when relaying their stories even though this experience in some cases was years earlier. Most perceived this event as a negative encounter with the health care system. Others described their feelings of shock at the reality of the diagnosis, while a few recalled their distress at a perceived lack of empathy from health care professionals.

When she was unable to receive a satisfactory explanation from the family physician for her husband's problems, Mrs. Decker took her husband to an Aging Center where a battery of tests was conducted to diagnose his condition. Upon completion of the testing, the family was called together for a meeting with the doctor. It was at this time, in the presence of his family, that the doctor told Mrs. Decker's husband: "I have good news and bad news, you are very bright but...you have Alzheimer's...I wouldn't trust you with my bank account or I wouldn't trust you driving." While this diagnosis accounted for the behaviors that Mrs. Decker had been reporting to the physicians, it was still devastating news for her. She said: "When they said Alzheimer's...really, I didn't know that much about it. It was kind of tough...I knew it wasn't curable...I did a lot of crying, an awful lot of crying."

Ruth's response to the diagnosis consisted of "shock and disbelief". She tearfully described her reaction as follows:

It [the diagnosis] just hits you like a ton of bricks. Everything is coming down and it doesn't seem like anything is going right...and the denial....I just wasn't sure I could handle it. I still don't think I can handle it.

Mr. Jaffar, too, expressed shock. He had hoped his wife would recover and the realization that she wouldn't discouraged him. He kept a positive outlook, however, and said, "I was always optimistic, hoping that something would change," "expecting a miracle." Mr. Jaffar noted, "The most difficult thing was accepting that situation."

Mrs. Jackson recalled that she reacted with fear when she first learned her husband had dementia. She had been reporting her husband's difficulties with his memory, such as forgetting how to get dressed and brush his teeth, to the neurologist. The physician instructed her to post signs around the house to remind her husband to do these things. As she recounted those physician visits she said, "I would always tell him [the physician], [her husband] is not remembering to do certain things. He told me two years later, "That comes with the dementia." I said, "You never told me about that." Her fear, she mentioned, stemmed from the realization that she wouldn't know what to do or what to expect. For Mrs. Jackson, a preferred scenario would have been for the doctor to sit her down when the symptoms first occurred, explain dementia to her and provide advice on how she should deal with her husband.

Mr. Adler still felt a considerable degree of anger towards the medical system. He expressed disappointment with the manner in which he was treated when his wife was eventually diagnosed with dementia:

When he [physician] said "dementia," I said, "That's Alzheimer's," but he didn't answer. For weeks, when...relatives and friends called, [I] said, "The doctors

classify her as a dementia patient.” That’s all I would say because that’s all I knew. ...I think it was pitiful, really, the way that the diagnosis was rendered. I think it was pitiful on the neurologist’s part, because he couldn’t ...wait on our last trip there to get rid of her.

These thoughts seemed to sum up Mr. Adler’s perception that the medical system had deserted both he and his wife when they needed them most.

For some caregivers, the diagnosis confirmed their fears. Mrs. Lang was very matter-of-fact about receiving the dementia diagnosis. She stated, “...it [diagnosis] just put a name on it; I knew there was something wrong.” Similarly, Lisa said, “We weren’t surprised because I think we had seen evidence of it in the years leading up to that.”

Tonya, too, seemed resolute about the diagnosis. She shared both her and her father’s reactions:

Well that [the diagnosis] just changed some things. I remember coming out of the building and telling him that he could no longer drive. He said, “Okay”, and that sort of shocked me. Then I got in the car and we talked. I said, “We need to go over and take the test to see if you can still drive.” He said, “No, I just won’t drive anymore.” That was the first bit that shocked me because he’s very independent. I said well, if he is giving up the car, then he’s aware that there’s a problem.

Mrs. Weiss found that the physicians were very open with both her husband and herself when the actual diagnosis was made. However, it was her husband’s reaction that she recalled most vividly. After the doctor explained to them that Mr. Weiss’s symptoms were most likely a progression of Alzheimer’s disease, the doctor asked her husband if he had any comments to make. Mrs. Weiss said this about her husband:

[Her husband] turned around to me and had tears in his eyes and said, “Well I’m so sorry what my wife’s gonna go through. I feel bad for my wife.” Well...that’s the kind of guy he was. That just devastated me terribly.

Mrs. Weiss also believes that her husband’s Alzheimer’s diagnosis influenced the quality of care he received during subsequent hospitalizations. She described one occasion when her husband was hospitalized after suffering a stroke: “As soon as these people saw Alzheimer’s... [he received] a different kind of care. And that really pissed me off!” She suggested that healthcare personnel need to be educated to understand that persons with Alzheimer’s disease can respond to rehabilitative care. The attitude that Mrs. Weiss observed directed toward her husband though was, “He’s got Alzheimer’s, he can’t do anything...forget it...next.”

Lisa, too, shared an unpleasant encounter with an emergency room resident that she described as “nothing short of horrific.” She had brought her mother-in-law to the emergency room with what was ultimately diagnosed as a urinary tract infection. She laughingly shared this story:

They [emergency room residents] didn’t seem to understand that they could have been in the room five minutes ago, but when they come back she [mother-in-law] has no clue as to who they are. You can’t give her a cup to pee in, send her on her own to the bathroom and then get mad at her when she comes back and says, “What cup?”

Lisa felt that her experience provided evidence that health care professionals need training on how to deal with persons with dementia.

Even though these events occurred years ago, the negative memories were still very fresh for all of the caregivers.

Mr. Adler shared his distress when he recently applied to a continuing care community. He was interested in the independent living housing options and had completed extensive financial paperwork and a medical history for both of them. When he went in for the consultation he was shocked when he was told they would not be eligible. He was offended by this and upset as he relayed those events:

She saw she takes a drug Namenda and Aricept and she said we couldn't admit her. I was shocked, I was shocked, I read a brochure about [this community] that they were community-wise and that they help people with all sorts of illnesses and they had the infirmary. You go into the hospital, once you are released from the hospital you go back to them. I said to the lady, "Why didn't you tell me that in the first place?" I said "The way you talked as long as they were ambulatory [they could be admitted]." I had told her, "They asked if we had illness, yes my wife is ill" but they didn't ask what, they just said "as long as they are ambulatory."

Mr. Adler felt that his wife was being labeled because of her diagnosis and throughout the interview expressed feelings of abandonment from the medical system.

Theme 3: Shifting Roles and Relationships: Losses and Challenges

Caregivers were asked how their lives had changed since they assumed that role. As they spoke, it was apparent that there was no distinct point at which the caregiver role was assumed, but that it evolved over a period of time. Some caregivers relayed that changes in their responsibilities did not increase immediately, but became more

pronounced over time as their loved ones' abilities diminished. This evolving caregiver role affected three major areas: social; work; and interpersonal roles.

Social roles.

For Ruth and Mrs. Lang, financial matters became their primary worry. Ruth shared that she had to attend to financial issues at once since Jane [who has early onset AD] could no longer work, and they needed two incomes to support their expenses. Ruth had to apply for unemployment and disability benefits for Jane, and assume the financial responsibilities of the household. Ruth tearfully described the emotions she experienced when she shared these comments:

I just felt that I was too young, there were so many changes. I didn't really want to....it's almost like you have to put your life on hold. I had no idea how long that it's going to be. I remember...I just told [Jane], "Let's just go into the garage and turn the car on and just end it"...rather than go through it. I guess I was trying to feed her an idea. Isn't that awful?

Ruth became very emotional when she shared that thought. I suggested that she take time to compose herself and to proceed only when she felt ready. She seemed ambivalent about sharing these emotions and the accompanying guilt that she harbored, yet did continue with the interview.

Mrs. Lang also found finances to be one of her biggest challenges in the early stages of her husband's dementia. She stated: "I guess the biggest thing for me was suddenly having to take over the finances and the decisions. That took a while to get the hang of because he always did most of it."

Mrs. Cohen felt very fortunate that she did not have the sudden financial concerns that burdened many women who essentially function as widows as the result of this diagnosis; she had gradually assumed those responsibilities over time as her husband's abilities diminished. In fact, even though her husband received a dementia diagnosis five years ago, she has only identified herself as his caregiver for the past two years.

The two caregiver husbands expressed challenges in performing household and personal care tasks for their wives for which they felt unprepared. Mr. Adler said:

Here's a woman who bathes daily, showers daily, made up daily...took care of her hair. Now she's not doing that and I have to remind her it's shower time, or... [she's] worn those clothes the last couple of days. I do the laundry now and I have never done the laundry before.

Since both Mr. Jaffar and his wife had shared responsibility for cooking, it was easy for him to take on that chore. However, he also had to assume responsibility for all of her personal care and grooming. Mr. Jaffar took a great deal of pride in caring for his wife; on each visit she was immaculately dressed and groomed. In order to accomplish that though, Mr. Jaffar stated that he is required to spend time to "dress her and find the appropriate clothes, the matching shoes and jewelry, and all that to go with it."

The onset of dementia and the ensuing caregiving role also affected social relationships. Three of the caregivers addressed this particular issue. Mrs. Decker saw friends retreat once they learned of her husband's dementia diagnosis. She had this to say:

When someone knows [about the Alzheimer's]...the friends fall away. They don't know how to handle it, and it's when you need them the most that they start to fall away...maybe they are scared that it is going to happen to them.

Mr. Jaffar wanted to retain as much normalcy in their lifestyle as possible and tried to keep his wife active with social engagements and trips. He stated, "You know I just want to do the things we did. See we've been married now 50 years." He shared that, "...it is getting very tiring for me because even if it is a trip somewhere, I have to do the packing for me and for her, and make sure we don't forget anything." Mr. Jaffar did not seem to experience the isolation and loss of friends that Mrs. Decker did.

Mrs. Cohen said, "...life changed drastically. [Mr. Cohen] and I were always on the go despite the fact that we both worked. We took cruises twice a year. We would go out to dinner all the time. We would be with friends." As her husband began to retreat into himself, Mrs. Cohen said, "I've had to make a life of my own in order to have companionship, and for my own survival." This was a new experience for Mrs. Cohen; all through their married life she had put her husband first and friends second. Therefore, she did not have a large network of friends and has had to cultivate her own social network. Since the couple has no children, Mrs. Cohen now regards that network as essential for her emotional well-being.

Work roles.

Five of the caregivers had been working and the onset of the dementia necessitated a change in their work role. Mr. Jaffar was about to sign a contract to perform some consulting work when he realized that he needed to be present to care for his wife. Similarly, Mrs. Weiss attempted to continue working until her husband's

wandering became a very serious issue. At first, she tried to handle this problem by bringing her husband to the office but, as she shared, this seemed to make her feel guilty:

I took him into work with me a couple times but I felt bad because he had to sit there while I was doing my work. We did go out to lunch but then he had to come back and sit there and it wasn't fair to him. I was a nervous wreck anyway. So I retired in 1990 after working all those years and that was it. I had to get rid of the car because when I was away sometimes at work he would get in the car and drive to the mall and then forget where he put the car.

Tonya had retired as a school teacher but was an active volunteer with a variety of organizations. She was forced to relinquish these activities in order to accompany her father to appointments and handle his financial affairs once the dementia diagnosis was confirmed. This included obtaining her father's power of attorney, a complicated and time-consuming process. Tonya said:

... [to get] everything situated, I think that was the biggest thing. It took me about six to seven months to get...everything transferred over to me and all his bills paid up, and out of the way...doing all those little things so that...I [didn't] have to worry about...that financial situation at all.

Interestingly, Tonya has considered herself as her father's caregiver for seven years. This was when both he and her mother moved in with her family. This move was designed to offer assistance to her parents because of their physical ailments. The dementia diagnosis however, was only one and a half years ago and has redefined for Tonya her caregiving responsibilities.

Mrs. Jackson retired from her position as an assistant teacher in order to care for her husband at home and avoid having to place him in a nursing home. Due to complications from surgery, his medical needs were heavy, and the rehabilitation center had recommended nursing home placement. Mrs. Jackson seemed to almost regard this as a challenge and her comments reflected that:

They suggested that I put him in a nursing home and let them take care of him. I don't like nursing homes and I didn't like to do that. Plus, I didn't know what I could really do because I've never been in this situation before, so telling me to put him in a nursing home was telling me you just can't take care of him. I [felt] like, how do they know that?

Mrs. Jackson was very proud to tell me that she was able to provide care for her husband in their home with the help of home care professionals. Her comments reflected a "See, I can do it" attitude.

After the death of her father-in-law, when it became obvious that her mother-in-law needed supervision, Lisa notified her employer that she would need to take a leave in order to make arrangements for care. Her intent was to research the assisted living facilities in the area so that her mother-in-law could get the care she needed. Lisa felt as though she needed to assume this responsibility since her husband was grieving over his father's death. She had this to say:

It was about getting her placed. We never, ever went into it thinking that she would live with us permanently. Initially, that was never the thinking. It was okay, just take a deep breath every few minutes, this is really difficult but we'll get through it.

However, after researching the various facilities, Lisa, with the support of her husband, made the decision to have her mother-in-law reside with them and their three children. She explained the thought process that led her to this decision:

I was realizing that, in a facility she was going to get optimal care only if somebody's there very regularly...as on a daily basis. ...I said to my husband, "You know, in a way I think it will be easier to manage her in our own house... than if I have to go someplace." I also could see us as parents struggling and coming up with excuses to not bring our kids to visit her.

Once this decision was made, Lisa resigned her position and worked with contractors to have an addition built onto her home to accommodate her mother-in-law.

Interpersonal roles.

Caregivers also described the manner in which the relationship with the care recipient changed. For the spouse caregivers, sorrow at the loss of their partner and the relationship they once shared was a common theme. Six of the seven spouse caregivers became tearful as they shared this portion of their story. After pausing to compose themselves, however, all six caregivers were able and willing to continue with their thoughts. Mrs. Jackson had been caregiving for her husband for over ten years during which time he has remained relatively stable. She never appeared emotional during the interviews.

Mrs. Decker had only been married for six years prior to the onset of dementia in her husband and poignantly shared, "I have lost my companion; I am lonely. I said recently that I have the most silent house in the world. He never talks." She described her first marriage as "a very bad marriage", and said that when she met her husband she

“...found out what companionship was all about...it was wonderful when we traveled. It was just such a closeness; we could always just talk to each other.” She was also used to being “spoiled” by her husband as he routinely performed household chores including preparing dinners.

Mr. Adler, too, misses the companionship he shared with his wife. Aside from the dementia, his wife is fairly healthy, but he is very troubled by her inability to initiate tasks and communicate. These comments reflected that sense of loss of companionship:

Yeah, that’s the worst thing about this whole thing, this whole venture. I remember her [as] good for a laugh, articulate, smart and intelligent, never nasty, a wonderful mother, a tremendous mother. To see her now, [she’s] almost like a vegetable...and it’s sad. Of our 63 or 62 years, it’s a hell of a way to end our life together. Because as much as people say the memories are there, you can’t take that away. The last couple years, the worst part of it is you see what’s going on and you can’t enjoy the time that you earned. And I’m not being selfish when I see that about myself. No...we earned [that] together.

Particularly troublesome to Mr. Adler is the fact that his wife sometimes confuses him with someone else. He became tearful several times during the interview and movingly shared this story:

We were riding along in the car the other day and stopped at a red light. She grabbed my arm and she said, “I want you to tell me the truth.” I couldn’t imagine the way she said it, what is she going to bring up now? That I didn’t do something? [She said] “Who is that person that I slept with in bed this morning?” I tried to explain to her, “It was no one but me.”

Mr. Jaffar, too, became tearful at times as he shared his story and apologized for becoming emotional. He recalled a therapist who told him that he had to accept the fact that his wife was not the person who used to be his wife. He said, “That is to me...the most difficult part; but still...to me, it is the same. She is still the same”. He told me he liked to think that her personality had not changed. He tries to preserve their social connections and even plans regular vacations with friends. For example, between my first and second visits, Mr. Jaffar and his wife had traveled to an island resort with friends.

Several caregivers referred to their changing role from one of partner to parent. Mrs. Lang compared caregiving for a spouse with dementia to her parenting role when she said, “I’ve raised three children and at least they learned and they changed. He’s going backwards.” Nonetheless, she still seeks some glimpse of the close relationship that she shared with her husband in the past as evidenced by the following:

He needs his hugs and so do I (laughing). That’s all we have...that’s all the affection that I get out of him...I know that an Alzheimer’s patient needs them. I’ve read that somewhere and I need them. He likes giving them, thank goodness. I hate to see that stop. He also likes to be hugged, yes he does. He’s childlike that way.

Mrs. Lang and her husband have been married for 61 years and she recalled that the memories of the good times they shared together are very comforting for her. Those positive memories seemed to enable her to continue in the caregiving role and constituted a positive aspect of caregiving which other caregivers also spoke to.

Similarly, Mrs. Cohen has pleasant memories that sustain her in the caregiving role. She is now dealing with her husband’s incontinence of bladder and bowel. She quite

matter-of-factly stated, "I'm the mother and he's the child, and that's just the way I view it. I don't have a husband; I don't have a mate." She explained her changed role: "Sometimes I think I'm the maid with the cleaning him up; with the making the meals; doing his clothes; doing his laundry." She also divulged that her husband's sexual needs have not disappeared with the onset of his dementia. However, she is not at all interested in having sexual relations with him. She stated, "I would love at times to hug him or cuddle with him, but the thought of getting into his bed that's been wet, or he could wet his pajamas, I just.....can't do it." It is the wonderful memory of their married years that sustains her in the caregiving role. "If it had been a not fabulous marriage I would have been out of here. But because it was such a good marriage, and I have those good memories, I stick around."

At times, Lisa's mother-in-law refers to both Lisa and her husband as her parents. Lisa seemed able to accept this and used the following analogy to describe how unpredictable life can be with her mother-in-law: "I very often have said from the beginning, 'I feel like I'm Alice in Wonderland sometimes.' Just this like topsy-turvy, make-believe world, you never know what the next moment is going to present." As she has assumed responsibility for her mother-in-law's care, Lisa has been surprised by friends who question how and why she is doing this. Lisa attributed her ability to implement the role or the "how" when she said:

I think on one level it's because I didn't have a really close, loving relationship with her. It has made it easier for me to say, "You know what, you've had your calories for today.... no more exchanges, you're done." I don't say it in that

language of course, but ...not being emotionally churned when she yells back at me...I'm able to be very pragmatic about it.

Unlike the other participants in this study, Lisa was not overly invested in the relationship with her mother-in-law prior to her assumption of the caregiver role. She agreed that in the beginning she had almost taken on the responsibility as "a job". Her humanism and caring, however, are reflected in the following comment about why she is caregiving:

.....we've been very blessed and we have a great family life. I have my wonderful husband because of her [mother-in-law], you know. That's just the way it is. I think she herself has had a very tough life and she deserves the best level of care that she can get, whether she realizes how to get that or what it is.

Lisa is a very family-oriented person and her remarks reflect her belief that her actions provide the best lessons for her children: "We feel good about showing our kids that this is what family is about. Yes, your grandmother has a terrible disease but she is your grandmother nonetheless, and you're getting to know her as she is." Lisa stated that her children are able to induce her mother-in-law to reminisce about her years growing up on a farm and the animals they raised. This is time that all of the family enjoys sharing together. The idea of positive role modeling for her children seemed to reflect a positive aspect of caregiving for Lisa.

Ruth seemed very conflicted over her changed relationship with her partner, Jane. As her responsibilities for Jane's care have increased, so has her frustration with the situation. These comments reflect that sentiment:

..... [I'm] resenting the increase in work and the distractions, when that wasn't what I wanted in the relationship and in my life at this time. It's almost like bringing an infant home but it's [bringing an infant home] by choice...and you're prepared for...a happy occasion, something that's going to grow and develop. I wonder if it's sort of similar with someone who has a child who is physically or mentally disabled. They must go through a lot, too, realizing that their child is always going to need care and that it just changes your life.

While Ruth held back at times during the interviews, the distress and conflict she is experiencing concerning her relationship was readily apparent.

Theme 4: Seeking Knowledge and Support: Solutions and Frustrations

All of the caregivers reflected on their attempts to obtain information about the disease and its management when they first assumed this role. Some had positive experiences, while others shared the frustrations they felt as they began to learn the caregiving role. This section will review those experiences.

Reading was fundamental.

An essential strategy for all of the caregivers was to read anything they could find about the disease. According to Mrs. Decker:

I think reading is very, very important. Trust me, I am a reader. If I want to know something, I get books and I read it. I find out. I didn't have the support group at first. That [reading] was a tremendous help.

Eight of the caregivers mentioned *The 36-Hour Day* (Mace & Rabins, 1999) as their lifeline for information. Some had learned of the book through their support group;

others found it through their participation in Project ACT. In addition to *The 36-Hour Day*, Mrs. Decker mentioned that:

...the best book I read was *Sourcebook for Caregivers* [Gray-Davidson, 1999]...it gave you a lot of information about what to do, how to handle it. I think the most important thing I learned was that you have to take care of yourself because if you don't; you can't take care of him.

The subject of "taking care of self" will be explored further in Theme 6.

Lisa referred to *The Forgetting: A Portrait of Alzheimer's* (Public Broadcasting System, [PBS], 2003), a PBS documentary film based on the book entitled *The Forgetting* (Shenk, 2001), as a valuable resource. Lisa shared that after watching this documentary and reading parts of the book:

It was the wake-up call to me that made me realize that if she...ended up dying from pneumonia that would be a blessing compared to dying of Alzheimer's....that's what that documentary taught me. Allowing the brain to shut down on every level...is not the most pleasant way to go.

This knowledge also created a conflict for Lisa related to future healthcare decisions for her mother-in-law.

Actively seeking help.

Tonya and Lisa were the youngest participants in the study and employed similar approaches to obtaining information concerning the disease and its management. Both aggressively researched options for care and support. Tonya shared:

As he [her father] progressed I started looking for things that would help me. I read up a lot on Alzheimer's at that time, started going to meetings [support

group], and decided that I needed to get involved to try to find out more ways to help him.

Tonya attributed her skill in seeking out available resources to her career as a teacher. Early on, she attended a workshop at her church for caregivers of person with dementia. Tonya was so impressed with what she learned that she decided to undergo training in order to become the support group leader for her church. She had this to say:

.....they had an all day workshop at my church. I attended that and...learned so much more. I said, "...I need to find out some more about what's going on."

That's when they wanted to start a support group at my church, and...that's when I took the training so that I could do that.

Lisa, as previously mentioned, thoroughly researched living options for her mother-in-law. Her initial intent was to find an appropriate assisted living facility and she described this process:

I really sort of just stepped in and started doing all the research and visiting places. We would make appointments and he [her husband] did come visit...I had narrowed it down to five, and he came with me and we visited. He came with me on the "...announced tour" kind of visit, and then I would pop in unannounced.

It was during these unannounced visits that Lisa realized that the assisted living option would only work "if somebody's there very regularly...as on a daily basis." From that point, Lisa shifted her focus into searching for an adult day program.

Support groups.

Seven of the caregivers attended support groups at some point during their

caregiving career. They had learned about these groups through various sources and all but one, Ruth, believed their group was essential for their well-being. Mrs. Decker has been involved with the same support group for several years and continues to meet with them weekly. She said, "I don't know what I would do without the support group." The support group members seem to function as an extended family for her. The downside of her closeness to the group has been the distress she suffers when one of the group's care recipients dies. She expressed those sentiments when she said:

....we've gotten very close. We had six deaths in, I think, seven months. It got to the point that the moderator would call and we would say "no, no, no." It was really horrible. I cannot go to a funeral home, I cannot do it. I went to the one. I walked in, and they had you sign your name. I signed my name, walked out and started crying. I couldn't do it. I will go to the church if they have a service but it was just so many, so fast; it was horrible. One woman lost her husband and one week to the day she lost her mother. It was really awful.

It is at the support group where Mrs. Decker says she can share strategies that work for her and learn new ways to deal with her husband. She said, "It's the little things that they tell us, you know, and the fibbing. You really do fib." She credits her group with giving her suggestions that range from how to awake her husband in the morning to the type of products that work best for dealing with incontinence. Mrs. Decker has also gauged the length of time she feels her husband has to live based upon the number of years the group's care recipients have endured with dementia. She shared, "I want to have a 25th wedding anniversary celebration. So I thought, he's 92, so he'll be...100, I'll be 85.

But that's only 10 years [until a 25th anniversary]." She seemed to have hope where other caregivers did not.

Similarly, Mrs. Cohen has found her support group to be a lifeline for herself. She spoke enthusiastically to her good fortune that a social worker suggested this particular group to her. The group meets monthly, but she also speaks with a couple of the women in between meetings either to vent or to offer support to each other. Mrs. Cohen spoke animatedly about her group:

...it was '04, he started getting incontinent...and I thought, "Oh God, I need help," so I started going to a support group in town. And when everyone got done discussing their problems, I thought, "Gee, mine isn't so bad at all." I just couldn't believe it...I've been with them for over two years. It meets once a month, the third Wednesday, and we just laugh and we cry and we carry on and it is so good. I told [my husband] I belong to a nutrition group. But you know, we talk, and we learn things from one another, and what techniques work. I'm so proud; I let them all know, after buying ten thousand different kinds of diapers and Depends, I've hit upon a combination that's finally working 90% of the time for us, so I let everybody know. I said, "I got big news!"

As mentioned earlier, after attending a training workshop for caregivers, Tonya began a support group at her church. She had this to say about this group:

We meet once a month which is good. It helps me because I can talk about what's going on and then other people are talking about what's happening to them, and we try to see what someone else is doing and see if it will work for us. And I think that's what support groups are for actually. Listen and take what you need and run

with it, and if it doesn't work, then you come back next time and try something else.

When her husband was in the initial stages of the disease, Mrs. Weiss attended a support group to which she was also able to bring her husband. The caregivers would meet in one room and the care recipients would meet in another room. Mrs. Weiss had this to say about that group:

I used to take him to the Alzheimer's meetings, which were very good because we brought our mates. He was walking at the time and our mates, the husbands and wives who had the disease, would go in another room with the nurse. They would discuss things about the disease and we as caretakers would sit in another room. That was an excellent program...met one person that we sort of became friends with. Our husbands both had the disease and we'd sit them in the back. They'd talk to each other. We wouldn't even know if they understood each other [laughing]. And we'd go out to a movie and dinner...you have to find things to keep you sane a little bit.

Mrs. Lang and Lisa have also attended support groups and reiterated the benefit of having them as a resource for sharing and finding solutions to common problems and concerns. The groups were also a means of expanding a social support network.

Ruth attended some caregiver meetings but did not have the same positive experience that the others shared as reflected in the following comments: "I went to some of the caregivers' meetings; you just can't really feel connected. I mean, it was helpful, but it wasn't the real answer that I was looking for." She did, however, seem to express a need for an outside source of support when she said, "I think having someone to talk to,

maybe some kind of a...buddy to hook up with, someone who's going through the same sort of thing..." Throughout the interviews, Ruth seemed to hold back a bit emotionally; it may be that her reserved nature has contributed to her reluctance to open up with strangers in a support group.

Three of the caregivers had not participated in any type of support group. Mr. Jaffar has a network of friends, some of whom are physicians, that he told me acts as his resource; he did not feel a support group would be of benefit to him. Mr. Adler mentioned that his doctor recommended a support group to him on a recent visit, but Mr. Adler was waiting for the office to provide him with additional information. He did not seem to know how to access information regarding available resources on his own and expressed his frustration as follows:

You see, there's not that one kind of person...like the priest; you go to the priest and confess and get some counseling. I don't have that. I haven't that person in the medical field that can tell you what's the better road to take.

Seeking answers from health care professionals.

While Mrs. Jackson had not participated in any type of support group, she did express interest to me in finding a group that might be convenient and accessible to her.

In the meantime, she attempts to locate any available resources. She mentioned:

...talking to different people, they either had someone who had dementia or are associated with people who had dementia, and that's how I kind of got that information. And every chance I get, anybody who's in medical service in any kind of way, I ask them questions.

Mrs. Jackson also shared that she has devised a strategy that works well in

obtaining information from her husband's doctors:

I think doctors don't like you coming in knowing too much and asking too many pertinent questions [laughing]. They don't like for you to ask too many questions...they will try to give you as short an answer as possible and steer you off to another conversation but they don't like you asking questions...especially pertinent ones. I had to get him [her husband's doctor] in front of some students; that's how I did it. He had students that were observing him [with] patients. I knew that with the students he had to come up with the right answers. So I asked a lot of questions and then I asked him, "How come you didn't put the dementia down on his record?" That's how I did it.

Trial and error.

Three of the caregivers described the large part that trial and error initially played in the caregiving process. Ruth had this to say about her early struggles with communicating with Jane:

At first it was like, alright, what doesn't work...unfortunately I went through a lot of sarcasm...treating her as if she was stupid...very demeaning. Not that it was all the time. There was times I would say these things and I'd feel awful again [crying]. Learning how to communicate is very important, what they can comprehend and what they can't comprehend.

Mrs. Jackson also learned communication techniques through trial and error. She shared that becoming familiar with her husband's nonverbal cues directed her on how to proceed with his care. She spoke to the importance of simple communication and described how her husband became frustrated when given multiple directions at one time.

Eventually Mrs. Jackson adjusted her communication techniques as she learned that her husband responded better when he received only a single instruction at a time.

Lisa has also learned the cues that allow her to recognize her mother-in-law's reality. She explains with these thoughts:

I learned if it's not right here in front of her it doesn't exist. Don't...talk about somebody who's not with you in the room, because you don't know if in that moment they're [the person with dementia] going to be able to recall that person or not. She operates in varying levels of reality. So when she starts talking, I'm always trying to figure out which reality are we talking about, are we talking about New York or Germany?

Theme 5: Adapting to the Topsy-Turvy World of Caregiving: Finding Purpose

Even though the focus of the interview was on the transition to caregiving, the caregivers could not settle on a distinct point when this role began and, as will be discussed later, had no sense of when it would end. All of the caregivers acquired strategies for dealing with their charges from various sources, including reading, support groups, trial and error, participation in Project ACT, or their healthcare providers. As these veteran caregivers indicated, these methods evolved over time.

Maintaining normalcy.

For some caregivers, strategies that allowed them to maintain a sense of normalcy became important. These tactics became a means of allowing their care recipient to keep up with past roles and pleasurable activities. For instance, Mrs. Decker and her husband had enjoyed dining at restaurants in the past and she had this to say:

We used to go out to dinner a lot. Have you ever seen a couple who sit there and don't say a word to each other? That's no fun going out to dinner. So I have learned now, I go to the grocery store, there's all kinds of stuff you can buy prepared, that you only have to take ten minutes in the microwave, and we sit in the living room and watch TV.

On those occasions when they do dine at a restaurant, Mrs. Decker will bring along second or third-grade level word-find books and they will work on them while at their table. This activity has served a dual purpose of giving them an activity to engage in together and simplified a hobby her husband has enjoyed in the past. She has also become comfortable with what she called "fibbing" because ".....it's easier to say whatever you want, because five minutes later he'll [her husband will] forget." Mrs. Decker uses this strategy frequently. It allows her to get her husband to places she needs him to be and to avoid needless arguments.

Mrs. Weiss, too, had a strategy that she used when she and her husband were at a restaurant and waiting to meet friends. She always liked to arrive early or on time, yet would be embarrassed if her husband immediately begins to eat all the rolls that were on the table. She had this to say:

We used to go to dinner and we were waiting for one more couple. He wouldn't wait; he'd eat all the rolls. And one time I got mad and I said, "[her husband] don't start eating yet. We're here like we went to services, wait." "I want that roll." And that's not like him. So I saw myself and then I knew how to sort of temper it. I wouldn't get there as early as I did. I'd get there later. So instead of sitting waiting twenty minutes and eating rolls, we'd get there just when it started

and he could eat as many rolls as he wants. And my friends knew and they would look and they would laugh. I mean, they knew what was happening and they excused a lot of his “shtick” as they would call it.

Lisa implemented a protective strategy for her mother-in-law after suffering through a number of embarrassing occasions when out in public. She printed cards to have available to pass to strangers when her mother-in-law was not behaving in a socially appropriate manner. She described the cards as follows:

.....little cards that we just printed at home on the printer that said “please pardon the behavior of my loved one, she’s affected by a terrible disease, Alzheimer’s,” and then having the website of the Alzheimer’s Association on it, because...if I did get her out to the grocery store, she sometimes [exhibited] just a little...skewed social behavior, you know. And in a restaurant one time...she walked up to a baby and...she said to them, “this baby should have a hat on and this baby isn’t dressed properly,” and I had one of the cards at the time...I think it’s a great way of doing a public educational...I think that a lot of people have...heard of Alzheimer’s.

Lisa seemed to feel good about devising something that not only alerted strangers to her mother-in-law’s deficiencies but also served as an educational tool.

Simplifying tasks.

Other caregivers spoke to measures they used to simplify activities and aid in prolonging their loved one’s independence. As these caregivers shared their strategies, their pride in finding some thing that worked was evident. Ruth for example has tried to formulate routines that are easier for Jane to follow. Ruth shared that she learned the

importance of task simplification through her participation in Project ACT. Jane is home alone most mornings while Ruth is at work. Ruth will check on Jane by telephone until she arrives home at noon to transport Jane to a friend's house for the afternoon. However, Jane is having trouble answering the portable phone and pushing the button to talk. Ruth has put a green sticky on the call pick-up button and a red sticky on the button which ends the call, as she believes that Jane can still understand that green means "go" and red means "stop". While this strategy has proven to be effective most of the time, there have been occasions when Ruth has telephoned Jane without receiving an answer.

Three of the caregivers mentioned using notes as reminders for care recipients of tasks to be completed or information to be shared. Since Mrs. Cohen lives in a large apartment complex, she will allow her husband to roam about the facility to areas such as the pool, restaurant, or even the lobby. She uses notes to remind her husband of her whereabouts during the day. She stated:

...when I'm not here, I'll leave a note on the toaster and on the front door...I've got...clipped together, a million little sheets that I can take out: getting a massage, going for coffee, going to the grocery...and I put that on the toaster...that's his card for today [pointing to the card on the toaster], his appointment.

Mr. Jaffar noted that when he and his wife are in the car, she will inquire repeatedly about their destination. He explained his strategy for handling this situation:

One of the things that happens is that when we are out driving to some place, every few minutes she'll ask me where are we going. So what I started doing was, I would write it down on a piece of paper and let her hold it. So that from time to time, she would look at it and it would remind her.

Mrs. Jackson, too, used notes as a cue for her husband to complete his morning care routine after she recognized that he would become disturbed when he didn't know what to do. She described the contents of some of the notes:

...brush your teeth, rinse your mouth out, flush the toilet. The "flush the toilet" is the hardest one he can't do. That seems to just go right past him. He can read it and won't do it. I'm working on those things. And he gets frustrated when he's placed in a position where he doesn't have an instruction.

Five of the caregivers spoke about simplifying hobbies or past-times that their loved ones used to enjoy. This has allowed the care recipients to participate in an activity, and per the caregivers, has given them a sense of purpose. As mentioned previously, Mrs. Decker purchased children's word-find books for her husband. This gave him the opportunity to continue a form of the hobby he had enjoyed so much before the onset of his dementia. Mr. Jaffar shared that his wife had been a proficient piano player and, in fact, had given lessons at one time. In order to allow her to engage in the activity that she once loved, he simplified the hobby. He explained:

I found a book that had most of the pieces that she used to play, but written in a simple way. And she can play those, and she enjoys it. And she just keeps on and on. There is a lot of repetition. She plays two or three pieces, and then she comes back and plays it again, and she goes on, over and over again.

While Mr. Jaffar admitted that he tires of hearing the same songs repeated continuously, he expressed pleasure in her accomplishments. He also showed me some beautiful embroidery his wife had begun but has been unable to complete. He struggles with disposing of reminders of things she can no longer do because "...sometimes the

presence of that is also disturbing. The fact that it sits there and it cannot be used.” Mr. Jaffar became emotional as he shared this thought; he seemed to feel ashamed that he would occasionally experience irritation with his wife’s behavior.

Lisa draws on her mother-in-law’s former craft of sewing to engage her in the evening when Lisa has to tend to her children. She told me: “We sort buttons. If I thread a needle and give her a holey sock...it’s not the neatest thing anymore but...she’ll have fun. You know...it’s all about making them feel purposeful.”

Mrs. Weiss and her husband were lovers of the arts and frequently attended shows and plays. During the ten-year course of his dementia, he also suffered a stroke and became wheelchair bound. While it became very costly for Mrs. Weiss to employ the help she needed to maintain her husband in their home, she also used that help to keep him engaged in those activities. She had this to say:

I had aides come in morning and evening, and during the day I took him to the movies.1 ...there were always people there helping me get him in and out of a wheelchair; people are so nice. And he loved movies. He loved anything.

These activities kept Mrs. Weiss and her husband connected to pleasant memories of the past.

Managing personal care.

All of the caregivers expressed some difficulties with managing personal care issues, especially when incontinence was involved. Mrs. Lang expressed her concern about her husband’s incontinence and constant drooling when she said:

He’s beginning to wet the bed which, of course, is from the prostate problem. And [it’s] also wet wherever he’s sitting now, so I guess he has to wear Depends or

something or other all the time, which is going to be trouble, but he's wearing them at night comfortably. He calls them his diaper. I thought, "I won't be delicate about it" (laughing). But it's his messiness that drives me crazy. Absolutely. He drools constantly. And he's on two different pills to help curb it and it doesn't... I wonder how bad it would be without them. And he's very awkward, both walking, getting up out of his seat, his hands, eating, everything. He's just a mess [with a] capital "M".

Between my first and second visits with Mrs. Lang, her husband had been hospitalized. He was then moved from their assisted living apartment to the skilled nursing unit due to difficulty with ambulation. Mr. Lang's Parkinson's disease seems to have worsened, and Mrs. Lang is waiting to learn when he can return to their apartment. She would like to try and manage his care in their apartment but is aware that may not be possible. She finds solace in the fact that they reside in a continuing care community; therefore, even if he must transfer to the hospital section of the facility, she will be able to visit him regularly.

Mr. Adler has found that his wife resists bathing now even though she formerly prided herself on her appearance and cleanliness. He told me he has to "almost embarrass her, saying, 'It's been two or three days...you better take a shower'" before she will agree to bathe.

Lisa, too, has struggled with the problem of getting her mother-in-law to bathe. She has found an effective strategy to deal with this issue, using verbal cues and gently physically guiding her mother-in-law to the shower. She laughed when she shared that her mother-in-law's reaction then is usually "I'm so glad I took that shower, I wanted it

so badly, I wanted a shower so badly.’ And it was a painstaking struggle to get her in the shower.”

Lisa also had to bring her mother-in-law’s diabetes under control when she first moved in with the family. This proved to be a challenge since her mother-in-law was what she called a “compulsive eater”, whose blood sugar was out of control. Lisa attempted to dole out occasional snacks but found that her mother-in-law soon forgot that she had even eaten the snack. Lisa described the strategy she employed to handle that situation, “When we do snacks now, I get those 100-calorie individualized packets, and it’s great because then there’s always evidence, the wrapper. Always retain the evidence.” Lisa shared with pride that since she assumed the role of caregiver, her mother-in-law has lost 50 pounds, the diabetes is being managed with oral medication only, and her antihypertensive medication is no longer necessary. Lisa believes her mother-in-law is healthier than she has been in a long time.

Adult day centers.

Four of the ten caregivers have used adult day centers for their loved ones. For these caregivers, the benefits of the adult day center was that it gave purpose to the care recipient and provided respite for the caregivers, even if only for a few hours each day. Once Lisa decided that assisted living was not an option for her mother-in-law, she knew from her research on dementia that the availability of a well-managed adult day center would be a very important resource. Lisa spoke in extremely complimentary terms about the program to which she sends her mother-in-law:

.....adult daycare really saved our...our family life..... I completely credit them with giving her a sense of purpose in life. She says she works there; she’s going to

the shop. In the evening if you ask her what she did, she said, “Well I did piece work and patterns and you know all that stuff”She just loves it and I think their formula has just worked really, really well. I can see it may not work for everybody, but it’s great for her, and she wants to go there seven days a week (laughing). She’s very disappointed when it’s a Sunday.

Mrs. Decker’s husband has been attending an adult day program and she said, “That’s absolutely imperative”. Her husband’s physician had recommended a day program as a necessary form of stimulation almost immediately after the dementia diagnosis. The day care program has also allowed Mrs. Decker time to participate in activities she enjoys, such as spending time with her daughters, her support group, and even roller skating once a week.

Tonya initially placed her father in a senior center to occupy his time. However, as his abilities declined, she realized that this was not the best option for him. Tonya’s father now attends an Adult Day program, specific for those with memory problems. For those caregivers who may say their loved one does not want to attend such a program, Tonya had this to say: “I didn’t give him a choice.”

This solution has allowed Tonya the time to return to volunteer activities and even some small part time jobs that she enjoys.

Mrs. Jackson is not as pleased with the quality of the day program her husband has been attending; however, she continues to send him there on the advice of his physicians. She said:

I don’t mind day programs, but I’ve come to find out that they do very little for the patients. ...All they do is sit, and I’ve taken him to quite a few of them and I

do observe...So [her husband] would be in the programs, he was just playing musical chairs, he was going from one seat to another seat, and it wasn't helping his physical condition any. So I kind of pulled him out of quite a few of them, and then I started working with him at home, and right now he's into a day program at their [the physicians'] request.

Mrs. Jackson said that she might research other programs that could offer her husband additional physical activity and may not be as costly.

Sharegiving

Most of the caregivers felt they had valuable information and advice that they wanted to share with other caregivers and health care professionals. Their participation in my study seemed to offer them a voice to do that. This included Mrs. Decker's advice that she relayed to me:

...I think that's the most important thing: be easygoing and to just learn to accept it, which is not easy. I mean this is the way it is going to be...whether you like it or not, so you [had] better accept it.

She also offered the following suggestions, "...one of the most important things is to keep your sense of humor. If you don't laugh, you'll cry, better to laugh" and she frequently laughed throughout our interviews as she shared her stories. Tonya echoed that thought.

Ruth suggested that caregivers focus on "communication, understanding the disease, not to take it personal" and, also, to "find a buddy to hook up with, someone who's going through the same sort of thing." Ruth often finds herself becoming frustrated with Jane's behaviors and "lack of common sense." She offered advice for caregivers to

“not to read into situations...and flexibility...to sort of just go with the flow, to accept the bizarre way of thinking.” Ruth admitted that she has sometimes learned these lessons with great difficulty.

On my second visit, Mrs. Cohen was prepared with a list of suggestions and very animatedly shared the following:

One of the things is, you'll never be able to change the person so don't try. They just don't know what they're doing. If you don't like a behavior and you kind of want to change it, you can't. You are just powerless to change it because they're in their own world and they're doing or not doing what they can do. So you can't reason with a person who has Alzheimer's because they forget.

This is a lesson Mrs. Cohen has had to learn herself over time. Mrs. Cohen is also very connected to her support group and highly recommended that as a resource. Through her reported two years of caregiving she has come learn that support is essential and also to be an active manager of your own destiny. She said:

I would encourage anyone to immediately find a group close to where they live and go to it.... And if you don't like the support group, then find another one to go to. There are also all-day caregivers' workshops given by the Alzheimer's Association. Start building a good support system around you. I didn't have one because I don't have family, he doesn't have family. But get other family members involved to give you a break, because things are going to get tougher, not easier. And don't be passive; see your neurologist. If you're not happy with that one, then go to somebody else who's going to be helpful to the two of you because down the road you're really going to need it. Also, if medication is

recommended, then give that a shot, and if it doesn't work, then it doesn't work.

But there are always things out there that can possibly ease the caregiver and the person for whom they're caregiving.

Lisa, like Mrs. Cohen, offered suggestions about trying different strategies when dealing with the unpredictable nature of dementia caregiving. She had this to say:

I think the best piece of information [is]...when something doesn't work, just try something else, because they're not going to remember that you've been trying something. They don't recall what you've been doing five minutes ago, so you can change your story and try a totally different approach and they're not going to think you're lying to them. And if that doesn't work, then try something else five minutes later.

Tonya suggested that healthcare professionals immediately provide new caregivers with information regarding available resources and how to access them. She had spent a great deal of time researching that information herself when, in fact, a local geriatric center had a listing of many of the resources. She also recommended that caregivers remember to focus on themselves when she said:

The caregiver has to really think about themselves as well as the person that they're caring for.... You know, regular trips to the doctor, dentist...put all of those things into their own schedule as well as the person they're caring for, because they need to stay on top of themselves as well.

This concept of caring for self will be explored in Theme 6.

Theme 6: Preserving Self without Guilt

Caregivers began to realize over time from personal experiences, advice from

others, and through their reading that caring for one's self was essential if they hoped to successfully continue in the caregiving role. All of the caregivers were able to offer at least one strategy that they employed to do so, however, the caregivers admitted that giving themselves permission to have time for themselves did not come without some feelings of guilt and frustration.

The value of communication.

A common belief among the caregivers was the therapeutic value of having someone to talk to about their situation. I was very humbled when several caregivers shared that being able to tell their story to me was very valuable. Mrs. Decker's comments reflected that feeling: "I mean to me, right now, this is the most wonderful thing, because I don't get people to talk to." Mr. Adler also remarked, "You know more about my life than anyone."

On my first visit, Mrs. Lang had taken me to the chapel in her continuing care community for a private place to talk. At times during the interview, Mrs. Lang expressed the sentiment that she hoped that the information she was conveying was what I was looking for. I let her know that my goal was to begin to understand her experiences and that seemed to offer her the permission to be open and forthcoming with me. As she shared these comments, the value of having someone to just listen in a non-critical or judgmental manner became apparent: "I've talked to you more than I've talked to anybody...I've covered a lot of things that bothered me. Feels good to talk about them, I must say. It gets bottled up....you don't want to complain." While these caregivers had accessed formalized services, the simple action of just listening was important to them.

Therapeutic diversions.

Travel was a very beneficial distraction for some. Mrs. Decker had recently traveled to a resort island with her daughters. Even though preparing for the trip was work and entailed arranging full time care for her husband in their home, she thoroughly enjoyed herself and said:

I was snorkeling all over the place. I had such a wonderful time. I came back and I said to my group...“Everybody should go away by themselves.” I had somebody to talk to all the time, it was unbelievable.

The fact that Mrs. Decker had previously left her husband with friends or family for short periods of time made it easier for her to take the trip. She realized that her husband does not remember when she is gone. She told me, “...when I came back from this trip, he didn’t know I was gone.” This thought seemed to relieve her of any sense of guilt she may have felt for leaving her husband to another’s care.

Between my first and second visits, Lisa and her family went on a skiing trip. While they were away, her mother-in-law stayed at a facility which provided wonderful temporary care. The family plans to vacation regularly now that they can do so without worry. Lisa did share, however, that “reentry” to everyday life could present a challenge:

We had this great family vacation and it was really, really terrific, but then you come back. I was almost in a real funk that week when we came back, because I felt like...my life is really like a switch, there’s no dimmer control. When she’s here, when we’re home it’s just hard to have peace. My evenings, I sit down, and I could...spend 10, 20 minutes, make sure her needs are met, make sure she’s got what she needs, but I leave her for two seconds and she is looking for me. It is just

constant, that is the pattern...I don't know if someone said it to me or (if) I read it, "Caring for someone with dementia, they will take up as much time as you permit them to. They will take up all 24 hours of your day if you let them."

Lisa found that she had to set boundaries on time spent with her mother-in-law, especially in the evening. This may mean guiding her mother-in-law to her own room in order that Lisa may have quality time with her children.

Ruth trains show dogs and she described that as what she "enjoyed doing, a good distraction."

Several caregivers have used deep breathing techniques when feeling angry or irritated with their charges. Ruth has found that she has to occasionally stop herself when she is trying to argue or rationalize with Jane. "[I] tell myself to stop it, because I'm just getting angry. I think about it; it's time to breathe and relax." Just prior to my second visit, Ruth had to cancel an appearance at a dog show because Jane would not cooperate and resisted getting ready that morning. While Ruth was very disappointed that she had to miss this event, she found the deep breathing technique was an effective tool to help handle that frustration.

Mr. Jaffar's children and friends remind him of the need to care for himself, and not to pressure himself to do everything as he did them in the past. He commented:

I feel it's selfish to do things for myself, things that would benefit me alone, because we have been doing stuff together, and I feel we should still be doing things that both of us would enjoy. Even if she doesn't remember it, at least she enjoys the moment.

Mr. Jaffar has been trying to participate in activities on his own that bring him pleasure and, in fact, has joined a senior golf league. However, he said with some humor, “....sometimes on the golf course I would think of what is happening here at home, which is not the best thing for the game.”

Mr. Jaffar, too, has found that deep breathing can be an effective strategy to use when he is feeling irritated with his wife’s habits of repetition or talking in the past. To regain a sense of calm, Mr. Jaffar said he tries to “.....take a deep breath and just release very slowly before you do anything, and I think that seems to work. Or sometimes I say a prayer in my head very quickly and that also helps to calm me down.” He was proud to share that he has suggested this strategy to his daughter when she is having a difficult time with her eight-year old triplets. The deep breath allows for time to become calm before reacting to situations. His daughter has reported that the strategy is working for her as well.

Mr. Jaffar is also working hard to lighten his household responsibilities. He retained a person to clean the house and tries to keep meals as simple as possible. While he and his wife took great pride in preparing their ethnic dishes, he now limits that endeavor to once a week.

Mrs. Lang takes much comfort in the friends she has made in the continuing care community in which they reside. She is careful not to burden her friends with complaints but expresses that her friends are the best part of living there.

Mr. Adler enjoys the social time at his church on Sunday mornings as one of his few social outlets. He has found a way to get his wife to remain after the service though she usually doesn’t want to stay there. He had this to say:

...I say, "I'm going downstairs," and usually my excuse is, "I want to go to the men's room; do you have to go to the ladies' room?" And I know she probably does, so she'll go to the ladies room, I'll go to the men's room. I'll get out quick before she does. I go down and get my cup of coffee and by that time, she's ready to come out...then she gets involved with these people. So I trap her only to the extent to get her to mingle.

Mrs. Cohen is a runner and was nursing an injury on my first visit to her home. During the second visit, she happily reported that she would be returning to competition in the next few weeks. Running seems to be her passion and her outlet. Mrs. Cohen has also developed the outlook that it is important for her to have her own friends and activities. She rationalizes:

Whatever happens will happen [with her husband] whether I'm here or I'm not here, and I have to have space of my own in order to be able to deal with and take care of [her husband].

Mrs. Cohen also uses lunch dates with friends, computer clubs, a Scrabble club, and exercise as other forms of diversion for herself.

Tonya shared that for herself, "the challenges are more so the diagnosis ...finding the resources, and then the daily struggles of what you have to do and maintain your sanity and health." Her sister provides a great outlet for her to vent. Although her sister lives in another state, they spend a great deal of time in conversation on the telephone. She had this to say about her sister:

I can call my sister at any time and I'll just say, "Guess what your father did today", and we will laugh for a half-an-hour. I mean we will literally go through and laugh for a half-an-hour and that really relieves a lot of tension.

Humor was a strategy that all of the caregivers utilized at some point in time.

Throughout our interviews, each shared humorous anecdotes relating to their loved one's care. Their laughter seemed therapeutic when dealing with such a difficult situation.

Theme 6: Finding a Way Out

Some caregivers expressed their concerns about the future, especially with regard to potential health care decisions. These were difficult issues for the caregivers to verbalize and there are no easy answers for any of them. Their stories reflect their anguish over possible decisions with which they may be faced and how long they foresee themselves holding onto the caregiving role. Emotions such as self-doubt, confusion, ambivalence, and guilt prevailed. Some of the caregivers have already been confronted with the realities of making difficult decisions.

Mrs. Lang shared that her husband had been diagnosed with prostate cancer several months ago. She and her sons had decided to forgo radiation treatments for her husband that she said, "...would kill him." He is being treated with some "hormone pills" but she seems to have some ambivalence about the decision, even though her sons fully agreed with this choice. She had this to say:

He had a bone scan and several X-rays. That's where they found out it hadn't spread, which is wonderful, just wonderful. You sort of feel like you're condemning them when you decide not to go through with treatment. I didn't

know whether he was going to go through a lot of pain or what, but I guess everything will be alright, I hope.

Mr. Lang's uncertainty over that decision, however, was still burdening her. She also tearfully shared her concerns about the time when her husband may not know her any longer. This is a possibility she has learned through reading *The 36 Hour Day* (Mace & Rabins, 1999).

Lisa and her husband have had similar discussions about how much preventative medicine they should continue for her mother-in-law, such as yearly mammograms and colonoscopies. Lisa shared these thoughts:

So I struggle with that and I also think about...if she was diagnosed with cancer at some point. I don't see us ever taking an aggressive approach to treating the cancer. My husband and I have talked about it, and of course every cancer situation is different, but I think we would be looking more for keeping her comfortable.

Lisa has engaged in similar discussions with her mother-in-law's physician but has not been satisfied with that physician's feedback. She expressed her need to obtain additional information on this issue:

I think every doctor's experience with people with dementia is limited and...while this doctor cares for many elderly patients and patients with dementia, it's very different to spend 10, 15 minutes with a person with dementia versus living with them day in, day out. And I don't feel judged by any of it. I feel like she [the physician] has left it up to be our decision. But I guess I wish that either she [the physician] could help us sort through these issues or be able to direct us

to someone who could. I understand that...every doctor in the practice can't be an expert on this. But there [should be]...somebody who...has read the medical ethics issues on this and...has a better understanding of what it means to die when your brain is the organ that is shutting down...to help weigh the options. I think I'd find that helpful. That's been something that we haven't really come across. I feel like we're in a big open field as far as this subject goes.

Between my first and second visits with Lisa, her mother-in-law had undergone a physical and her stool sample tested positive for a trace amount of blood. Lisa's response was, "Now what?" She and her husband had decided not to put her mother-in-law through a colonoscopy, but now the precise ethical issue they had anticipated has come to pass. Her struggle was apparent as she shared:

At times I almost ask myself, "Morally, did I do her a disservice by making her physically well?" And my husband...he counters it with, "Well you know, it's not like she would have died overnight of diabetes either. She would have lost a toe, she would have lost a foot...and the less mobile she was, the more difficult it would be for us to care for her." I think she's got a better quality of life now...than she did when she was a shut-in. She gets out, she socializes, she gets to see her grandchildren everyday. And I think that there's an element to that that is really good for her.

Fear of the future and the unpredictable course of the disease have created great stress for Ruth. Her partner, Jane, has asked that she never be placed in a nursing home; however Ruth knows that she can not make that promise. She shared that she hoped she could honor Jane's wishes; however, the reality of her situation became apparent when

she said, "I'm walking on eggshells, everything's very fragile right now." During my second visit, she assured me that she had "no intentions of suicide". She did indicate, though, that if she found herself in Jane's same condition she would "probably tie up my loose ends and you know, put my affairs in order and end it." After that interview, I encouraged Ruth to seek out her psychologist as needed.

Mr. Adler seemed to be experiencing distress and turmoil over this very same issue. While his wife appears physically healthy, he feels she is suffering and these comments reflect that:

In fact I said to my daughter the other day, and I know she was shocked about it, "It would be good if she would die tomorrow and not linger and go through this phase, it's going to get worse." It's not that it's affecting me personally but I don't want to see her suffering that way.

Mr. Adler is unsure of how to proceed as he anticipates the future need for increased assistance with his wife's care. Her doctor has recommended a screening colonoscopy but he cannot imagine being able to manage the preparation that is entailed by the procedure. During my second visit, Mr. Adler appeared to have lost weight and looked very tired. He had this to say: "And I've noticed [from] about the time before you first interviewed me up to now, that I can see physically I've changed, and I feel somewhat depressed." The toll of caregiving seemed to be mounting for him.

Even though her husband is deceased, Mrs. Weiss recalled her having similar feelings when she said:

Sometimes I'd lay in bed and cry and ask God to take him, which is not such a nice thing to do, but I just didn't want him to suffer...I don't know if he did suffer

or not. The only thing he suffered was maybe not being able to go all the time, because we always were going, always.

When her husband was hospitalized at the end, however, Mrs. Weiss experienced conflicting emotions. These expressions reflected those sentiments:

It became so bad toward the end that I was really confused about wishing he would die with no pain, or having him still live on. I mean, you reach that point. And that's when he had a heart attack in the hospital and they were pounding his chest to bring him back. I looked at them and I said "Leave him alone, just leave him alone." I was crying... [They said] "You sure?" I said, "Yeah, leave him alone. What are you doing to bring him back to?"

These caregivers expressed ambivalence about conflicting emotions for which there were no easy answers or definitive advice. They freely shared their thoughts and did not seem to have any professional avenues to sort through these feelings.

Summary

The goal of this hermeneutic phenomenological study was to uncover the lived experiences of caregivers as they transitioned to the caregiving role for their loved one with ADRD. Phenomenological reduction and data analysis were performed with data collected through in depth interviews with ten caregivers. Seven themes were identified from the informants' descriptions and interpretations of their experiences. Their descriptions allowed an understanding of their journey from diagnosis to their current concerns.

CHAPTER V

DISCUSSION, SUMMARY, AND RECOMMENDATIONS

This chapter contains a discussion of the seven major themes identified through a hermeneutic phenomenological inquiry into the experience of transitioning into the role of a caregiver for a person with ADRD. Study findings are presented according to themes and discussed in the context of the published literature. Also included are recommendations for future research, followed by implications for practice, education, and policy.

Theme 1: Something is Wrong

Many of the caregivers in this study reported a long journey to diagnosis. They reflected on episodes that preceded the diagnosis by long periods of time, in some cases years, and which eventually caused them to seek out medical assistance. During this pre-diagnosis stage, caregivers were compiling evidence of behaviors and episodes indicating that something was wrong. Aneshensel et al. (1995) in *Profiles in Caregiving: The Unexpected Career* refer to this beginning period as the “role acquisition” stage. During this stage, caregivers in this study were adapting to their loved ones’ difficulties with normal, everyday routines, including household tasks, driving, and work responsibilities, initially unaware of the true cause and scope of the problem with which they were to be faced.

Compiling evidence.

Likewise, in Wackerbarth and Johnson’s (2002) survey of 528 family caregivers of persons with dementia, study participants reported delays of up to 22.4 months in seeking medical evaluations after noticing symptoms. These findings were also

comparable to those in the Teel and Carson (2003) study, in which participants encountered delays in diagnosis and treatment that in some cases extended to several years. In their descriptive, qualitative study with 14 caregivers of persons with dementia recruited from support groups, Teel and Carson (2003) reported that participants had observed the gradual deterioration of their care recipients' abilities over a period of several years. Often, however, the caregivers were confused about the significance of these events. As noted by the caregivers in this current study, those in Teel and Carson's (2003) study reported changes in their care recipients' behaviors and difficulties with memory, finances, and driving.

In Shue et al.'s (2005) study with 38 caregivers of persons with AD, caregivers also identified "small problems" (p. 235) that generally occurred before diagnosis but that took on added significance once the dementia diagnosis was obtained. These "small problems" included difficulties with retaining information, inability to complete routine tasks, loss of interest in activities, and communication problems. Shue et al. (2005) also reported that some participants noted that in the earliest stages of AD, their loved ones were able to participate in normal interactions because they had learned how to "fake appropriateness in conversations" (p. 237). Mr. Adler suggested this very situation as he recalled dining out with friends when his wife would "order what the person next to her orders." He began to recognize that she was unable to make decisions when faced with choices and he attributed the aforementioned behavior as her strategy to compensate for that deficit.

In Adams' (2006) phenomenological study with 20 caregivers of persons with dementia, family members noted signs of apathy and problems with memory as the

earliest changes in their loved one. Similarly, all of the participants in this study noted memory impairments prior to diagnosis. Mrs. Cohen also recalled the apathy that became apparent in her husband ten years prior to his diagnosis: “When we’d go on a cruise; he would sit at the table and not say a word, like with his head down.” While at the time Mrs. Cohen attributed this apathy to fatigue resulting from a long work career, she later came to recognize that behavior as a sign of the impending dementia. While several caregivers in Adams’ (2006) study were able to identify a single event that finally alerted them to the need for a medical evaluation, the study findings did not include negative emotions regarding the diagnostic process.

Theme 2: A Journey to Diagnosis: Ambiguity and Negative Emotions

As caregivers in this study began to seek out help, many reported the challenge of actually obtaining a diagnosis. This experience led them to feelings of self-doubt, frustration, and dissatisfaction with the medical community, emotions that were still very powerful for them today. As Mrs. Decker shared, “Only the person who lives with him really recognizes it [the changes].”

Experiences of seeking a diagnosis.

Seven of the caregivers in this study felt that their concerns were dismissed by the physicians they had approached for help. In some cases the care recipients were initially treated for depression, thus delaying the process of obtaining an accurate diagnosis while caregivers sought advice from other physicians. This finding was comparable to the experience of participants in Teel and Carson’s (2003) study. Teel and Carson (2003) reported that the caregivers encountered hesitancy on the part of their primary care physicians to make a diagnosis, and needed to consult several physicians before the

diagnosis was obtained. This long process to diagnosis left those caregivers with feelings of distrust towards the medical community. Those same negative emotions regarding the diagnostic process were prevalent in this study. This diagnostic delay, as both Teel and Carson (2003) and Wackerbarth and Johnson (2002) noted, is significant because earlier diagnosis may lead to earlier treatment, which has the potential to delay progression of the disease.

A review of the literature suggests why the caregivers in this study may have encountered delays in diagnosis and early treatment. In their focus group interviews with 78 physicians, Boise et al. (1999) identified barriers to diagnosis that included: failure to recognize and respond to symptoms; perceived lack of a need to determine a diagnosis; time constraints; and negative attitudes towards the value of assessment and diagnosis. Families were found to have an influence on what tests were ordered, whether specialists were consulted, and the terms used to name the diagnosis.

In a study which involved an assessment of 553 persons aged 75 years or older from three managed health care systems Boise, Neal, and Kaye (2004) reported that 43% of the participants were identified as cognitively impaired. However, of those, less than one half had previously undergone a clinical evaluation for dementia. The authors suggested possible factors which may have contributed to this result, including the limited time available to detect dementia symptoms during a routine office visit; and the belief that a dementia diagnosis is not useful since little can be done to alter the progressive nature of this disease.

Solomon and Murphy (2005) reported that less than one-half of all AD patients are currently diagnosed and examined the evidence for and against dementia screening.

The authors presented that due to the prevalence of AD and the fact that the population is aging rapidly; routine screening may combat the current underdiagnosis of AD. Barriers to diagnosis in primary care settings, Solomon and Murphy (2005) note, may include the fact that a patient with AD may appear entirely appropriate during a brief office visit, or may be unaware of and minimizes symptoms. This speaks to the necessity of involving the caregiver or significant other, referred to as the “lay practitioner” by Hasselkus (1988), in the assessment process. Their first hand knowledge of the care recipient’s limitations may provide meaningful insight (Jorm, 2003; Ready et al., 2004) into the patient’s condition.

Solomon and Murphy (2005) presented the following factors as additional barriers to a dementia diagnosis: the belief among healthcare professionals and the public that AD is not treatable; memory loss and cognitive decline are a normal part of aging; and additional screening processes may be lengthy and poorly compensated. The study also notes, however, that immediate treatment with medications can provide some benefit in maintaining remaining function and delaying the progression of the disease. Early diagnosis also facilitates patient and family planning regarding future healthcare, living arrangements, financial, and legal decisions when the person with AD is functioning at his/her highest level. These issues became concerns for the caregivers in this study as their caregiving roles evolved.

Solomon and Murphy (2005) also presented rationales against routine screening for AD. The position of the U.S. Preventive Services Task Force is that there is insufficient evidence to demonstrate that screening provides better outcomes for patients with AD. The Alzheimer’s Association advises caution in proceeding with public

screening due to the variability in training of those performing the screening as well as the challenge of providing proper follow-up after a positive dementia diagnosis has transpired. Solomon and Murphy (2005), however, conclude that early detection and the use of appropriate medication and treatments to slow disease progression are essential to successfully manage AD.

Milne et al. (2005) offered some hope with respect to the dementia diagnosis process. In their comparative analysis of general practitioners' attitudes towards early diagnosis of dementia (Time 2 in 2001 compared to Time 1 in 1997), the authors found there was a greater commitment to early diagnosis at Time 2. Contributing factors to this change in perspective include better access to psychiatric colleagues, an increase in support services, and policies which emphasize the value of early diagnosis. It was also noted that national support for memory clinics and anticholinesterase inhibitors which were not noted at Time 1 may have contributed to this attitudinal shift.

Responses to diagnosis.

Caregivers in this study described emotions they experienced, including shock, anger, and disbelief, once the ADRD diagnosis was disclosed. For some, the diagnosis confirmed their suspicions. Similar to the participants in Adams' (2006) study, the realization that their loved ones, once so bright and intelligent were slipping, was devastating.

These negative emotional responses were also comparable to those reported by participants in the Connell et al. (2004) study. Connell et al. (2004) conducted focus group interviews with 52 caregivers and 39 physicians about the process of dementia assessment and diagnosis. Many of the caregivers expressed negative emotional

responses to the diagnosis, including disappointment that some physicians did not even suggest a return visit once the diagnosis was disclosed. Mr. Adler exemplified this negative manner when he recounted that the neurologist just could not wait to get them out of his office once the diagnosis was given. Mrs. Jackson also expressed her belief that the physician was reluctant to use the word “dementia.”

For some of the caregivers, the diagnosis served to confirm their suspicions. Mrs. Lang, Tonya, and Lisa found that the diagnosis was the impetus to begin to seek out supportive services. These findings were similar to those in Smith and Beattie’s (2001) study. Smith and Beattie (2001) conducted a qualitative study with 14 patients and their families as they underwent an assessment for dementia at an outpatient clinic. After the assessment, three patients were diagnosed with probable AD, five had possible AD, and six were not demented. The families of those who were diagnosed with probable AD expressed relief as the diagnosis marked the end of their uncertainty regarding the cause of their loved one’s memory problems. These family members also felt the diagnosis facilitated their ability to obtain proper care for the patient and prompted discussion with friends and coworkers about their family member’s problems.

In this study, Mrs. Decker’s husband was ultimately diagnosed at an aging center that focused on memory impairments. While the physicians were very direct about the diagnosis, she still experienced distress over the news. Mrs. Weiss also found the physicians to be very frank with her and her husband once the dementia diagnosis was finally disclosed; however her reaction was still devastation once she became aware of the implications of the disease.

Vernooij-Dassen et al. (2006) conducted a qualitative study with 18 couples, one of whom was diagnosed with dementia at a memory clinic. The authors also found that for most individuals and their caregivers, the diagnosis confirmed what they had suspected and prompted them to make decisions about the future. While not all of the caregivers in this study were anticipating the dementia diagnosis, the point of diagnosis served as the stimulus to seek out resources for knowledge and support. Vernooij-Dassen et al. (2006) noted that the caregivers in their study did not report devastation over the diagnostic process, a result that was attributed to the fact that the memory clinic offered a sensitive disclosure process and subsequent support. All of the caregivers in this study, however, reported negative emotions regarding the diagnostic process.

Theme 3: Shifting Roles and Relationships: Losses and Challenges

All of the caregivers in this study were able to articulate how their role had changed as they transitioned into a caregiver. Some mentioned taking on unwanted responsibilities and others described the burden these new tasks and the unfamiliar role of caregiver represented. While the caregiver role did not seem to have a definitive starting point, but rather evolved over time, it did seem to be a role in which the caregivers eventually became captive, similar to the phenomenon of “role captivity” as described by Aneshensel, Pearlin, and Schuler (1993).

Social roles.

Aneshensel et al. (1993) described “primary stressors” (p. 54) and “secondary stressors” (p. 55) which can contribute to feelings of burden. Primary stressors consist of daily care tasks which include personal care, supervision, and household management tasks such as paying bills. The caregivers in this study also referred to taking on such

tasks with varying degrees of hardship. Secondary stressors, however, are the demands related to economic hardship, social roles, and feelings about themselves. As Aneshensel et al. (1993) note, caregivers “become captive of an unwanted role” (p. 55). Prior to caregiving, these individuals were wives, husbands, sons and daughters. However, as they acquire the role of caregiver, they find themselves in a position that requires the unilateral provision of care. The term “role captivity” describes a “situation in which people are unwilling incumbents of social roles. The distinguishing characteristic of role captivity is not whether the role is difficult or stressful, but that the role is unwanted” (Aneshensel et al., 1993, p. 55). In this study, all of the caregivers expressed in some manner that they were enacting an unwanted role. They also addressed the fact that the caregiving role affected work and social roles as well as their relationship with the care recipient.

Croog, Burleson, Sudilovsky, and Baume (2006) conducted a study with 199 spouses of Alzheimer’s disease patients regarding responses to the stresses of caregiving. They found that feelings of anger-resentment towards the care recipient and restrictions on time and social life contributed to feelings of burden. All of the spouses in this study related examples of the restrictions caregiving had imposed on their life. Mr. Jaffar in particular was ashamed to admit that he would become irritated at times with his wife’s behavior. While his friends and children had tried help him normalize those feelings, he seemed to be struggling to give himself permission to do so.

Work roles.

Five of the caregivers had been working when they took on the caregiving role and their increased responsibilities defined a new role for them. The found that

continuing in a work role was not possible as their care recipients needed both care and supervision. All of the spouse caregivers in this study had looked forward to an active, enjoyable retirement with their partner; none had envisioned the role of caregiver as part of their future. For Lisa and Tonya, the demands of the caregiving role had created further strains on their professional and personal roles. Ruth seemed not only to be experiencing role captivity, but also role confusion as she was unsure how her future would unfold and her place in it.

Skaff, Pearlin, and Mullan (1996), in their longitudinal study of spouses and adult children caring for persons with dementia, described role captivity as a period of time in which caregivers have put their lives on hold while enacting a role which they had not anticipated. For children, it may have meant postponing events, for spouses it interfered with plans for retirement. The caregivers in this study had all in some form or another placed their life on hold.

Interpersonal roles.

Caregivers in this study addressed the change in relationship with their care recipient, in some cases from spouse to parent and in others from child to parent. These changes brought on additional demands and losses. Jordan (2005) describes this phenomenon as one in which the caregiver has lost not only the person their loved one once was but the person they were with them. Similarly, caregivers in Adams' (2006) study recounted examples of changes in both the tasks they had assumed and their relationship with the care recipient.

For the spouse caregivers in this study, all noted the loss of companionship or intimacy that they had previously shared with their spouse; however, fond memories

seemed to sustain them in the caregiving role. For several of the caregivers in this study, feelings of competence and confidence in their roles emerged as they shared knowledge and advice for use by other caregivers and health care professionals. Similarly, in their triangulated study, Narayan et al, (2001) examined the relationships between 50 spouse caregivers' positive and negative subjective responses to caregiving. The authors found that spouse caregivers concurrently viewed caregiving as self-fulfilling and affirming while at the same time experiencing loss and hardship. Those caregivers who believed that caregiving had enriched their lives regarded themselves as competent and confident caregivers. Those who suffered from a loss of their intimate relationship were more likely to feel trapped in the caregiving role. Mr. Adler seemed to be only experiencing captivity and did not express any feelings of competence in the role. His lack of knowledge on how to manage his wife's care and feelings of abandonment most likely contributed to that sentiment.

While the spouses, children, and partner in this study, had not anticipated the role of caregiver, neither were they prepared to take on a parenting role for their loved one. In his book, *The Forgetting: Alzheimer's: Portrait of an Epidemic*, Shenk (2001) refers to dementia caregiving as "reverse parenting" and notes that "reverse parenting lasts significantly longer and is more draining than conventional parenthood" (p. 66). Shenk (2001) also presents the analogy to childhood, first introduced by a neurologist named Barry Reisberg. He uses a step-by-step method to compare the developmental progression of a child to the progressive deterioration of an Alzheimer's patient. The inverse relationship between developmental tasks can be quite eye opening. Mrs. Lang most clearly illustrated this when she said, "I've raised three children and at least they

learned and they changed. He's going backwards." She is now burdened with incontinence care and envisions that it will only get worse.

In a phenomenological study with 26 Italian caregivers, Vellone et al. (2002) explored the experiences of family members caring for a person with AD. The theme of "changes in relationships" (p. 325) described some of the same findings in this study as caregivers conveyed their loss at changes in relationships with the patient from that of spouse to child. The theme of "changes in lifestyle" was also similar in that caregivers had to relinquish previous activities and were burdened with the continuous demands of caregiving.

Theme 4: Seeking Knowledge and Support: Solutions and Frustrations

Reading is fundamental.

As the caregivers spoke to learning the role of caregiver, reading emerged as an important source of information. For most of the caregivers, *The 36-Hour Day* (Mace & Rabins, 1999) was their "bible" of information. This book was first published in 1981 and a new edition was released in 2006. *The 36-Hour Day* is designed for family caregivers of persons with dementia. It provides information on Alzheimer's disease and related dementias; practical strategies to use as guidelines for handling problem behaviors; and information on further research and other resources. One caregiver mentioned the value of *The Alzheimer's Sourcebook for Caregivers* (Gray-Davidson, 1999). This book suggests strategies to cope with the personal issues that result from the disease, and provides information on ways to anticipate and prepare for the challenges that lie ahead for both the patient and caregiver. Another caregiver praised *The Forgetting: A Portrait of Alzheimer's* (Public Broadcasting System, 2003), a documentary film which provides

an all-encompassing look at dementia that “weaves together the history and biology of the disease, the intense real-world experiences of Alzheimer's patients and caregivers, and the race to find a cure” (¶ 1). For Lisa, this film served as a “wake-up call” because it presented the harsh reality of what dying from AD could entail and initiated the ethical concerns she expressed in this study.

While studies were not found that addressed the benefits of reading alone, one study in particular focused on testing an intervention for caregivers of persons with early stage AD. Kuhn and Fulton (2004) researched the effectiveness of an AD Knowledge Building Program designed for caregivers of relatives with early stage AD. The AD Knowledge Building program consisted of five weekly sessions and focused on the medical, legal, financial, and psychosocial aspects of caregiving. Forty-five caregivers participated in the intervention which was found to significantly increase caregivers' knowledge about AD, improve their self-efficacy and decrease their level of upset with problem behaviors in their care recipients. While all of the caregivers in this study had participated in Project ACT and received information on caregiving strategies, few had reported obtaining information from other professional sources. The topics included in Kuhn and Fulton's (2004) AD program could have been helpful to the caregivers in this study. Also markedly absent in this study, as was found in Teel and Carson's (2003) study, were any mentions of interactions with nurses during the beginning stages of dementia caregiving.

Support groups.

Support groups provided another means of obtaining knowledge for seven of the caregivers in this study. Most the caregivers in this study who joined support groups

spoke very highly of the groups in which they participated. They provided a supportive environment where caregivers were free to share worries and concerns. As in Teel and Carson's (2003) study, participants noted that support groups also offered a venue where learning needs could be met and other community resources could be accessed. While in some cases, it was a challenge to consistently attend the meetings; several caregivers indicated that they found regular attendance to be a necessity for their own well being.

Much has been written about support groups in the literature and their overall impact on the well being of caregivers (Connell & Gibson, 1997; Graham et al., 1997; Meuser & Marwit, 2001; Sorensen & Pinquart, 2005). Sorensen and Pinquart (2005) found that individualized caregiver interventions are more likely to achieve success; however group interventions can be more effective in improving care recipient symptoms. The authors attribute this to the process of mutual learning that occurs in the group setting. As caregivers exchange ideas and techniques to manage problem behaviors, they in turn are able to positively influence care recipient behaviors. The support group also had the added benefit of mobilizing a supportive social network.

One caregiver also noted the value of a support group she attended during the initial stage of her husband's disease which included both the caregiver and care recipient. According to Mather (2006), this type of program has the benefit of providing services, education, and a social network for persons with early stage dementia and their caregivers. Mather (2006) described a program called *Memory Lane Cafe* which began in 2002 in Melbourne, Australia and has enjoyed tremendous success.

Telephone support groups have been evaluated as a practical, low-cost alternative for caregivers who may not be able to regularly attend traditional support group meetings

(Smith & Toseland, 2006; Winter & Gitlin, 2006). Winter and Gitlin (2006) tested the efficacy of a telephone-based support group for female family caregivers of persons with dementia. The authors found that the older caregivers in the treatment group reported less depression at six months, compared to control group participants. The authors suggest that further research on this intervention is warranted due to its potential benefit for caregivers who might otherwise be unable to attend group meetings.

Theme 5: Adapting to the Topsy-Turvy World of Caregiving: Finding Purpose

All of the caregivers in this study shared strategies they have implemented to manage the care of their loved one with dementia. These strategies were acquired through various sources, including reading, support groups, healthcare professionals, and trial and error.

Task simplification.

Environmental modification and task simplification are recognized in the field of Occupational Therapy as factors which can contribute to higher functioning and reduced agitation among dementia patients. Gitlin et al. (2002) researched the daily activities that caregivers employed to simplify routine tasks for their loved one with dementia. From this, Gitlin et al. (2002) developed a *Task Management Strategy Index* (TMSI) which identified these strategies, and tested the tool with 202 family caregivers. The 19 strategies measured by the TMSI were intended to reduce the numbers of steps in a task, clarify the progression of steps, or to reduce negative consequences when errors occurred. The results demonstrated that higher TMSI scores, related to number and frequency of strategies being used, were significantly correlated with greater functional dependency of

the ADRD patient, and higher self efficacy and greater use of positive coping strategies among the caregivers.

The caregivers in this study reported using some of the same strategies identified in the TMSI. While they did not report where they had learned them, some of the strategies that they shared included the following from the TMSI:

Introduce an activity that uses the same motion over and over,

Give short instructions,

Keep talking to CR when he/she is doing something so he/she knows what to do,

Place your hand over CR hands to guide him/her through an activity.

Take CR arm to get him/her to go somewhere with you,

Have CR do simple chores such as folding laundry, making beds, or drying

dishes,

Try to ignore CR's mistakes,

Plan a routine for CR and try to stick to it (Gitlin et al., 2002, p. 66).

Shue et al. (2005) identified "togetherness moments" (p. 239) as ways in which caregivers tried to maintain their connection and quality time. Many of the caregivers in this study also described their efforts to keep their loved one involved in activities. Shue et al.'s (2005) critical incident category of "assisting events" (p. 239) was also evident in this study as caregivers spoke to the measures they used to assist their charges in remaining as independent as possible. These ranged from posting reminder notes throughout the house to modifying activities that the care recipients had formerly enjoyed, such as piano playing, household activities, puzzles, and word-find games.

de la Cuesta (2005) conducted a qualitative study with 18 Colombian dementia caregivers and two health care professionals to identify strategies that families used in their homes as they provided care. One theme identified by the study was “ruses of care” (p. 886), which describes stratagems employed by caregivers to deal with difficult situations. Caregivers in this study also shared such “ruses” as “fibbing”, and allowing the care recipient to believe that the Adult Day program is his workplace.

Adult day programs.

Four of the caregivers in this study utilized Adult Day services for their loved ones. They described the research they performed to identify a satisfactory program that would allow the care recipients to be engaged in meaningful activity. Also, by making use of this resource, caregivers provided themselves the opportunity to pursue personal interests and time to complete other responsibilities. Adult Day Services allow individuals with Alzheimer’s disease or other chronic illnesses the ability to live at home and as Lisa shared, can give a “sense of purpose in life” for the person with ADRD. Day Centers can be particularly helpful to family members who work outside the home and need caregiving services (Robert Wood Johnson Foundation, 2007b). For those caregivers who do not work outside the home, Day Programs allow them relief from their caregiving responsibilities and a regular period of free time (Jarrott, Zarit, Parris-Stephens, Townsend, & Greene, 1999).

In 2001-2002, the Robert Wood Johnson Foundation funded a national survey of Adult Day Services. The survey found that there were 3,407 centers nationally, well below the projected need of 8,520. The average age of participants was 72 years, about

52% of the persons were diagnosed with dementia, and costs averaged about \$56 a day (Robert Wood Johnson Foundation, 2007a).

Reever, Mathieu, Dennis, and Gitlin (2004) reported on an Adult Day Service Plus program that was tested with 67 family caregivers of persons attending an Adult Day Program in the Philadelphia region. The program, which consisted of enhanced individualized support for caregivers via counseling, education, and referrals, was compared to an Adult Day Program through which 62 caregivers received usual services. At three months, caregivers who had participated in the Adult Day Service Plus program demonstrated increased self-efficacy, a reduced sense of burden, and a trend towards decreased depression compared to the control group. At six months, these benefits were sustained among those caregivers in the treatment group, who also displayed a significant reduction in depressive symptoms. Reever et al. (2004) recommended further research into the most effective components of this program and ways to maximize its cost-efficiency. This type of program might serve as a beneficial point of entry for those caregivers who have been unable to access services due either to inability to identify resources or difficulties with scheduling due to work and family commitments.

Robinson, Buckwalter, and Reed (2005) evaluated the use of community services by a sample of 241 caregivers of an individual with memory impairment. They found that 64% of the group did not use services, and that depression and perceived burden were not correlated to the use of services. Robinson et al. (2005) suggested that although higher rates of depression may indicate a need for assistance, it may be that the depression itself has immobilized the caregiver in his/her search for community services. This situation was exemplified in this study by one caregiver, Mr. Adler, who seemed to need direction

to identify options for his wife's care. He had been waiting for some time for return telephone calls from his physician and the local Alzheimer's Association Chapter for direction. He acknowledged depression and certainly appeared immobilized by it.

Sharegiving.

Each of the caregivers expressed in their own way their sense of satisfaction in participating in my study. They had been on a journey and had learned much along the way. They were eager to share their stories, their successes and failures, and to have others understand their experiences. Without being asked, several caregivers compiled lists of suggestions that they presented to me when I returned for a second visit. These included messages for health care professionals as well as other caregivers. This information can only better serve our understanding of their experience.

Caregivers in Teel and Carson's (2003) study also offered suggestions for healthcare professionals. Specifically, they expressed the need for additional support from the medical community, such as allowing extra time to talk during office visits and referrals to resources. These caregivers also wanted to know that their health care providers were well informed about dementia and current treatments.

Theme 6: Preserving Self without Guilt

"Burden" has been well documented in the caregiving literature (Kinney, 1989; Morimoto et al., 2003; Novak, & Guest, 1989; Vitaliano et al., 1991; Zarit et al., 1980) and most of these caregivers had identified at least one way to preserve their own well-being. Mace and Rabins (1999) spoke to the importance of caring for self in *The 36-Hour Day*. They stress that it is essential to take time out or away from the care recipient so the caregiver does not exhaust all his/her own emotional and physical resources. Caregivers

need to feel empowered to address their own physical and emotional health without feelings of guilt; however, caregivers may perceive activities for themselves as self-centered. The danger of failing to spend the time to restore one's own resources can be manifested in depression and physical symptoms.

Mrs. Decker had shared a story of taking her husband on a cruise, which only confused him and which she did not enjoy. When she vacationed without her husband, she thoroughly enjoyed the time with her daughters. Mrs. Decker was able to absolve herself of any guilt because she knew her husband was receiving excellent care and would not remember that she was gone. The caregivers in this study seemed to have given themselves permission over time to engage in activities that were therapeutic for them. While some shared that family and support group members had encouraged them to care for themselves, others had learned through experience that taking time out to renew themselves sustained them in their caregiving role. Jordan (2005) acknowledged as well that self care may be seen in our society as selfishness so suggestions for regular self-care activities should be part of any treatment plan for dementia caregivers.

All of the caregivers in this study expressed that having an opportunity to share their thoughts and emotions was very therapeutic. The extent to which they felt candid to verbalize with me suggests that knowing they would not be judged or criticized for their feelings provided an important outlet for them.

Caregivers in Adams' (2006) study did report experiences of guilt, however, they did not report on strategies to preserve themselves without guilt. This may be attributed to the fact most of their care recipients were in the earliest stages of AD and for the most

part, the caregivers had expressed a reluctance to seek outside help and had not experienced for themselves strategies to take care of self.

Theme 7: Finding a Way Out

Several of the caregivers in this study expressed feelings of sadness and apprehension as they considered a very uncertain future. Mr. Adler's thought that his wife would be better off dead and Ruth's thoughts of "suicide" for her partner exemplified those feelings. Boss (1999) coined the term "ambiguous loss" (p. 6) referring to the grief that caregivers experience over the loss of the person who once was. There is no clear beginning or ending point due to the insidious course of the disease.

Aneshensel et al. (1995) acknowledged that depression is a common occurrence among dementia caregivers and the amount of role overload, defined as "the internal experience of being overwhelmed by care related tasks and responsibilities" (p. 80), and the rate at which it increases contributes to depression. Aneshensel et al. (1995) had this to say about this stressor:

The impact of the persistent amount of role overload is somewhat more important than the rate at which it is increasing. Thus, feeling overwhelmed by the rigors of caregiving is depressive, especially when this sentiment continues over time and when it becomes more intense. In addition, an increasing sense of role captivity tends to exacerbate emotional distress (p. 137).

All of these caregivers had examples to share of the overwhelming nature of the care they were providing on a daily basis and as such have the potential to experience depressive symptoms. Even Lisa, who appeared to be managing her mother-in-law's care

well, acknowledged that coming back from a wonderful vacation can put her “in a real funk”. It brings her back to the reality and demands of everyday dementia caregiving.

Sanders and Adams (2005) found that such feelings may highlight the need for interventions directed towards the “ambiguous grief” of dementia caregiving. Sanders and Adams (2005) gathered pilot data from 122 caregivers of persons with AD who were affiliated with an east coast chapter of the Alzheimer’s Association. Caregivers completed a survey which measured grief, depressive symptoms, and frequency of care recipient problematic behaviors. The results indicated that the caregivers were experiencing symptoms of grief which could be a predictor of increased depressive symptoms. Sanders and Adams (2005) recommended that further research in this area is warranted as strategies traditionally used for end-of-life issues may not be effective for this type of grief. The authors note that caregivers may be reluctant to discuss these feelings of grief due to expected social norms.

Mace and Rabins (1999) in their guide to family caregiving, *The 36-Hour Day*, acknowledge that grief may be a very common emotion for caregivers of a person with a dementia diagnosis. Unlike the grief associated with death, which may be overwhelming at first and then lessens, grief in this situation can continue for a long period of time. The caregiver is grieving the loss of the person who once was and the relationship they shared. Mace and Rabins (1999) also noted that a caregiver may feel misunderstood when friends and family members suggest that the care recipient looks well and that the caregiver should be happy to still have him/her. Many of the caregivers in this study echoed that sentiment because, aside from the dementia, their loved ones were otherwise healthy and appeared well. Mr. Adler shared his disturbance that family members who

visited his wife doubted his descriptions of her limitations. This situation occurred six weeks prior to my visit. His wife's sister told Mr. Adler that she only noticed difficulties when Mrs. Adler attempted to rise from her chair and when she was indecisive while ordering dinner at a restaurant. This caused Mr. Adler to doubt himself and his perception of his wife's condition, even though he is faced with her limitations on a daily basis.

The losses in dementia caregiving have been referred to as "expirations along the way" (Shenk, 2001, p. 224) and "a long train journey with the ultimate destination of death, no fixed route and no estimated time of arrival" (Dempsey & Baago, 1998, p. 87). Dempsey and Baago (1998) go on to say that "along the way there are many stations where 'mini-deaths' occur, and these can be conceptualized as 'stations of bereavement'" (p. 87). All of the caregivers in this study reflected on the losses they have experienced during the process of caregiving.

Shulz et al. (2003) assessed the responses to the demands of care for 217 caregivers of persons with dementia during the year before the patient's death and their responses after the death. While providing care, caregivers showed evidence of high levels of depression but demonstrated significant resilience after the death of the loved one. For 72% of the caregivers, death came as a relief, and more than 90% reported they believed it was a relief for their family member with dementia. Mr. Adler suggested these very same sentiments as he shared his belief that his wife was suffering and that death would be a relief for her.

Similarly, Sanders and Corley (2003) interviewed 253 dementia caregivers on the topic of grief. Caregivers were asked to respond to the question, "Do you believe you are grieving the loss of your loved one even though he/she is still alive?" (p. 40). Sixty-eight

percent of the respondents (n= 173) indicated that they were grieving and feelings of ambiguity, hopelessness, and guilt emerged, similar to the participants in this study. Caregivers also expressed losses related to the relationships they once shared with their loved one.

Much of the literature focuses on interventions to delay institutionalization of the care recipient, which is seen as a highly negative outcome, once the demands of care surpass resources (Farran, 2002). While some caregivers in this study expressed their anxiety about possible institutionalization, they also presented their conflicts about health care concerns and how to make decisions for the future, a finding not reported in any other studies. These concerns included a struggle with deciding on the appropriate course of treatment for prostate cancer for one care recipient; how to proceed after a positive colorectal screening result for another; and whether it was possible to prepare a third care recipient for a screening colonoscopy.

Adams (2006) noted that the caregivers in her study seemed to delay planning for the future. Most avoided conversation surrounding “issues of progressive inevitable deterioration in their loved ones” (p. 20). Those caregivers reported an average of 3.8 years since the signs of memory loss, and many were still hopeful about both the availability of medications for AD and a slow progression of symptoms. It can be assumed, however, that they, too, may eventually reach the point where they are confronted with difficult ethical decisions.

Death due to Alzheimer’s disease is a process that can continue over months or even years. Shenk (2001) offered the scenario of death for the Alzheimer’s patient who does not ultimately die as the result of another medical condition such as pneumonia,

stroke, heart failure, or cancer: “speech dissolves completely, incontinence sets in, muscles become stiff, walking becomes impossible, the face loses all elasticity, breathing becomes labored, swallowing ceases” (p. 221). An added concern is the fact that Alzheimer’s patients live for an average of eight years and as long as 20 years after the initial diagnosis (Prigerson, 2003). Given the ultimate scenario of death from Alzheimer’s disease, what are the ethics of everyday medical decisions?

The literature offers little regarding the ethics of treatment for a person with dementia and, at times, may seem contradictory. While research continues on measures to delay progression of the disease, Post and Whitehouse (1998) suggested that the introduction of the drug Aricept for treatment of mild to moderate AD may present ethical concerns for the individual who has already suffered cognitive decline and adjusted to that loss. Improvements in function may enable the care recipient to “live through the same decline twice” (p. 785). The question then becomes: “Is this morally and ethically in the patient’s best interest?”

Sachs (1998) addressed this very ethical issue and the dilemmas surrounding appropriate dementia care. Sachs (1998) suggested that before decisions can be made about treatments such as antidementia drugs, CPR, flu shots, or even mammograms, health care providers and families must have a discussion about the goals of care. In the absence of specified goals of care, patients may be victims of the “fix everything” (p. 782) approach which may become burdensome for the patient. Conversely, the person with dementia may be deemed inappropriate for most treatment by healthcare professionals, regardless of the patient’s and family’s wishes. Sachs (1998) proposed that goals of care should be based on the preferences of patients and families, stage of

dementia, the presence of comorbid conditions, the severity of symptoms, and the risks/benefits of any proposed course of action. Sachs (1998) presents the example of a woman in the early stages of dementia who is aggressively treated for pneumonia. However, a patient with severe dementia, who resides in a nursing home and is no longer able to recognize family, may be more appropriately treated with palliative care measures. These kinds of decisions require discussions among family and healthcare professionals that may not be occurring routinely. Offering opportunities for candid discussions can help to normalize feelings of guilt and grief. Advocating for early health care planning which includes living wills and durable health care powers of attorney, may also help to guide caregivers as they are faced with difficult decisions.

When faced with healthcare decisions, Mace and Rabins (1999) recommend that caregivers first obtain the best medical information available, including the benefits and risks of each intervention. The study also stated that family should proceed in a cautious manner, and weigh decisions based on the patient's preferences and best interest rather than simply accepting opinions of healthcare professionals.

Hirschman, Kapo, and Karlawish (2006) interviewed 30 family members of persons with dementia about their standard of decision making when faced with a medical issue. They found that 43% of the family members used "substituted judgment" when making medical decisions. This refers to basing decisions on what the patient would want if they were capable of making that decision. However, many of these caregivers saw their decisions as also in the best interest of their loved one. For the 57% of the sample who used the "best interest" standard, more than half shared that they did not know the healthcare preferences of their family member. A common reason for this

situation was that no conversation regarding health care was held with their relative before he/she became too impaired to make a decision. This finding supports Solomon and Murphy's (2005) contention that earlier diagnosis may offer opportunities for advance health care planning while the care recipient is at their highest level of function. The caregivers, however, will need guidance from health care professionals as they are embarking on an uncertain future.

Summary

Alzheimer's disease and related dementias are progressive, debilitating diseases that affect not only the afflicted individual but, also, their family caregivers. Participants in this study highlighted seven themes that characterized their transition into the caregiving role that included: *Something is Wrong; A Journey to Diagnosis: Ambiguity and Negative Emotions; Shifting Roles and Relationships: Losses and Challenges; Seeking Knowledge and Support: Solutions and Frustrations; Adapting to the Topsy-Turvy World of Caregiving: Finding Purpose; Preserving Self without Guilt; and Finding a Way Out*. These themes were consistent with those from the Teel and Carson (2003) and Adams (2006) studies especially with regard to the process of diagnosis. However, two new themes emerged in this study: *Preserving Self without Guilt*, and *Finding a Way Out*. Their stories reflected the issue of burden that is abundant in the literature but there were few references to religious or cultural influences to caregiving.

Limitations

This research was based on the assumption that the phenomenological approach represented a valid strategy to begin to understand the process of transitioning to the role of caregiver for a family member with ADRD. As such, participant selection was based

on purposeful sampling which is a typical qualitative method. It is acknowledged, however, that the individuals who participated in this study are not reflective of the larger population of caregivers of persons with ADRD. All of the informants were drawn from a research database and, therefore, may possess certain characteristics that prompted them to participate in a research study. The caregivers were also asked to reflect back, in some cases several years, to the beginning of their caregiving career, and in effect were reinterpreting their experience at the time of diagnosis.

The transferability of the findings, however, should be enhanced through the rich and thorough descriptions of the data that are presented (Polit, Beck, & Hungler, 2001). This richness increases the probability that these findings will have meaning to other caregivers in similar situations.

Recommendations

There have been a wealth of studies presented in the literature on Alzheimer's disease and caregiving; however, only one study found by this researcher addressed the experience of transitioning to the role of caregiver for a person with ADRD and one other on the experience of the dementia diagnosis. Due to the increasing number of elderly individuals in the population, this disease is projected to be a growing health problem, likely to affect 13.2 million by 2050 (Hebert et al., 2003). This increase will have profound implications and recommendations for research, education, practice, and policy.

Recommendations for Research

The themes highlighted in this study suggest areas for future caregiving research. As caregivers recounted their journey to diagnosis, impediments to timely diagnosis and difficulties in accessing appropriate services were noted. Further studies on the

experiences and needs of family members during the earliest stages of a loved one's memory loss are warranted. Additionally, research on the socialization to the caregiving role and the positive aspects of caregiving may offer information and strategies to support future caregivers and their well-being.

The unique themes of *Preserving Self without Guilt* and *Finding a Way Out* suggest that these are areas to be further explored as well. A study that investigates the ethics and patterns of health care decision-making is suggested, as this became a major source of concern for some of the caregivers in this study. As Sachs (1998) has recommended, matching services to the goals of care can effectively direct health care planning. Caregivers in this study were open to sharing negative feelings associated with their concerns of "finding a way out" of the caregiving role. A study investigating how caregivers actualize those decisions may assist health care personnel as they advise future caregivers.

Recommendations for Nursing Education

As in Teel and Carson's (2003) study, nurses were not identified in this study as potential primary sources of caregiver support or education. Nurses encounter patients in a myriad of settings throughout the healthcare spectrum. As caretakers, educators, and advocates, they are in a unique position to provide caregivers with the skills, knowledge, and resources they require to successfully function in this role. As our population continues to age, it is imperative that both nursing curricula and practice address this issue which affects so many.

Specific areas for inclusion in curricula that emerged from this study included the benefits of providing opportunities for open communication, access to resources,

strategies to manage behaviors, and measures to care for self. Caregivers also need detailed information on the disease process of ADRD, changing roles and relationships, and the benefits of health care planning early on in the disease process so that they can incorporate the wishes of their loved one.

The John Hartford Foundation in collaboration with the American Association of Colleges of Nursing (AACN) (2007b) has developed a Geriatric Nursing Education Consortium (GNEC) with the aim of improving the care of older adults through “curriculum enhancement, faculty development, and scholarship opportunities” (¶ 1). This program is similar to the work that was done through the End-of-Life Nursing Education Consortium (ELNEC) (American Association of Colleges of Nursing 2007a). This national program has set out to improve end of life care and prepares faculty, staff development educators, and specialty nurses with the tools and training to teach both nursing students and those in practice. This researcher will be attending the inaugural GNEC Faculty Development Institute in June 2007. The AACN has developed *Older Adults: Recommended Baccalaureate Competencies and Curricular Guidelines for Geriatric Nursing*; specific strategies designed to facilitate integration of the geriatric nursing content (AACN, 2005) Results of this study can be incorporated into nursing curricula and these guidelines when addressing the role of the nurse in the care of the patient with ADRD and their caregiver.

Implications for Nursing Practice

A significant percentage of our population is affected by ADRD and the numbers are only expected to rise. Nurses are at the forefront of health care delivery. As such, they are in a pivotal position to respond to the needs these participants experienced as they

embarked on the caregiving journey. Continuing education on ways to provide information and support regarding the disease process, safety measures, available community resources, stress reduction, and planning for the future should be offered for nurses and other members of the interdisciplinary team. These strategies should be components of a comprehensive plan of care and included in the content for certification for geriatric nursing (The John A. Hartford Foundation Institute for Geriatric Nursing, 2005). This plan can also serve as a model of interdisciplinary care for caregivers of persons with any chronic disease.

Alzheimer's disease caregivers are also known to suffer from more depression and burden than any other group of caregivers (Alzheimer's Association & NAC, 2004). The caregivers in this study provided specific examples of resources that proved helpful to them such as reading, support groups, and Adult Day programs. Caregivers also expressed the benefit of simply having the opportunity to verbalize their thoughts and concerns. In primary care settings, the nurse's plan of care should incorporate strategies to maximize open communication with dementia caregivers. This would allow caregivers time to tell their stories, express feelings, and address the ethical dilemmas they may be facing.

Implications for Policy

As the numbers of those affected by ADRD increases, the social implications are overwhelming. As these caregivers spoke to their experiences it became evident that early support is essential. Without adequate support networks and services, caregivers will be unable to manage the care of the person with ADRD in the home. Home-based care is significantly more cost-effective than institutionalization. However, the 44.4

million caregivers in the U. S. providing unpaid care to adults (NAC & AARP, 2004) are in need of financial and social resources if they are to continue in their role. The *Alzheimer's Family Assistance Act of 2007* (Kantrowitz & Springen, 2007) was introduced to Congress in March of 2007. If signed into law, this bill would provide tax credits for caregivers that could be used to pay for healthcare costs and day care.

The public must be educated to: recognize the early warning signs of cognitive impairment; understand that early treatment may delay progression of the disease; and dispel the myth that ADRD is a normal consequence of aging. As Solomon and Murphy (2005) have also reported, early diagnosis of AD facilitates access to pharmacologic and nonpharmacological treatments which may delay the progression of the disease. Public support for family leave and respite care is also essential if caregivers are going to be able to continue to manage their loved one in their home setting.

Conclusion/Reflections on the Study

The purpose of this study was to explore the lived experience of transitioning to the role of caregiver for a family member with ADRD. All of the participants in this study had experienced caregiving for a loved one with ADRD and had unique as well as similar stories to tell. They were considered both “veteran” and “expert” caregivers because of their familiarity with health care professionals, pharmacologic therapy, and services and information that would have been helpful during their transition. Prompts were used to attempt to keep the participants in the experience of transitioning; however, as caregivers spoke to that beginning experience, it became apparent that the caregiver role evolved over time and did not have a definitive beginning. I came to realize that their experience could not be isolated to one particular point in time, such as the period of

diagnosis. All caregivers, however, were able to share about life before the ADRD diagnosis and reflect on how life has changed since then. Most caregivers began to assume responsibilities and tasks gradually and continue to this day to adapt to an unpredictable role. Caregiving seemed to envelop every part of their life, from the time they embarked on their caregiving career to their current concerns and worries. They were open to sharing their stories.

The in-depth interviews offered an understanding of the meaning that the caregiver attributed to the experience. They freely shared their thoughts and emotions and thanked me for allowing them to tell their story. In one case a caregiver said, "It's nice to talk to somebody that knows and doesn't criticize." I was humbled by their willingness to be candid with me and the ease with which they welcomed me into their homes and lives. The interviews seemed to be an outlet for these caregivers to acknowledge and share their innermost feelings. It was difficult to say goodbye to them after the second interview. For three of the caregivers, I followed up with some written information from the Alzheimer's Association on support services in their communities. As I offer these findings, I believe I have captured the essence of these individuals, and I am grateful for their participation. They have enabled me to gain a brief understanding of their experience. This type of understanding is significant for nursing in that "the meanings that patients attribute to their experiences help create the needs they have and how those needs can best be met" (Cohen et al., 2000, p. 4).

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APPENDICES

Appendix A

Letter to Potential Participants from Project ACT

Dear Study Participant;

Thank you for your participation in Project ACT. As a participant, you had expressed interest in learning about other related research studies. I am writing to inform you of another opportunity to participate in an important research study on family caregiving that may be of interest to you.

Kathleen Czekanski, MSN, RN, the Thomas Jefferson University Nurse Interventionist for Project ACT, is conducting a research study as part of her doctoral studies at Duquesne University School of Nursing. Ms. Czekanski is examining the early experiences of becoming a family caregiver for persons with Alzheimer's disease or a related disorder. The study involves two 1 ½ hour interviews that take place over a months time. Each interview can be conducted in your home at a time convenient for you. In the interview, you will be asked to think about and share your experiences when you first learned about your family member's diagnosis and what that was like for you.

The interviews will be audio taped and kept confidential and used for research purposes only. The tapes will be stored without names or other identification in locked filing cabinets at Thomas Jefferson University.

As a way to thank you for your time and participation, you will receive a \$10 gift certificate for each completed interview from your choice of a local convenience store or one of three local pharmacies.

Your participation in this study is voluntary, and you can end your participation if you wish at any time. If you decide not to participate, it will not affect your care at Jefferson or other agencies or your participation in other studies that may be of interest to you in the future.

If you are interested in participating or would like more information, please fill out and return the self addressed and postage paid card enclosed or call Ms. Czekanski at . We hope you will consider participating in the study. Should you have any further questions, please feel free to call Ms. Czekanski.

I hope you will consider participating in this important study. I believe you will find the interview interesting and by sharing your experiences you will be helping us learn more about the role of families in providing care to persons with dementia.

Sincerely,
Laura N. Gitlin, Ph.D.
Director

Appendix B

Demographic Data

Care recipient demographic data:

Dementia diagnosis from physician?

Yes _____

No _____ If no, ineligible to participate in the study

Care recipient age: _____

Care recipient sex: _____

Care recipient relation to caregiver: _____

Care recipient culture/ethnicity: _____

Care recipient marital status: _____

Care recipient highest level of education: _____

Care recipient past occupation: _____

Caregiver demographic data:

Caregiver age: _____

Caregiver sex: _____

Caregiver relation to care recipient: _____

Caregiver culture/ethnicity: _____

Caregiver marital status: _____

Caregiver highest level of education: _____

Caregiver occupation: _____

Length of time in the caregiving role: _____

Average number of hours per day spent caring for person with ADRD: _____

Appendix C

The interview will begin with social greetings and then the researcher will ask the questions from the demographic questionnaire. The in-depth interview will start with a global interview question.

- Tell me about the day you learned about your family member's ADRD diagnosis.

Additional open-ended questions and probes that may be used to gain an understanding of this experience will include:

- Tell me about key events that led up to the diagnosis.
- Did your life change from the time of diagnosis? If yes, tell me more about those changes.
- How did you know what to do for your family member?
- Tell me what was or would have been helpful to you during this time of diagnosis and early caregiving for your family member.
- Can you describe anything that made this time period of diagnosis and early caregiving for your family member more difficult?

General Probes:

- Can you give me an example?
- Tell me more about that...
- Go on...
- How did you feel?
- What did that mean to you?
- Please recall an incident that best describes.....

Appendix D



DUQUESNE UNIVERSITY

INSTITUTIONAL REVIEW BOARD

424 RANGOS BUILDING ♦ PITTSBURGH, PA 15282-0202

Dr. Paul Richer
Chair, Institutional Review Board
Phone (412) 396-6326 Fax (412) 396-5176
e-mail: richer@duq.edu

November 2, 2006

Ms. Kathleen Czekanski
[Redacted]

**Re: "The experience of transitioning to the caregiving role for a family member with Alzheimer's disease or a related dementia: a phenomenological inquiry"
(Protocol # 06-107)**

Dear Ms. Czekanski:

Thank you for submitting your research proposal to the IRB.

Based upon the recommendation of IRB member, Dr. Kathleen Sekula, along with my own review, I have determined that your research proposal is consistent with the requirements of the appropriate sections of the 45-Code of Federal Regulations-46, known as the federal Common Rule. The intended research poses no greater than minimal risk to human subjects. In addition, the proposal has been reviewed and approved by the University's HIPAA officer, Dr. Joan Kiel. Consequently, under rules 46.101 and 46.110, your proposed research is approved on an **expedited** basis.

The IRB stamps the consent form with an approval date and one year expiration date. This stamp appears on the front page of the form, which is enclosed with this letter. You should use it as the original for your copies. Please remember that there should be two copies of the consent form with original signatures, one for you and one for the subject.

This approval must be renewed in one year as part of the IRB's continuing review. You will need to submit a progress report to the IRB in response to a questionnaire that we will send. In addition, if you are still utilizing your consent form, you will need to have it approved for another year's use.

In correspondence with our office about the study, please refer to the protocol number shown above after the title.

If, prior to the annual review, you propose any changes in your procedure or consent process, you must inform the IRB Chair of those changes and wait for approval before implementing them. In addition, if any procedural complications or adverse effects on subjects are discovered before the annual review, they immediately must be reported to the IRB Chair before proceeding with the study.

When the study is complete, please provide us with a summary, approximately one page. Often the completed study's Abstract suffices. Please keep a copy of your research records, other than those you have agreed to destroy for confidentiality, over a period of five years after the study's completion.

Thank you for contributing to Duquesne's research endeavors.

If you have any questions, feel free to contact me at any time.

Sincerely yours,

A white rectangular box redacting the signature of Paul Richer.

Paul Richer, Ph.D.
IRB Chair

C: Dr. Kathleen Sekula
Dr. Joan Lockhart
Dr. Joan Kiel
IRB Records

Appendix E

	Thomas Jefferson University	Office of Human Research Division of Human Subjects Protection Institutional Review Board
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November 22, 2006

Kathleen Czekanski, MSN, RN
JCHP School of Nursing
130 S. 9th Street – Suite 1208

Founded 1824

Jefferson Medical
College

Jefferson College of
Graduate Studies

Jefferson College of
Health Professions

Jefferson University
Physicians

Dear Ms. Czekanski:

The **Institutional Review Board (IRB)** has reviewed the proposed changes with regard to the involvement of humans as research subjects in your study entitled:

"The Experience of Transitioning to the Caregiving Role for a Family Member with Alzheimer's Disease or a Related Dementia: A Phenomenological Inquiry" (Unfunded) Control #06U.398

Amendment: Adding contact at Duquesne University and contact info to the consent form. *Revisions to consent form only.*

In accordance with Federal-Wide Assurance #00002109 with the U.S. Department of Health and Human Services, this **amendment** was administratively approved on **11/21/06**. Board #152 will be notified of this approval at its meeting on 11/30/06.

EXPEDITED (X) Board Review

THIS APPROVAL REQUIRES THAT INFORMED CONSENT BE OBTAINED FROM ALL PERSONS PRIOR TO THEIR INVOLVEMENT IN THE STUDY BY THE USE OF THE LATEST APPROVED SUBJECT CONSENT FORM.

EACH SUBJECT MUST RECEIVE A COPY OF THEIR SIGNED CONSENT FORM.

This approval expires 9/12/07 one year from the original approval date of the study, unless suspended or terminated earlier by action of the IRB. Prior to the expiration date, a report (Form OHR-9) must be submitted to the IRB summarizing progress on the study during that period.

If you wish to continue the study beyond the expiration of this approval, an application for continuation of your study must be submitted to the IRB at least one month prior to the expiration date.

Any injury and/or unanticipated problem involving risks to the human research subjects not included in the written consent form must be reported promptly to the IRB using Form OHR-10 ON-SITE or OHR-10 OFF-SITE. This report should describe the event, evaluate its probable relationship to the experimental treatment received by the subject, and summarize the resulting outcome of the event.

Any proposed change in the protocol or in the written consent form must be submitted to the IRB for review and approval using Form OHR-12 before the proposed change can be implemented.

This approval verifies that the IRB operates in accordance with applicable ICH, federal, local and institutional regulations.

Sincerely yours,

Kyle Connor, MA, CIP
Associate Director
Division of Human Subjects Protection

KC/pmo

www.jefferson.edu

1015 Chestnut Street, Suite 1100, Philadelphia, PA 19107-4022 • 215-955-8000 • Fax: 215-955-3492

Appendix F

Thomas Jefferson University
Informed Consent Document for Human Subjects Research

Department: Center for Applied Research on Aging and Health

Principal Investigator: Kathleen Czekanski, MSN, RN **Telephone:** _____

Medical Title: The Experience of Transitioning to the Caregiving Role for a Family Member with Alzheimer's Disease or a Related Dementia: A Phenomenological Inquiry

Lay Title: The Experience of Becoming a Caregiver for a Family Member with Dementia

What Is an Informed Consent?

You are being asked to take part in a research study. Before you can make a knowledgeable decision about whether to participate, you should understand the possible risks and benefits related to this study. This process of learning and thinking about a study before you make a decision is known as *informed consent* and includes:

- Receiving detailed information about this research study;
- Being asked to read, sign and date this consent form, once you understand the study and have decided to participate. If you don't understand something about the study or if you have questions, you should ask for an explanation before you sign this form;
- Being given a copy of your signed and dated consent form to keep for your own records.

You should understand that your relationship with the study nurse is different than your relationship with a nurse in an office or hospital setting. Be sure to ask questions of the research nurse if you want further clarification of this relationship.

Introduction and Study Purpose

You are being asked to participate in a research study that seeks to investigate how caregivers of persons with Alzheimer's disease and related dementias enter into the caregiving role. The purpose of the study is to share those experiences with other caregivers and healthcare workers.

This study is being performed as partial fulfillment of the requirements for the doctoral degree in Nursing at Duquesne University. The researcher has also received partial funding for this project through the Center for Faculty Development Summer Exploration Fund at Thomas Jefferson University.

Procedures/Treatment

For this study you will be asked to participate in 2 interviews with the researcher in order to describe your experience. These sessions will be audio taped and transcribed. The purpose of the interviews is to share your experiences about becoming a caregiver with the researcher, Kathleen Czekanski, MSN, RN. The interviews are expected to last between 45 to 90 minutes and will occur about three to five weeks apart. These are the only requests that will be made of you.

Risks/Discomforts

There is a slight possibility that you may become upset as you discuss your experiences about becoming a caregiver. If this occurs, please let me know. You can stop and rest for a while or we can continue with the interview at another time. If needed, you can be referred to the Alzheimer's Association 24 Hour Helpline.

Alternative

Your alternative is not to participate in this study.

Confidentiality

There are federal regulations about protecting information about you. This information is called "protected health information" (PHI). PHI includes things that identify you personally like your name, and address. According to federal and state regulations, you may see your health information at any time.

By signing this consent form, you are allowing the research team to have access to your PHI. The research team includes the investigator listed on this consent form and other personnel involved in this specific study such as my faculty advisor at Duquesne University. Your PHI will also be shared, as necessary, with the University's Division of Human Subjects Protections and the Institutional Review Board (a University committee that reviews, approves and monitors research involving human subjects).

All of the above entities are obligated by law to protect your PHI.

Your PHI will be used/disclosed indefinitely.

You may quit the study and revoke permission to use and share your PHI at any time by contacting the principal investigator, in writing, at: 130 South 9th Street, Suite 1208, Philadelphia, PA 19107. If you quit the study further collection of your PHI will be stopped, but PHI that has already been collected may still be used.

The information from this study may be published in scientific journals or presented at scientific meetings but you will not be personally identified in these publications and presentations.

Your name will not appear on any transcripts from the interviews. Both audio-tapes and transcripts will be kept confidential. Audio-recordings made during interviews will be destroyed after transcription. Transcription of audiotapes will be conducted by a researcher or researcher-trained transcriptionist who has signed a confidentiality statement. Transcriptions of tapes will delete all identifiers of subjects or anyone subjects talk about. De-identified quotes will be used both in publications and presentation. All materials, including audiotapes and raw data will be stored in a locked box at the researcher's office. All materials will be destroyed when all activities related to the research are completed.

Benefits to Subject

There are no benefits to participating in this study other than the knowledge that you may be helping future caregivers.

Payment

There is no cost to you for being in the study. You will be compensated with a ten dollar gift certificate, at the conclusion of each interview, from your choice of a local convenience store or one of three local pharmacies.

Contact Information

If you have any questions or concerns about this research call the Principal Investigator, Kathleen Czekanski, MSN, RN at 215-503-8318. Should you have any questions regarding your rights as a research participant, you may contact Thomas Jefferson University's Institutional Review Board, which is concerned with the protection of participants in research studies, at: (215) [503-8966](tel:215-503-8966) or Dr. Paul Richer, Chair of the Duquesne University Institutional Review Board at: (412) [396-6326](tel:412-396-6326).

Voluntary Consent and Subject Withdrawal

You voluntarily consent to be in this research study. You have been told what being in this study will involve, including the possible risks and benefits. You may refuse to participate in this study or withdraw your consent and discontinue participation in this study without affecting your ability to receive medical care at Thomas Jefferson University.

Non-Waiver of Legal Rights Statement

By your agreement to participate in this study, and by signing this consent form, you are not waiving any of your legal rights.

In order to be in this research study, you must sign this consent form.

You affirm that you have read this consent form. You have been told that you will receive a copy.

Signatures:

_____(Date)
Your Name *(please print or type)*

_____(Date)
_____(Date)
Your Signature

Witness Signature

(Only required if subject understands and speaks English, but cannot read English, or if subject is blind or cannot physically sign the consent form—delete if inapplicable)

_____(Date)
Name of Person Conducting Consent Interview

_____(Date)
Signature of Person Conducting Consent Interview

_____(Date)
Signature of Principal Investigator or
Co-Investigator

Appendix G



600 FORBES AVENUE
PITTSBURGH, PA 15282

CONSENT TO CONFIDENTIALITY

I, _____, agree to transcribe the contents of
the
audiocassettes given to me by Kathleen Czekanski, MSN, RN for the study entitled, “The Experience of Transitioning to the Caregiving Role for a Family Member with Alzheimer’s Disease or a Related Dementia: A Phenomenological Inquiry” and promise to keep confidential all information I gain access to through the transcription process. All documentation and audiotapes will be returned to Kathleen Czekanski and I will erase the hard drive of my computer when instructed.

Signature: _____

Date: _____

Witness: _____

Date: _____