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Forget me not : a retrospective, exploratory study of daughters caring for a mother with Alzheimer's disease

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Pamela Sloane Rich
Forget Me Not – A
Retrospective, Exploratory
Study of Daughters Caring
for a Mother with
Alzheimer’s Disease

ABSTRACT

The purpose of this study was to explore the experiences of daughters who were a caregiver to a mother with Alzheimer’s disease. In particular, women were surveyed about their experiences surrounding relationships, grief and loss, difficulties and role reversal. Additionally, participants were asked about possible family conflict and positive experiences that occurred as a result of caring for one’s mother.

11 women were interviewed for this qualitative study. Open-ended questions were used in order for participants to provide narrative, descriptive accounts of their caregiving experiences. Additionally, participants were given the opportunity to provide thoughts on experiences not addressed in the interview guide.

Findings emphasized the uniqueness of caring for a mother with Alzheimer’s, even within the participant population. However, many women noted that they experienced grief and loss during the caregiving process. Additionally, the majority of participants experienced some type of role reversal while caring for one’s mother. More research is needed in order to address the lack of diversity represented in this sample. Additionally, sampling women who simultaneously cared for both a mother as well as young children would provide for meaningful results as society continues to battle the ongoing effects of this tragic disease.

FORGET ME NOT – A RETROSPECTIVE, EXPLORATORY STUDY OF
DAUGHTERS CARING FOR A MOTHER WITH ALZHEIMER’S DISEASE

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work.

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Additionally, I would like to thank my parents, who have always gone above and beyond in order to ensure my success and happiness. I also commend my friends, who constantly acted as a supportive outlet during times of both happiness and frustration.

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CHAPTER I

INTRODUCTION

Modern society has come to appreciate the miraculous advancements developed in the field of medicine both in the past as well as currently. In many areas, scientists have celebrated crucial breakthroughs that have occurred for many medical illnesses. However, for many of these diseases, there has yet to be a cure, and in turn, those who become ill are faced with a long journey ahead of them. Additionally, the patient's loved ones are deeply affected by these tragic events, often taking on the role as a caregiver in order to assist in alleviating the effects of the illness. All of these diseases take a toll on the everyday lives of victims and their families, and one particularly distressing illness affecting today's society is Alzheimer's disease.

Individuals afflicted with Alzheimer's disease suffer from distressing cognitive and physical deterioration, and their loved ones are often called upon to act as caregivers. More specifically, spouses and adult children often take on this role, and its effects can be physically, emotionally and financially devastating. Additionally, public policy is lacking in that it inadequately supports individuals during the caregiving process. According to Riggs (2001),

Current caregiver support policies are based on the way families have provided care historically...Little consideration has been given to how the role of the family caregiver is changing as the responsibility falls to baby-boomers, and how it will change as baby-boomers begin to need care themselves" (p. S143).

For the significant other who functions in the role of caregiver, there is a struggle to cope with the long and painful decline of a life partner, and various emotions can accompany this process. For the ill individual's son or daughter, the emotions that arise are similar to those experienced by spouses. In addition, the son or daughter must deal with the fact that the roles have reversed, with the adult offspring taking on the leading role that was once embodied by the parent. The effects of this role reversal and the emotions of grief and loss that are experienced during and after the caregiving experience can leave a lasting impression on a caregiver.

It has been argued that mother-daughter relationships are extremely unique, with "attachment and conflict most often identified as themes or key components of this relationship" (Pohl, Boyd, & Given, 1997, p. 134). However, what happens to this relationship when a mother experiences a devastating decrease in cognitive functioning? How does a daughter go about handling this situation? In an effort to shed some light on these ponderings, this study will retrospectively examine the mother-daughter caregiving experience as well as the effects of possible role reversal and loss on daughters who provided care for their mothers who suffered from Alzheimer's disease.

Several studies (Croog, Burleson, Sudilovsky, & Baume, 2006; Burns & Rabins, 2000; Cox, 1995; Donaldson, Tarrier, & Burns, 1998) have examined the effects of the caregiving experience on various populations. Spouses, children and other family members have been questioned in order to assess the impact of grief and loss during a loved one's struggle with Alzheimer's as well as after his or her death. In general, it has been found that mourning and loss are experienced during both of these times, in part because of the disease's ongoing deteriorating effects on the Alzheimer's victim.

However, there is a gap in the literature in that very few studies focus on the mother-daughter caregiving relationship as well as whether or not role reversal is experienced by the caregiver. This study aims to gather firsthand accounts from daughters who cared for their mothers who were diagnosed with Alzheimer's disease in order to explore how the caregiving process affects everyday life.

The participants in this study consisted of 11 women who have cared for and have lost a mother to Alzheimer's disease. These women resided in Maryland, Virginia, New York, Boston and Texas. Individuals in the Maryland and Virginia areas participated in face-to-face interviews, while others were interviewed by telephone. In order to respect the grieving process, these individuals were not interviewed unless it had been at least a year since their mothers' deaths. Descriptive, narrative accounts were collected in order to gather information about their experiences with possible role reversal and loss throughout the different stages of the illness.

The purpose of this study was to collect narrative data about the various details of the caregiving process by looking at retrospective accounts of daughter caregivers who have lost a mother to Alzheimer's disease. Hopefully, the findings of this study will help to further explore the possibility of role reversal and the grieving process so that the mental health profession can better serve caregivers who seek assistance. Research surrounding this area is important due to the fact that "the population of both impaired elderly and those providing care for them is likely to grow steeply in the coming decades" (Pearlin, Pioli, & McLaughlin, 2001, p. 252). Additionally, it is important to note that grief and depression are often confused in the diagnosis process. Sanders and Adams (2005) looked at the overlap between experiences of grief and depression and

found that, “many symptoms of grief may receive a diagnosis of depression and not be adequately treated” (p. 293). It is crucial that social workers acknowledge these differences so that caregivers can receive appropriate support both during and after the caregiving process.

CHAPTER II

LITERATURE REVIEW

The literature review of this study will focus on issues surrounding the Alzheimer's disease caregiving experience in general as well as the effects of this process on daughter caregivers. Additionally, the concepts of role reversal and loss will be addressed in order to examine the various emotions that may come into play during and after an individual cares for a loved one with Alzheimer's. More specifically, previous research surrounding the consequences of an impaired mother-daughter relationship due to Alzheimer's disease will be reviewed and critiqued for a better understanding of how that process may affect the daughter caregiver.

The first section of this literature review will address the current status of the aging population in the U.S. and the various illnesses that typically affect this group. Next, information will be provided surrounding Alzheimer's disease as well as how it affects both victims and their families. The third section of the literature review will examine caregiving and the potential stresses that accompany this role, focusing on the various emotions experienced throughout the caregiving process. Next, the impact of loss on caregivers will be examined both during and after a loved one's passing in order to recognize the intensity of the emotions that are experienced in a caregiving role. Lastly, the concept of role reversal will be examined, focusing on research that both confirms and denies the existence of this process.

The Aging Population

The following section will discuss the process of aging as well as how it relates to the aging individual's family. First, a general overview of what constitutes an aging individual will be addressed. Next, statistics about the elderly population will be presented, followed by the impact of aging on families. Finally, illnesses that often arise during the aging process will be discussed, focusing on gender and racial differences within the elderly population.

What is "Old?"

The 21st century has provided a significant increase in the number of individuals who are living longer lives (Villa, 1998). Due to the fact that the vast majority of Americans are achieving old age and beyond, gerontologists have recently begun to differentiate between young-old, old-old, and oldest-old cohorts among the elderly (Gonyea, 1997). For example, Neugarten (1974) (as cited in Marshall, 1989) discussed young-old individuals as those between the ages of 65 to 75, while old-old individuals represent 75 to 85 year olds. The oldest-old, or individuals 85 and older, are the fastest growing cohort among the elderly population as well as the U.S. population in general (Gonyea, 1997). For the purpose of this study, the term "older" will apply to persons 65 and over.

Statistics

Approximately one in eight individuals in the United States comprises the older population (U.S. Department of Health and Human Services, 2004). According to a report compiled by He, Sengupta, Velkoff and DeBarros (2005), in 2003, "35.9 million people were aged 65 and older in the United States. Among the older population, 18.3

million people were aged 65 to 74, 12.9 million were aged 75 to 84, and 4.7 million were 85 and older” (p. 1). At the time this statistic was compiled, 21 million of these elderly individuals were women, and roughly 15 million were men (U.S. Department of Health and Human Services, 2004). It has been predicted that these numbers will increase once the Baby Boomer generation reaches age 65, and by the year 2030, approximately 72 million individuals (20% of the total population) will represent the older population (He et al., 2005).

In looking at race and ethnicity, it was noted that 83% of the elderly population was comprised of non-Hispanic Whites (He et al., 2005). Specifically, in 2003,

17.6% of persons 65+ were minorities - 8.2% were African-Americans, 2.8% were Asian or Pacific Islander, and less than 1% were American Indian or Native Alaskan. Persons of Hispanic origin (who may be of any race) represented 5.7% of the older population. In addition, 0.5% of persons 65+ identified themselves as being of two or more races (U.S. Department of Health and Human Services, 2004, p. 6).

The fact that persons of color are underrepresented in the elderly population suggests a shorter life expectancy for these individuals.

Over the course of several years, researchers have examined the disparities that exist between the aging Caucasian population and elderly individuals of color. According to the Gerontological Society of America (1994) (as cited in Villa, 1998), research has demonstrated that older minorities experience higher rates of poverty and poorer health compared to non-Hispanic white. Additionally, this disparity is important to note due to “the impact that racism, segregation, and oppression, often experienced by minority group members, have on their life choices and opportunities, mental and physical health, and, life course trajectory” (Villa, 1998, p. 212).

Impact of Aging on Families

Although there is a wide variety of research surrounding the impact of aging on families, for the purpose of this study, the review of the literature will focus mainly on the effect of Alzheimer's disease on families, which can be found in subsequent sections. However, the following paragraphs provide a general description regarding the impact of the general aging process on families.

The aging process can be a pivotal experience for both the aging individual as well as for his/her family. Depending on one's physical and mental state, many aging individuals lead healthy, active lifestyles, living independently up until the time of their death. However, others may require assistance, calling upon assisted living facilities and professional caregivers in order to take on everyday activities. Often times, the family of the elderly individual may step in to care for their loved one, and this can alter the family's dynamics in both productive and unproductive ways.

For example, families who take on the responsibility of caring for an aging family member may create cohesiveness amongst the different generations, causing opportunities for different age groups to interact. On the other hand, families may become immersed in conflict, creating stressors on both the caregiver as well as the rest of the family. Lieberman and Fisher (1999) noted

The degree to which caregiving families can contain the stresses of caregiving from influencing nondisease-related personal and other family roles has implications not only for the caregiving process, but also for the personal health and well-being of all family members (p. 209).

The potential for family conflict and role strain may arise when that family's needs are not met, and in turn, this can be harmful to the family as well as to the elderly individual requiring assistance.

Illnesses of Aging

It was reported by LaRue (1992) (as cited in Knight, 2004) that "about 80% of older adults have at least one chronic condition" (p 160). He et al. (2005) reported that arthritis was extremely common among the elderly, with a 1998-2000 report showing that "19.3 percent of people 75 years and older and 11.8 percent of people aged 65 to 74 had activity limitations caused by arthritis and other musculoskeletal conditions, compared with 2.2 percent of those from the ages of 18 to 44" (p. 54).

The potential for heart disease and stroke are also among the worries of the elderly. It was reported that older men were more likely to have coronary heart disease or strokes than older women, whereas there was a higher prevalence of hypertension among elderly women when compared to elderly men (He et al., 2005).

The prevalence of diabetes, another debilitating health problem, may vary in the elderly population depending on several factors. In a 2000 analysis, it was noted that "the prevalence of diabetes was higher among older Hispanics (22.4 percent) and non-Hispanic Blacks (22.8 percent) than among older non-Hispanic Whites (12.5 percent)" (He et al., 2005, p. 56).

Cancer, an illness that affects individuals of all ages, can be especially detrimental to the elderly in that the aging process often weakens the immune system as well as many other important mechanisms that help to ward off disease. It was noted that elderly men were at greater risk for cancer as opposed to elderly women (He et al., 2005). As well,

“older non-Hispanic Whites (1 in 5) were twice as likely as older Hispanics and older non-Hispanic Blacks (1 in 10) to report some form of cancer” (He et al., 2005, p. 56.)

Further research is needed in order to assess the impact of various types of cancer on additional diverse populations.

Osteoporosis, a disease that “reduces bone density and raises the risk for potentially disabling fractures,” is an ongoing concern for elderly individuals (He et al., 2005, p. 57). In particular, a recent report noted that women were about four times more likely to develop osteoporosis, and the risk for osteoporosis as well as osteopenia increased with age for both men and women (He et al., 2005).

Both chronic and progressive, Parkinson’s disease (PD) is a debilitating movement disorder that also affects elderly individuals. The Parkinson’s Disease Foundation (2006) noted that “approximately 40,000 Americans are diagnosed with Parkinson’s disease each year,” and that the incidence of this disease increases with age (p. 1). Resulting in the malfunctioning and eventual death of cells in the substantia nigra (an area of the brain), individuals afflicted with PD are unable to control movement normally, often resulting in: hand, arm and leg tremors; slowness of movement; and impaired balance or coordination (Parkinson’s Disease Foundation, 2006). Lastly, a significant number of individuals in the elderly population often struggle with dementia, a particularly devastating disease. Aspects of dementia will be discussed in the following section.

Dementia

When considering the various illnesses that are prevalent in elderly individuals, it is necessary to first focus on dementia, an unfortunately common impairment. The

Alzheimer's Association (2007) defines *dementia* as the "loss of memory and other mental abilities severe enough to interfere with daily life" (p. ¶). Physical changes in the brain account for this occurrence, and the symptoms can affect both the ill individual as well as their loved ones.

Various illnesses and impairments can put an elderly individual at risk for acquiring dementia. Mild cognitive impairment, Parkinson's disease, Creutzfeldt-Jakob disease, Huntington's disease and Wernicke-Korsakoff syndrome are just a few of the conditions that may cause a person to present with symptoms of dementia (Alzheimer's Association, 2007).

Additionally, *vascular dementia*, the second most common type of dementia, occurs when "impaired blood flow to parts of the brain deprives cells of food and oxygen" (Alzheimer's Association, 2007). Vascular dementia often results after a stroke, and symptoms can vary depending on which part of the brain has been affected (Alzheimer's Association, 2007). The most common form of dementia is Alzheimer's disease, which will be discussed in detail in the following section.

Alzheimer's Disease

The following section will address various components of Alzheimer's disease. First, a general definition will be provided in order to paint a picture of what the disease entails. Next, the prevalence of Alzheimer's will be addressed, followed by risk factors for the disease. Because different symptoms emerge throughout the course of the illness, a general summary regarding stages of the disease will be introduced. Lastly, symptoms of Alzheimer's will be discussed, leading into symptoms that are experienced by caregivers as well.

Definition

Alzheimer's disease, the most common type of dementia, is defined 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, 2006). Biologically, even before symptoms emerge, the brain’s nerve cells have begun to deteriorate. In addition, scientists have cited Amyloid plaques and tangles as abnormal structures attacking these cells (Alzheimer’s Association, 2006). Though scientists have made significant advances in recent research, there is currently no cure for this disease (Alzheimer’s Association, 2007). However, according to the Alzheimer’s Association (2006), there are a handful of drugs approved by the Food and Drug Administration (FDA) that temporarily delay the worsening of symptoms for a short period of time, although these medications have been shown to work for only about half of the population who takes them.

Prevalence

According to the most recent facts and figures reported by the Alzheimer’s Association (2007), an estimated 5.1 million Americans have Alzheimer’s disease, and 4.9 million of these individuals are ages 65 and older. Not only does the treatment and maintenance of those with Alzheimer’s require a significant amount of money from both state and federal governments, Alzheimer’s also financially stresses individuals and families who are caring for a loved one, with Medicare and Medicaid covering some, but not all, of the disease’s expenses (Alzheimer’s Association, 2007).

Various groups are affected by Alzheimer’s disease, regardless of their racial and ethnic identities. However, an alarming trend is starting to emerge among the African

American population. The Alzheimer's Association (2007) found increasing evidence concerning Alzheimer's disease as being "more prevalent among African-Americans than among whites - with estimates ranging from 14% to almost 100% higher" (p.¶). Also, it is predicted that the African American 65+ population will more than double in size from 2.7 million in 1995 to 6.9 million in 2030 (Alzheimer's Association, n.d.). Being that age is one of many risk factors in developing Alzheimer's disease, it is likely that the percentage of elderly African Americans at risk for Alzheimer's will greatly increase, necessitating the need for appropriate interventions for victims as well as their families.

Additionally, research has shown that the genetic and environmental factors that put African Americans at risk for Alzheimer's disease may be different when comparing these factors to individuals of other ethnicities (Alzheimer's Association, 2007).

Froehlich, Bogardus, and Inouye (2001) noted that "genetic etiologies of Alzheimer's-type dementia appear to differ between African Americans and Caucasians," with the APOE genotype (the most clearly established susceptibility gene for late-onset Alzheimer's) representing a potential risk factor for Caucasians but not African Americans (p. 483).

Studies have also shown that high blood pressure and high cholesterol are potential risk factors for developing Alzheimer's. This is significant in that these conditions disproportionately plague the African American population. Additionally, "screening and assessment tools and clinical trials are not designed to address the unique presentation of Alzheimer's disease in African Americans" (Alzheimer's Association, n.d., p. 2). In taking these differences into account, Froehlich et al (2001) concluded that "the variations in dementia etiologies and in cognitive testing accuracy between races

suggests the urgent need to develop racially appropriate cognitive assessment methods and to develop preventative and treatment etiologies differently according to racial background of individual patients” (p. 477).

Risk Factors for Alzheimer’s Disease

According to a recent publication by the Alzheimer’s Association (2005), “while scientists know that Alzheimer’s disease involves the failure of nerve cells, why this happens is still not known. However, they have identified certain risk factors that increase the likelihood of developing Alzheimer’s” (p. 12). Such factors include age, family history and genetics, and other issues surrounding brain and heart health (Alzheimer’s Association, 2005).

As age increases, the likelihood of acquiring Alzheimer’s disease increases. According to the Alzheimer’s Association (2005), most individuals affected by Alzheimer’s are 65 or older. “The likelihood of developing Alzheimer’s approximately doubles every 5 years after age 65, and after age 85, the risk reaches nearly 50 percent” (Alzheimer’s Association, 2005, p. 12). Although rare, cases of early onset Alzheimer’s in individuals in their 50’s have also been documented, causing confusion and stress for both the victims as well as for their families.

As stated earlier, family history and genetics can also be considered a risk factor for acquiring Alzheimer’s disease. “Research has shown that those who have a parent, brother or sister with Alzheimer’s are two to three times more likely to develop the disease” (Alzheimer’s Association, 2005, p. 12). In terms of genetics, scientists have discovered one gene that has the potential to increase the risk of developing Alzheimer’s. In addition, researchers have also provided answers about rare genes that practically

guarantee that a person will acquire the disease (Alzheimer's Association, 2005).

However, these genes have been found in only a few hundred families worldwide "and account for less than 5 percent of cases" (Alzheimer's Association, 2005, p. 13).

Therefore, it cannot be concluded that one's genetic make-up is entirely at fault for causing Alzheimer's disease.

Lastly, other factors related to brain and heart health can be viewed as risk factors for developing Alzheimer's disease. Scientists have recently discovered a significant link between serious head trauma and future development of Alzheimer's (Alzheimer's Association, 2005). In addition, keeping one's brain and heart healthy through daily exercise both physically and mentally may help to ward off the potential for acquiring the disease (Alzheimer's Association, 2005). As well, conditions that damage heart and blood vessels such as high blood pressure, diabetes and high cholesterol may increase the risk of developing Alzheimer's disease or other dementias (Alzheimer's Association, 2005). Once again, these conditions are especially prominent in African Americans, signifying the importance of assessment and treatment through a culturally sensitive lens.

Stages of Alzheimer's Disease

Although Alzheimer's disease affects each individual differently, researchers have discovered common patterns of symptom progression that can be identified through seven stages of the illness (Alzheimer's Association, 2007). According to the Alzheimer's Association's national website, Barry Reisberg, M.D. of New York University School of Medicine's Aging and Dementia Research Center developed the Functional Assessment Staging (FAST) scale, a framework that categorizes the disease into the following stages: 1) No impairment, 2) Very mild decline, 3) Mild decline, 4)

Moderate decline (mild or early stage), 5) Moderately severe decline (moderate or mid-stage), 6) Severe decline (moderately severe or mid-stage) and 7) Very severe decline (severe or late-stage.)

Both Reisberg (2007) and ElderCare Online (2006) discuss the FAST scale in detail. According to these sources, individuals who fit the criteria for stage 1 show no functional decline. Stage 2 involves forgetfulness, and individuals often present with subjective complaints regarding forgetting names or location of objects. Those who fall under stage 3 display decreased organizational capacity, and objective evidence of memory deficit can be concluded with an intensive interview. Stage 4 involves a decreased ability to perform complex tasks; denial, flattening of affect and withdrawal are common reactions to these difficulties.

Individuals who fit the criteria for stage 5 cannot function without assistance in making decisions, and relevant aspects of one's life are often unable to be recalled. Stage 6 demonstrates severe cognitive decline, with little to no knowledge about recent events as well as urinary and fecal incontinence. Personality and emotional changes also occur, including: delusional behavior, obsessive symptoms, anxiety agitation and cognitive abulia, defined as "the loss of willpower because an individual cannot carry a thought long enough to determine a purposeful course of action" (ElderCare Online, 2006, p. ¶). Lastly, individuals in stage 7, or late-stage dementia, demonstrate very limited speech ability, and any words spoken are usually unintelligible. Additionally, one cannot walk or sit up without assistance.

Keeping in mind that the course of the disease progresses at different rates for different individuals, this stage-specific framework can aid Alzheimer's victims and their

loved ones as a guide for predicting the course of the disease. Additionally, not everyone affected by the disease experiences the same symptoms, but years of research have provided general knowledge about symptoms that may occur.

Symptoms

As expected, individuals who fall victim to Alzheimer's disease experience a wide range of symptoms that affect themselves as well as their loved ones. According to Mace and Rabins (1991), those who have Alzheimer's disease struggle with memory problems, medical problems, combativeness, loss of coordination and sense of time, speech and communication and independent living, just to name a few. Additionally, persons with Alzheimer's often experience feelings of depression, helplessness, loss, worry, anxiety and vulnerability (Magnuson, 1999). With all of these symptoms emerging, one can only imagine the stresses that affected individuals and caregivers now face. The following section will address the caregiving process as well as the illness's effects on the caregiver.

The Caregiving Process

The following section will address the many components of the caregiving process. First, the concept of caregiving and gender will be discussed, focusing on theories that address the notion of caregiving as a woman's role. Additionally, there will be a general overview of caring for elders, followed by a specific focus on the provision of care for an individual with Alzheimer's disease. Next, caregiving duties will be examined. Finally, the effects of caregiving will be addressed, followed by supportive interventions for caregivers.

Gender and Caregiving

Over the years, the notion of “caregiving as women’s work” has been present in a vast array of literature (Abel, 1990; Walker, 1992). According to Walker (1992), this statement is true for “both informal caregiving (i.e., that provided by family members) and formal caregiving (e.g., that provided by paid nurses and social workers)” (p. 34). Statistically, Stoller (1994) noted that “among adult children assisting elderly parents, daughters outnumber sons by more than three to one” (p. 679). Additionally, the significant presence of women as caregivers was noted in a study by the Robert Wood Johnson Foundation (2001), with 68% of the 1005 individuals surveyed representing the female population.

In looking at these relevant statistics, it is important to discuss the various theories that offer explanations for the dominance of women in the caregiving field. From a psychological perspective, Graham (1983) (as cited in Walker, 1992), noted that “women’s caregiving is motivated by their attachment to care receivers by the fact that caregiving is central to the identity of women” (p. 35). It is argued that this natural tendency to nurture and provide care stems from the notion that “women have empathic personalities and define themselves in relation to others (Walker, 1992, p. 36). Additionally, Troll (1987) (as cited in Walker, 1992), studied gender differences in intergenerational relationships and concluded that men are strongly associated with “horizontal ties” (i.e. spouses) while women tend to cater to “vertical ties” (i.e. parents and children.)

However, the psychological perspective is not without its shortcomings. First, according to Walker (1992), many women are not nurturing while many men are.

Additionally, Cancian (1986) (as cited in Walker, 1992) has noted that “the dominant cultural definitions of love stress tenderness and emotional expressiveness, qualities usually associated with women, whereas practical activities designed to help others, usually associated with men, are not defined as love” (p. 38). Therefore, a psychological view of gendered caregiving offers suggestions, but not answers, to the disparities that exist between men and women caregivers.

Another popular perspective touches upon the ideas of socialization and social structure as influences in gendered caregiving. This sociological perspective posits that “individuals are trained or socialized into roles that define caregiving as women’s responsibility” (Walker, 1992, p. 39). From this approach, a woman caring for an elderly parent is natural in that this act is consistent with other roles that are defined within the female population; women are socialized to exhibit the expressive tasks that go along with caregiving, and in private domains (Stoller, 1994).

In looking at age stratification, Walker (1992) noted that “the vast majority of elderly men are married, and the vast majority of elderly women are widowed” (p. 39). As a result, elderly women often provide care for their elderly husbands, and female offspring often provide care for their widowed mothers. Additionally, Walker (1992) argued that differences within the distribution of females and males in the paid workplace increase the likelihood of women as caregivers in a family: these pay disparities produce a rational explanation for women as the more prevalent gender in caregiving.

It is important to discuss the weaknesses of the sociological perspective. First, while instrumental tasks may be viewed as more “masculine,” women perform both expressive and instrumental tasks while caring for an elderly loved one (Stoller, 1994). In

terms of participation in the labor market, Finley (1989) (as cited in Walker, 1992) noted that “the differences in work status between women and men are not sufficient to account for existing gender differences in caregiving” (p. 40). Additionally, women may provide care in both private and public domains, receiving salaries as employed caregivers (Stoller, 1994). Therefore, the sociological perspective alone does not explain gender differences in caregiving.

Lastly, feminist perspectives on caregiving embody the notion that “women do the caregiving in society because of the dominant ideology of caregiving, the low value placed on the work of women, social disregard for costs of caregiving to women, and lack of government support for meeting the needs of its citizens” (Walker, 1992, p. 41). It is argued that women are compassionate and intimate, thus emphasizing the emotional significance of being a caregiver (Stoller, 1994). In addition, Graham (1983) (as cited in Walker, 1992) elaborated on the feminist view, noting that “caregiving is less a natural expression of a woman’s personality or feelings toward others than a reflection of her place in the broader social system” (p. 41).

Some aspects of the feminist perspective collaborate with sociological perspectives in explaining caregiving. For example, Calasanti & Bailey (1991) (as cited in Stoller, 1994) noted

The assignment of unpaid domestic work to women is neither a reflection of their “natural” attachment to other people nor the result of preferences internalized through socialization. Rather, it emerges from the cultural assignment of unpaid domestic production to women that emerged historically from the dialectical relationship between capitalism and patriarchy (p. 690).

In examining social and economic values posited by society, feminist theorists call attention to gender inequality and power dynamics. Additionally, it is important to consider the actions of women as unpaid caregivers within a larger context of division of labor based on gender (Stoller, 1994).

Weaknesses surrounding feminist perspectives include the fact that much of the literature assumes the caregiving role to be oppressive, highlighting the notion of caregiving as a burden (Walker, 1992). Furthermore, Stoller (1994) discussed how “emphasizing the oppressive elements of women’s role as family caregiver overlooks the fact that unpaid labor often provides opportunities for creativity and satisfaction” (p. 691). Di Leonardo (1987) (as cited in Walker, 1992) also touched upon this issue, noting that the satisfaction and power achieved by women in the unpaid sector of the labor market may not be easily experienced in the paid work force. However, regardless of which theoretical construct is favored, providing care for an elderly individual is a unique experience that is influenced by both internal and external forces that often dictate the ways of the caregiving process.

Caring for Elders

According to a 2004 study by the National Alliance for Caregiving and AARP (as cited in Berman 2005), “32 percent of family members caring for aged and ill people are between the ages of thirty-five and forty-nine, while another 43 percent are aged fifty and older” (p. 11). Caring for elderly individuals can take a toll on one’s physical, emotional, and financial well-being. Depending on the physical and mental status of the elderly individual, caregivers may find themselves unable to live on their own. If the caregiver is a spouse, s(he) may continue to care for his/her loved one in their own home until the

caregiving demands become too overwhelming. Additionally, adult offspring may take their elderly mother or father into their place of residence, providing care until additional assistance is needed.

One of the hardest decisions for caregivers to make is whether or not to place their elderly loved one in an assisted living facility. When Perry (2004) interviewed 19 daughters and one daughter-in-law caring for a mother with dementia, some of the women saw placement as a relief while others considered it “an inevitable sorrow that they would have to cope with” (p. 63).

At times, caregivers will hire live-in or part-time nurses to assist with the needs of the elderly individual. However, when the demands become too strenuous, a facility that provides 24 hour care may be the most logical choice for the placement of the elderly individual. In a study conducted by Chenoworth and Spencer (1986) (as cited in McCarthy, 1996), it was concluded that nearly 72% of Alzheimer’s patients in their study were institutionalized due to the stresses of around-the-clock caregiving duties. Additionally, according to McCarthy (1996), “changes in the family caregiver, such as physical health and mental health, may be the most important factors in the decision to place a demented family member in a long-term care facility” (p. 792).

Caring for Individuals with Alzheimer’s Disease

According to a 2004 report by the Alzheimer’s Association and National Alliance for Caregiving,

Caregivers of persons with Alzheimer’s disease and other dementias shoulder a particularly heavy burden of care - compared with other caregivers, the type of care they provide is more physically and emotionally demanding and more time-consuming, and it takes a heavier toll on work and family life (p. i).

Many caregivers often disregard their own personal needs, and instead focus on those needs of the individual who is affected by the disease. In return, inadequate support is received by these caregivers, and the need to maintain their own mental and physical health is often forgotten.

Caregiving Duties

Caregivers are faced with several tasks in order to best meet the needs of the elderly individual. Caregivers often assist with “activities of daily living” (ADL’s), which include bathing, dressing, and eating; they may also help the individual with Alzheimer’s disease with other everyday activities such as cooking, cleaning, transportation and shopping (Robert Wood Johnson Foundation, 2001).

In addition to everyday activities, caregivers assist with medical and other health-related issues for the elderly individual. According to a recent report on caregiving in the United States, about half of the caregivers surveyed reported “spending a ‘great deal’ of time and effort trying to make sure the medical needs of the care recipient are being met by doctors or other health care providers” (Robert Wood Johnson Foundation, 2001, p. 11).

Caregivers also serve as emotional supports. In addition to physically assisting the older individual, caregivers provide companionship in the form of friendship, love, hope and support (Robert Wood Johnson Foundation, 2001). Especially since the elderly individual may be grieving over the loss of his/her independence, it is necessary to have a support system consisting of both professionals as well as family members in order to deal with the physical and emotional suffering that may occur (Robert Wood Johnson Foundation, 2001).

Lastly, caregivers are a vital part of maintaining the physical safety of the individual with Alzheimer's. Daughters surveyed in a study by Perry (2004) noted that they learned to be protective in order to ensure their mothers' safety both at home and in public. Additionally, from an attachment perspective, Ciricelli (1993) hypothesized that adult children seek to protect and provide care for the same dependent parent who provided them with a sense of security during childhood. Because of this need, programs such as "Safe Return" created by the Alzheimer's Association (2007) serve as a helping tool to protect individuals with Alzheimer's when they wander off or get lost.

Effects of Caregiving

With the many emotions that are experienced by those who actually have Alzheimer's, it is also important to consider the feelings that may be experienced by the caregiver as well. According to the Alzheimer's Association (2007), caregiver stress can include feelings of denial, social withdrawal, loneliness, anger, anxiety, exhaustion, irritability, lack of concentration, and both mental and physical health problems. In particular, depressive disorders often plague those who are caring for Alzheimer's victims. Cuijpers (2004) wrote,

The presence of depressive disorders is important in caregivers, as it is a disabling condition that is associated with problems in daily functioning and with a variety of psychological and somatic symptoms that tend to compromise caregivers' ability to continue to maintain themselves adequately in their role (p. 325).

Given that mental health issues can jeopardize the productivity of a caregiver on numerous levels, it is noted, once again, that those who care for Alzheimer's patients need to be made aware of the different types of support that are available. Frias, Tuokko, and Rosenberg (2004) define the term *caregiver burden* as "the physical, psychological,

emotional, social, and financial problems that can arise in the caregiver situation” (p. 331). In addition to the emotional and physical difficulties, caregivers experience hardships in their social and financial lives as well (Frias et al., 2004). Because of the increasing demands as the disease progresses, caregivers are often unable to leave the Alzheimer’s victim alone, thereby missing out on the social life they once had. Financial hardships are also usually experienced, adding to the stress of being a caregiver (Frias et al., 2004).

Frequently, caregivers of those with Alzheimer’s are spouses of the affected individual. According to Croog, Burleson, Sudilovsky, and Baume (2006), “spouse caregivers in particular constitute a special group, generally characterized by continuous intimate association with the patients at many levels and by special commitments and responsibilities associated with the marriage bond” (p. 87).

Because of the special relationship that may be shared by a couple, spousal caregivers often have an especially difficult time dealing with the slow and painful deterioration of a significant other. In studying caregiver burden in this particular population, it is common for spouses to experience feelings of anger and/or resentment toward their loved one (Croog et al., 2006). Additionally, spousal caregivers often express concerns about their newfound limitations on both personal time as well as their social life (Croog et al., 2006). More research is needed in order to be able to generalize these findings to larger populations, focusing specifically on socioeconomic status, race, and ethnic and cultural backgrounds (Croog et al., 2006).

Cox (1995) compared experiences of Black and White caregivers while caring for an individual with dementia. The sample consisted of 76 Black and 88 White individuals

from the Washington D.C./Baltimore area, with each individual as the primary caregiver for the Alzheimer's patient. Cox (1995) found that Black caregivers received more emotional support and informal assistance from friends and family than the White caregivers studied, supporting prior research "attesting to the strong support systems of Black elderly people" (p. 344). Although this study takes into account different racial populations, it is necessary to be mindful of cultural differences and involve several diverse populations in the study of Alzheimer's caregivers.

Additionally, issues surrounding caregiving within the lesbian, gay, bisexual and transgender (LGBT) community are important to address. Although there is some information regarding legal issues within this community, little is written about institutional care issues. As a result, same-sex couples may not be awarded the same rights as heterosexual couples surrounding caregiving. Furthermore, the Family Caregiver Alliance (2002) noted,

Without legal protections in place, these relationships might not be legally recognized, and could easily be questioned or contested by a biological family member. It is imperative that LGBT caregivers and care recipients understand relevant local, state and federal laws and act to secure legal protections.

More research is needed in order to address the disparities that exist in this important and necessary area of interest.

Impact of Caregiving on the Family System

In looking at research that has examined the concept of a family, Buckley (1967) (as cited in Campbell, 2000) borrowed factors from general systems theory in defining the family as a "social system comprising a number of people united by emotional ties and by some form of regular interaction" (p. 92). From this approach, it is necessary to

look at how family members relate to one another, how these members function together as a whole and how members are affected by the outside environment (Campbell, 2000).

According to Campbell (2000), “a major purpose of the family group is to maintain itself over time by meeting the needs of its members,” but changes in an elderly family member’s biopsychosocial functioning can greatly affect the ability to achieve this familial homeostasis (p. 93). Specifically, when an elderly individual in the family develops Alzheimer’s disease, his or her behavioral changes can lead to changes throughout the entire family. In order to effectively cope with this crisis, a family must be assisted in “reestablishing its equilibrium so that its stress can be lessened and the older member assisted” (Campbell, 2000, p. 99).

Murray Bowen, a pioneer in family systems therapy, theorized that “human relationships are driven by two counterbalancing life forces: individuality and togetherness” (Nichols, 2006, p. 115). Another prominent idea embodied by family systems theorists is that of the *family life cycle*, “a process of expansion, contraction, and realignment of the relationship system to support the entry, exit, and development of family members” (Nichols, 2006, p. 122). In dealing with a crisis such as the mental deterioration of an elderly loved one, it is possible for family members to experience dysfunction both within and outside of the family system. Depending on one’s *differentiation of self*, or degree of independence and ability to think before reacting to an emotional pressure, it is possible for an individual to become overly involved in the crisis, or emotionally cut off and distance him or herself from the family completely (Nichols, 2006). Due to the potential severity of these situations, it is necessary to

evaluate the effect of caring for an individual with Alzheimer's disease on that family's functioning.

The Sandwich Generation

A popular description that touches upon the caregiving experience as it relates to various impacts on the different generations of the family is that of a *sandwich generation*. Ward & Spitze (1998) (as cited in Robinson et al, 2003) define those who fall under this category as “middle-aged cohorts who are sandwiched between simultaneous responsibilities to the older generation and the younger generation by combining their roles as parents, children, workers, and spouses” (p. 84). A synonymous term used to describe this phenomenon is *women in the middle*, which also defines the struggle in balancing the responsibilities of caring for one's children and caring for an elderly relative (McCarthy, 1996).

Additionally, Pearlin, Pioli and McLaughlin (2001) noted that this idea “calls attention to the conflicts and dilemmas that adult children or grandchildren experience in the course of providing assistance to an impaired relative while at the same time having obligations to other activities and relationships, especially their own children” (p. 239).

Supportive Interventions for Caregivers

With all of the factors that go along with assuming the role of a caregiver, there is a dire need for interventions that will best support an individual and their loved one during the caregiving process. However, today's public policy fails to provide adequate resources that can alleviate the many stresses involved in caring for a loved one with Alzheimer's disease. According to Riggs (2001), “policy makers are focused on narrow concepts of caregiver support – small tax credits or deductions, and fairly traditional

caregiver support programs that include respite, support and counseling, and information services” (p. S142). Especially in looking at the possibility of developing long-term, affordable care plans to assist caregivers, more is needed in order to alleviate not only the financial burdens experienced by caregivers, but the physical and emotional burdens as well (Riggs, 2001).

The “2006 National Public Policy Program to Conquer Alzheimer’s Disease” proposed by the Alzheimer’s Association (2006) noted the importance of providing support for caregivers. Under the Older Americans Act (OAA), the National Family Caregiver Support Program (NFCSP) provides support for Alzheimer’s families. Specifically, “the NFCSP provides federal grants to all 50 states to expand and enhance existing caregiver-support services, particularly respite care and adult day care” (Alzheimer’s Association, 2006, p. 16). However, recent budget cuts have greatly affected funding for both Alzheimer’s research as well as for available resources to assist caregivers and Alzheimer’s victims. Additionally, President Bush’s 2007 budget proposal is expected to “further reduce the budget for Alzheimer’s research, eliminate all of the federally funded Alzheimer care programs and cut dollars for other programs that provide services to the frail elderly and their caregivers” (Alzheimer’s Association, 2006, 2).

Although funding is not always readily available in order to best serve caregivers, studies have shown the effectiveness of certain interventions on caregiver stress. In particular, support groups are especially helpful in providing caregivers with a sense of commonality as well as general support. Individual and family counseling has also had positive effects on caregiver stress (Burns and Rabins, 2000). Additionally, Burns and

Rabins (2000) noted specific types of services that are of use, including educational, environmental and behavioral interventions.

A longitudinal study by Mittelman, Roth, Coon, and Haley (2004) demonstrated that “a short course of intensive counseling and readily available supportive maintenance can have long-lasting effects in reducing symptoms of depression among caregivers of dementia patients” (p. 855). Because many caregivers do not have the time and/or energy to find such programs, it is necessary to seek these individuals out and provide them with information that may lessen the stressors associated with care giving.

In looking at the various emotions experienced by caregivers, it is important to note that each individual goes through his or her own unique process, and that (s)he may require different interventions depending on the various stages of the caregiving process. However, a few general themes have emerged through the examination of this process, and one reoccurring theme involves experiencing intense feelings of loss both before and after a loved one’s passing.

Loss

The following section will address the idea of grief and loss. First, the concept of loss as it relates to illness will be discussed, focusing on differences between sudden versus prolonged illness. Next, grief and loss in Alzheimer’s disease will be addressed. Finally, loss experienced by daughters whose mother have/have had Alzheimer’s disease will be talked about.

Loss and Illness

With illness comes loss. Depending on the type of illness, loss may be experienced in various ways by both the ill individual and their families. Additionally,

grief and loss may differ when comparing sudden-onset illnesses and prolonged, chronic illnesses. If the victim passes away soon after the illness is diagnosed, it often comes as a shock to the family, with little time to prepare for the death of their loved one. According to Sanders (1982-1983),

In short term illnesses, there is usually a rapid deterioration, loss of function, and even in some cases, personality change. For those who must care for a family member, these changes are difficult to process because they occur so rapidly (p. 236).

Lefebvre and Levert (2006) noted that “chronic health problems require that the person and his family give up the idea of being cured, to adapt themselves to the incapacities and learn to live with the health problem” (p. 338). Chronic illnesses take their toll in that the ill individual may deteriorate mentally and physically, with little that can be done by family members and caregivers. One such illness that embodies the slow and painful cognitive decline of an individual is Alzheimer’s disease, and often times, grief and loss are experienced both during the disease’s journey as well as after the individual has passed away.

Grief and Loss in Alzheimer’s disease

Caregiving in Alzheimer’s disease is complicated in that individuals may experience intense feelings of grief and loss both during and after the caregiving process. Boss (1999a) (as cited in Sanders & Adams, 2005) termed this concept *ambiguous loss* to define “grief that has no clear starting point and no clear ending point” (p.287-288). Ambiguous loss encompasses the difficulties of dealing with a loved one who is physically present but no longer cognitively present (Sanders & Adams, 2005).

Another relevant concept is that of *dual dying*, in which individuals deteriorate socially and intellectually but still maintain a sense of physical health (Jones and Martinson, 1992). This dual dying phenomenon perfectly describes an Alzheimer's victim, and its effects on a caregiver can provide further insight into the grieving process. Similar to this concept, daughter caregivers in McCarthy's (1996) study expressed their difficulty in coping with the "living death" of a parent with Alzheimer's disease.

The concept of *anticipatory grief* was noted as a factor in determining the length and intensity of the bereavement process. Defined as, "the nature and length of the illness and the amount of caregiver strain prior to the death of the relative," this concept is extremely relevant when looking at caregivers who are helping loved ones with dementia (Jones and Martinson, 1992, p. 172). Additionally, clinical findings by Dempsey & Baago (1998) described a "qualitative difference between the grief response of family caregivers of Alzheimer's individuals, and the grief response of family caregivers of those with other terminal illnesses" (p. 88).

When Perry (2004) sampled 20 women who were in the process of caring for a mother with Alzheimer's disease, "all daughters mourned the loss of the mother they once had" (p. 60). In another study that focused on women who were caregivers to a parent with Alzheimer's disease, participants discussed grief that was experienced in relation to specific phases of the caregiving process. Notably,

During the initial caregiving phase, daughters grieved the loss of life consistency, parents' identities, filial roles, and their parents' former lifestyle. During the middle phase, daughters mourned the loss of their own prior lifestyles, social relationships, sibling and family relationships, and loss of efficacy in the caregiver role due to parents' deterioration and tension between the spouse caregivers and themselves. In the terminal phase, daughters expressed

ambivalence related to multiple sayings of goodbye and a desire of life continuation (McCarthy, 1996, p. 799).

Jones and Martinson (1992) studied the bereavement experience of 13 Alzheimer's caregivers residing in California, interviewing these individuals after the death of their loved one. It was noted that caregivers often felt a sense of detachment while maintaining their role; when the ill individual passed away, a feeling of relief often coincided with feelings of ambivalence, sorrow or guilt (Jones & Martinson, 1992). Additionally, it was concluded that the "emotions observed in these caregivers appear to have been not anticipatory grief, but acute grief related to immediate and permanent loss of a relative's human abilities and personhood while still living" (Jones and Martinson, 1992, p. 175). However, this study did not describe the racial or socioeconomic composition of the participants, characteristics which can greatly impact the generalizability of the findings. More research is needed in order to take into account the diversity of today's caregiving population.

Sanders and Adams (2005) provided examples of studies that emphasized the notion that grief often fluctuates depending on the stage of Alzheimer's disease. Ponder and Pomeroy (1996) (as cited in Sanders & Adams, 2005) concluded that "the level of grief is initially high following a diagnosis, only to decline during the second through fourth year of caregiving and then increase again during the final stages" (p. 288). Related to that, Jones and Martinson (1992) suggested that grief is experienced when the Alzheimer's victim no longer recognizes the caregiver, which often occurs in the middle stages. As well, McCarthy (1996) noted that daughters grieved the loss of different aspects of their mother depending on the stage of the disease.

Daughter Caregivers and Loss

There are a few studies that focus on caregiving and loss while the Alzheimer's victim is still alive (Betts Adams & Sanders, 2004; Pearlin, Pioli, & McLaughlin, 2001; Jones & Martinson, 1992). However, little research has been conducted that has focused, retrospectively, on the grief and loss process in daughters who cared for a mother with Alzheimer's disease. This lack of research furthers the need for this study in that daughters will be able to recall their experiences during the various stages of the disease, as well as how they are currently functioning.

Role Reversal and the Caregiving Process

During times in which an individual is providing care for a parent, the dynamics of the parent-child relationship may begin to change. Not only are caregivers dealing with various emotions related to the mental and physical deterioration of their parent, they are also presented with the loss of a parent-child relationship that has played a defining role in the person they have become. Seltzer (1990) identified this concept of the relationship between adult-child caretaker and his/her elderly parent, defining *role reversal* as a process in which "the child becomes the caretaking 'parent' with the frail parent as child" (p. 6). There have been general studies on caregiver stress that have come across examples of the effects of role reversal on relationships (Betts Adams & Sanders, 2004; Dempsey & Baago, 1998; Blieszner & Shifflett, 1990), but little research on role reversal and daughters who have cared for mothers with Alzheimer's disease has been conducted.

An Idea Met with Skepticism

Some researchers argue that the concept of role reversal is unrealistic. Seltzer (1990) noted that role reversal assumes caregiving for an elderly parent to be the same

experience as caring for a young child. It is further argued that the adult-child/parent caregiving relationship can present role changes, but not in a literal sense (Seltzer, 1990). Assuming this position, Seltzer (1990) stated that “a focus on relationships between people rather than on their roles provides a more satisfying way of thinking about what occurs when children assume responsibilities for parents” (p. 11).

In relation to role reversal, Brody (1990) discussed the concept of *second childhood*, stemming from “observations of the declining functional capacities and increasing dependency needs of disabled older people, particularly those with Alzheimer’s disease and related disorders” (p. 18). Venturing into a second childhood assumes that the elderly individual’s behavior resembles that of a child, ignoring psychological and physiological processes accounting for this behavior (Brody, 1990). Brody (1990) also focused on the issues of dependence and independence, noting particular dynamics that can stem from the struggle between mother and daughter control over the caregiving situation.

Role Reversal of Daughters Caring for Mothers with Alzheimer’s

Despite skepticism concerning role reversal as an ordinary process, certain aspects of this concept have been found in previous research in the midst of examining larger concepts such as grief and loss. For example, one caregiver client interviewed by Dempsey & Baago (1998) described “the role change between herself and her mother as being an unconscious process that occurred gradually over a long period of time as her mother become more and more dependent and childlike” (p. 88).

Another study by Blieszner & Shifflett (1990) looked, retrospectively, at the effects of Alzheimer’s disease on patient-caregiver relationships, sampling spouses and

adult children. A 39 year-old daughter in the sample experienced role reversal, stating, “Our roles have switched in a way. I feel more like now I’m taking care of my mother, instead of her taking care of me” (Blieszner & Shifflett, 1990). Limitations of this study include a small sample size residing in one Virginia city, affecting the generalizability of the findings. However, this study is relevant in that a clear example of role reversal was noted in the examination of patient-caregiver relationships.

No research has been found to date that specifically examined the effects of role reversal on the caregiving relationship between daughters and their mothers suffering from Alzheimer’s. The lack of research in this area calls upon the need to gather real-life experiences involving daughters who went through this process. From these accounts, it will be possible to examine the effects of caregiving on both role perceptions and the daughter’s relational experience with her mother and other family members.

Summary

Alzheimer’s disease affects the everyday lives of both victims and their loved ones. Because of the disease’s devastating effects, it has been noted that caregivers experience extreme amounts of physical, emotional and financial stress. Additionally, feelings of grief and loss are also experienced both during and after the caregiving process, and this can often impact the quality of care provided for the ill individual. Although several studies have examined the caregiving process (Blieszner & Shifflett, 1990; Burns & Rabins, 2000; Jones & Martinson, 1992; Pearlin et al., 2001), the majority of the sample populations in these studies were not racially, ethnically and

socioeconomically diverse. Further research is needed in order to take into account these disparities.

Additionally, further research is needed on adult daughter-mother caregiving relationships, with a focus on gathering a culturally and socioeconomically diverse sample. The purpose of this study is to address these disparities, looking at various aspects of the caregiving process as it relates to mother-daughter relationships. In collecting direct accounts of daughters who provided care for a mother with Alzheimer's, it is hoped that this information will be able to shed some light on the caregiving process as well as how daughter-mother relationships are affected.

CHAPTER III

METHODOLOGY

The purpose of this study was to gather data regarding the experience of caring for a mother with Alzheimer's disease. Questions were tailored to address issues surrounding relationships, grief and loss, and role reversal. Attention was also paid to family conflict, difficulties experienced during the caregiving process as well as coping and positive experiences that occurred as a result of caring for one's mother. The following sections address the research design, sample, data collection and data analysis involved in conducting this study.

Research Design

A qualitative, exploratory study was conducted using flexible methods for research. Data was collected using semi-structured, open ended questions in order to gather rich narratives surrounding the participants' retrospective experiences of being a daughter caregiver. According to Anastas (1999), "flexible method research is aimed at generating in-depth understandings of people and events in context as they naturally develop and occur" (p. 73). Due to the sensitivity of this topic, these specific methods were chosen to ensure that the research process would allow for one-on-one interviewing of each participant, all while remaining mindful of any emotions that arose while retracing the steps of each woman's caregiving journey.

For the purpose of this study, the term “caregiver” signifies any woman who was involved in the responsibility of seeing that her mother was cared for. Additionally, the term “role reversal” refers to “mothering the mother.”

Sample

Participants in this study consisted of 11 women who took on a caregiving role in order to provide for a mother with Alzheimer’s disease. Of these 11 participants, one woman was African American, while the other 10 were Caucasian. The ages of these women ranged from 49 to 65, and participants resided in several states, including Virginia, Maryland, New York, Massachusetts and Texas. As noted in the requirements of this study, each participant’s mother passed away between one and five years ago, and the age of their mothers at the time of death ranged from 76 to 89 years old.

Participants were solicited through flyers, advertisements through the Alzheimer’s Association and word-of-mouth. Flyers were emailed to various organizations as well as placed in public areas including grocery stores, coffee shops and churches. In return, potential interested participants contacted this researcher via phone or email, and these women were screened in order to ensure that they fit the inclusion criteria. Originally, this researcher hoped for 12-15 face-to-face interviews in the D.C./Maryland/Northern Virginia area. However, after limited responses, the inclusion criterion was broadened to consider phone interviews with women residing in other areas, relying mainly on snowball sampling to achieve this. Additionally, it was hoped that the recruiting process would attract a culturally diverse group of women. Although acquiring a culturally diverse sample was attempted, the outcome was not successful, creating a significant study limitation that will be addressed in the discussion chapter.

Data Collection

After approval from the Smith College School for Social Work's Human Subjects Review Board, recruitment for this study commenced. The following paragraphs address the recruitment and interview process.

Participants contacted this researcher by phone or email, expressing interest in participating in this study. After meeting all inclusion criteria, each woman was given an informed consent form by mail, email or in person, which explained several aspects of this study, including its purpose, potential risks and benefits of participating, and ethics and safeguards that would be considered to ensure participant confidentiality. One copy of this form was signed and given to the researcher, while another copy was provided for the participant to keep. Additionally, each participant was given a list of mental health resources in their area should they have felt the need to further address their experiences with a professional.

Participants were interviewed either by phone (n=8) or in person (n=3), with each interview lasting between 25 minutes and an hour and a half. Interviews were recorded and transcribed, and hand-written notes were also taken by this researcher when appropriate. Strict confidentiality was maintained, as consistent with Federal regulations and the mandates of the social work profession. Confidentiality was protected by numerically coding the information, ensuring the protection of each participant's identity. All tapes, papers, and computer files were accessible only to this researcher, and after a period of three years, all information surrounding this study will be destroyed.

Interviews began with demographic information, including name, age, race/ethnicity, relationship status during the caregiving process and currently, and

occupation. Since this study was exploratory, participants were also asked open-ended questions such as, “What was your relationship like with your mother before she developed Alzheimer’s?” and “Describe any grief or loss you experienced during the caregiving process.” As certain themes emerged during the interviews, this researcher occasionally posed additional questions in order to acquire more information on what was being addressed. Additionally, participants were given time at the end to comment on anything that was not touched on during the interview.

In order to increase the validity and reliability of this study, two experts were asked to review the proposed interview guide in order to assess for any inconsistencies. Additionally, a pilot test was executed, with the researcher interviewing an individual familiar with the mother-daughter caregiving process but who did not participate in the study. Feedback was considered in order to accurately posit questions that would fully capture a retrospective look on caring for a mother with Alzheimer’s disease.

Data Analysis

Participant interviews were recorded by a digital voice recorder, and interviews were transcribed into Microsoft Word. The researcher then used narrative analysis in order to examine the data of this study. As noted by Anastas (1999), this method is the best way to summarize and describe the meaning and content of the participants’ responses.

According to Anastas (1999), coding is “the primary method of reducing narrative data to conceptual categories into which parts of the text can be grouped and in terms of which the text can be described or displayed” (p. 419-420). After all interviews were transcribed, the data was coded by content and theme. This was done by creating

spreadsheets and charts in both Excel and Word in order to analyze participants' responses across each question, noting similarities, differences, and other key components involved in the responses.

The analysis of this data uncovered general themes that arose as a result of caring for a mother with Alzheimer's disease. Unfortunately, due to a small sample size and lack of cultural diversity among participants, the results of this study cannot be generalized. However, these results can provide examples of possible experiences that can occur when looking back on one's journey as a daughter caregiver. The findings of this study will be addressed in the following section.

CHAPTER IV

FINDINGS

This chapter contains the findings from interviews conducted with 11 women who were caregivers to a mother who passed away from Alzheimer's disease between one and five years ago. This exploratory study provided an outlet for participants to talk freely about their caregiving experience, but also focused on themes specific to mother-daughter relationships and to caring for a loved one with Alzheimer's. The interview questions were structured to elicit information regarding participants' relationships with their mothers before and during the caregiving process; relationships with partners and/or children during the caregiving process; their experiences with grief and loss during and after the caregiving process and whether or not role reversal was experienced. To maintain consistency, *role reversal* was defined as "mothering the mother." Additionally, participants were asked if certain stages of the disease were especially difficult to deal with; if mental, physical or financial difficulties were experienced; if family conflict was experienced during the caregiving process as well as if positive experiences occurred as a result of caring for one's mother.

The data from these interviews are presented in the following order: demographic information, diagnosis and caregiving duties, the effect of caring for a mother with Alzheimer's on one's personal relationships, experiences of grief and loss both during and after the caregiving process, difficulties in caring for a mother with Alzheimer's disease, role reversal, family conflict and positive experiences.

Demographic Information

As stated earlier, this study was comprised of 11 women who were caregivers to a mother with Alzheimer's disease. Participants were between the ages of 49 and 65, with the average participant age as 57 years old. When asked about ethnicity, one participant identified as African American (n=1), while the other women identified as Caucasian (n=10). Participants resided in the following states: Virginia (n=2), Maryland (n=1), New York (n=6), Massachusetts (n=1) and Texas (n=1).

Regarding relationship status, the majority of the participants were married both during the caregiving process and currently (n=7). Three women (n=3) stated that they were single both during the caregiving process and currently. One woman (n=1) was married during the caregiving process, but is currently divorced. Five women (n=5) noted that they had children during the caregiving process, with the ages of these individuals ranging from 20 to 40 years old. The remainder of the participants (n=6) do not have children.

In terms of occupation, the majority (n=10) of participants maintained a job while caring for their mother. Of these 10 women, the following professions were identified: homemaker, licensed clinical social worker (n=2), psychiatric nurse, company executive, tax auditor, editor, writer and interior designer/safety educator. The two women (n=2) who did not hold a job during the caregiving process both identified as retired teachers.

As noted earlier in this section, all participants' mothers passed away anywhere from one to five years ago, and between the ages of 76 and 89.

Diagnosis and Caregiving Duties

This section reflects on participants' experiences regarding events that lead to their mother's diagnosis of Alzheimer's disease. Additionally, information regarding participants' caregiving duties is also addressed.

Diagnosis

In general, a few themes emerged when participants were asked to address events that lead to their mother's diagnosis of Alzheimer's. For example, some participants described certain behaviors that lead them to believe that something was wrong, using terms such as "daily forgetfulness" or "bizarre behaviors" when reflecting on their mother's actions. Participant #3 stated,

It became apparent in 1997 that she was really not functioning well. There a lot of things – no food in the fridge, outdated milk. I went down there once and she was, well, more than once, she was in Florida, and she wasn't bathing. She really covered it up for a period of time.

Participant #7 noted,

[My mother] was concerned about it earlier because it runs in the family, but she wasn't diagnosed until 1999. She was just terrified of it; both of her parents had it. Our concern about her behaviors was why we sought out diagnosis. She knew what she was talking about, but we didn't listen to her. Her behaviors – it was almost like her internal dialogue became external. She started to say outlandish things that she never would have said. We were just blown away. She had other health problems and had some part-time care coming in. It was actually one of her aides that suggested Alzheimer's disease.

Some women identified other health problems that lead to the discovery of Alzheimer's disease. For example, participant #1 noted,

In 2001, she had a massive stroke caused by a heart attack. She lost some of her short term memory, math abilities, and a few other things from the stroke. That remained constant for a few years, and then she started to deteriorate off in different directions. So the first thing we did was take her for an MRI, and there was no additional stroke activity and that it was Alzheimer's, so we immediately started her on Alzheimer's medication.

Participant #4 stated, “I think it was February of 1999 by a neurologist...She fell and broke her hip and at the hospital it was clear that she was demented. She was never the same after that.”

Lastly, a few participants attributed their mother’s behavior to other health problems such as depression or grief from losing a husband. Noted participant #8,

I’d say maybe 2000. She was just repeating herself so I asked her primary doctor about it and he said he didn’t really think so...she was really good at covering it up...so he didn’t really think anything was wrong. He thought she was maybe just depressed. But when she would be with me, I would notice this repetition...so I had her taken to a neurologist and as it turns out, she had suffered some mini strokes she wasn’t even aware of. That triggered the symptoms of Alzheimer’s.

Participant #10 also considered the possibility of misdiagnosis, stating,

We had her taken to a dementia clinic. She had originally been diagnosed with just having depression, even though we all knew it was Alzheimer’s – the family knew. But the doctor said, “Oh, you’d be surprised what dementia can do,” and I said, “Even with hallucinations?” He said yes.

Two women talked about their father’s death occurring prior to their mother being diagnosed with Alzheimer’s. Noted participant #5,

My father passed away in May of 1994. In December of 1994 we took [my mother] to a neurologist, and he thought it was the trauma of my father’s death, so then we waited I guess another year when she was formally diagnosed...My parents had been married for 44 years. When he passed away all of a sudden, she couldn’t balance a checkbook. But more than that, she was having trouble baking, so all of a sudden she kind of fell apart. I think some of it was really the trauma that really made the symptoms more obvious. There were probably minor things before, but this was a major shock.

Similarly, participant #7 stated,

My father passed away in 1996, so my mother, for the next year, lived in the house with my brother. We thought a lot [my mother’s] behavior was because of my dad (he dropped dead suddenly and they were very devoted to each other) or heart problems (she eventually had bypass surgery) characterized with a kind of depression during the recovery process. So she was just all over the place and we didn’t pinpoint it to Alzheimer’s for quite a while.

Caregiving Duties

When asked about caregiving duties, participants' responsibilities varied. For example, some participants noted that they were the sole-decision maker for their mother. Participant #6 stated, "I was the decision-maker. Absolutely. There was no one else. I was an only child, and my parents divorced when I was very young."

Others shared caregiving responsibilities with siblings. Participant #7 stated, "My sister lived in a duplex, and the other half opened up, so my mom moved in next to her. So caregiving was shared between myself and two sisters..." Additionally, two women assisted their father in caring for their mother. As noted by participant #9, "At first, I was there everyday, helping Dad get her up and helping her shower and get dressed and feeding. Later on, we hired a full-time caregiver"

Two women lived with their mother in order to provide care. For example, participant #4 moved in with her mother when she was unable to care for herself for three years until moving her to an assisted living facility when it was concluded that her mother needed professional care. Similarly, participant #8 noted, "She lived in Ohio, so I relocated her to New York to live with me. She did that for three years and then went into assisted living." Other participants cared for their mothers while in assisted living or dementia-specific facilities.

Lastly, during their time as caregivers, the majority of participants (whose mother was not residing with them) lived within 20 miles of their mother. However, for two women, their mother resided in a different state, causing them to travel by plane whenever visiting their mother. As noted by participant #2, "I used to visit frequently, probably every month, for a week at a time, for a number of years."

The Effect of Caring for a Mother with Alzheimer's on Relationships

This section contains participants' accounts regarding the effect of caring for a mother with Alzheimer's disease on personal relationships. The data are presented in the following subsections: mother-daughter relationships before Alzheimer's, mother-daughter relationships during the caregiving process and relationships with partners and/or children during the caregiving process.

Mother-Daughter Relationships before Alzheimer's

Responses varied when participants were asked to describe their relationship with their mother before she developed Alzheimer's disease. Several women regarded their mother-daughter relationship as positive, with three women stating that their mother was not only a mom, but a good friend as well. Participant #6 responded with: "Friends...very good friends. She made me laugh. She was always concerned about me. She always wanted the best for me. She wanted me to do better than she ever did." Participant #9 noted that she and her mother were, "very close. Very close. We took vacations together...just very close. We shopped together. She was my best friend really." Participant #8 went on to say, "Mostly, I just have memories of her being a very generous mom when I was growing up. She was pretty much a role model for me."

Two women addressed their role in relation to their siblings, using terms such as "good one or "eldest one." Additionally, participant #7 stated,

I was her favorite. I was the baby, the child most like her. We had a very strong and positive relationship. I was the youngest of five, did well in school...I did all those things. We had a very easy relationship.

In contrast, a few participants addressed the complexity of the mother-daughter relationship. Participant #3 noted, “It’s always hard to describe a relationship with one’s mother I think.” Participant #10 stated,

It was difficult. It was a loving one, and I probably saw her once a month. I would go over and see her. But it was difficult...and it was always kind of difficult. She had a difficult personality, and unfortunately, she didn’t really have any friends...very isolated. She had some kind of personality problems from a very early age. And I always loved her, and she me, but it was not an easy relationship.

Lastly, participant #11 noted, “It wasn’t great. It was difficult. She was a difficult lady, and I found it difficult to deal with her.”

Mother-Daughter Relationships during Caregiving

After their mother developed Alzheimer’s disease, several participants noted that the mother-daughter relationship changed. A few women addressed the switching of roles: Participant #1 stated, “It sort of switched, where I was the parent and she was the child.” Similarly, participant # 5 noted, “The roles obviously reversed – I ended up the mother and she ended up the child.” Participant #6 said, “I became her mother. I became the decision maker, mother, father, uncle, aunt...everything. I was everybody, and it ate my heart out.” Lastly, participant #9 noted, “I became the decision-maker and helped her make decisions and things.”

Additionally, some participants noted their mother’s reaction to their daughter as a caregiver. Participant #8 stated, “The roles started to reverse, and she started to resent that,” while participant #4 said, “Initially, she was very hostile while my father was still alive. She felt like I was taking over and she was the wife. She was very angry that I was making the decisions.”

Three women touched on their difficulties in accepting the fact that their mother had Alzheimer's. Participant #7 stated, "I wanted her to go back to being my mother," while participant #8 noted,

It was tough. It was frustrating because my mom was a teacher...she was very active. I always looked up to her for guidance and direction, you know. I would get annoyed with her because she wasn't the same person she used to be.

Two of the women who deemed their mother-daughter relationship "difficult" before Alzheimer's came into play stated that their mother-daughter relationship improved during the caregiving process. Participant #10 noted,

It got much better; it really transformed. Once I understood that she had Alzheimer's disease, then everything changed and I realized there was no sense in arguing with her. And we developed a very, very close relationship...one full of love. There were challenging times too, but I would say, on a whole, our relationship got better.

Participant #11 stated,

The weird part about it is that once she ended up in the nursing home and we knew what she was dealing with, our relationship got much better. Is that strange? Because she became much nicer...It kind of pushes your heart strings. So it was actually a relationship where we could manage and come together.

Lastly, aside from the common behavioral issues that accompany Alzheimer's, a few participants noted that their relationship with their mother remained positive. For example, participant #2 noted, "I don't know whether it was because I was in social work and had training in mental health issues, but the majority of the time, it was really good." Participant #9 stated that her relationship with her mother remained the same due to the fact that "we were very fortunate in that my mother retained her sense of humor."

Caregiving and Relationships with Partners and/or Children

Being that three of the participants did not have a partner or children during the caregiving process, they were not asked whether their role as a caregiver had an impact

on their relationship with a partner and/or children. For those who were married but did not have children, two women stated that caregiving put a strain on their relationship with their partner. Participant #5 noted, “he was definitely second,” while participant #6 went on to say that the relationship was,

very strained, because I felt my mother came first because she needed the care. When I moved her from the adult home to the nursing home, she needed the care. And I was there everyday. So it put a big strain on our marriage...very big.

Participant #10 noted that her husband was very supportive, but that it became more difficult in the last few years because,

my husband was diagnosed with cancer...So that became difficult, and I started having a lot of conflicts on whom to spend time with. That got hard and I got really exhausted. I found myself in a very strong caregiving role. Even though my mother was at an Alzheimer’s assisted living facility, I learned that problems do not stop when they go to assisted living and I wasn’t prepared to experience that.

The remaining five participants who had both a partner and children during the caregiving process noted that their children were supportive, but older, with the majority of them living outside of the home at the time. However, participant #1 expressed guilt in tending to her mother in crisis during a time period when her daughter was applying to colleges:

At the time when my parents were in their biggest crisis, that’s’ when [my daughter] should have been applying to colleges. Initially she said she didn’t want to go away, she wanted to go here. I just said, “Alright, if you want to stay you can stay,” but looking back, I felt really guilty about that. She felt that her grades weren’t that good so she wouldn’t get in anywhere, but there are colleges everywhere you can go to. She would have been fine. But if I wasn’t so preoccupied with my mother, I might have found her a school and she might have had an opportunity to go live in a dorm.

Three of these women noted that their husband was extremely supportive during the caregiving process. Participant #9 stated, “my husband was unbelievably supportive, he was just as much of a caregiver as I was” while participant #2 noted, “I have a very

compassionate husband, he's very understanding in terms of things like that." Participant #1 also noted that her husband was supportive, but added, "it was evident that taking care of my mother was a huge, like the elephant in the room..." Participant #3 was extremely busy with caregiving, her job, and other activities during the caregiving process.

Unfortunately, because of her numerous responsibilities, she revealed, "My husband announced that he was unhappy and needed to leave. I found out he had become involved in an affair while I was engaged in all of that, and I guess I was too busy to notice."

Grief, Loss and Coping

The following section illustrates participants' experiences regarding grief, loss and ways of coping both during and after the caregiving process. The data are represented in the following subsections, including grief and loss during caregiving; grief and loss after caregiving; methods of coping during the caregiving process; stages of the disease that were especially difficult; and financial, physical and emotional difficulties experienced during the caregiving process.

Grief and Loss during the Caregiving Process

In general, participants in this study noted grief and loss during the caregiving process. As participant #1 put it,

Absolutely because the person that's sitting in front of you everyday is becoming less and less of themselves and constantly you're thinking 'if there's anything I want to know I have to ask now before it's too late.' But you never can think of everything until after they're gone...From the very beginning, you think, their personality is disintegrating, their memory is disintegrating, and you have to constantly change your relationship to maintain a good relationship.

Some women described the loss of their mother's mental ability, while others noted the loss of physical abilities. As stated by participant #5,

Not being able to use the remote control, answering machine, putting something on backwards, having trouble. Every little thing was a loss. And I was it the second it happened. And I grieved every loss, some more than others, but it hurt seeing her not being able to do the things she used to do.

Added participant #6,

I definitely experienced loss. I experienced loss because she kept getting worse, and how do I explain this? I experienced the loss of her laughing, singing talking, everything, I experienced that loss. Every stage that she went through it became worse and worse, and it was a big loss. But I was always grateful that she was still here with me.

Participant #10 also touched on the stressors of dealing with new losses as her mother's disease progressed, stating,

I think it's a natural part of the Alzheimer's disease journey, because you're continuously having to cope with new losses. And at a certain point, you can't talk the way you used to, no simple conversations, I couldn't tell her that my husband had cancer - she couldn't really grapple with these kind of issues. That was difficult. I didn't feel like I could share my life anymore, and that was hard.

In describing their grief during the caregiving process, several women noted that they grieved the losses that were being experienced while caregiving, both for themselves as well as for their mother. Participant #7, who's father passed away suddenly from a heart attack, discussed the differences between sudden and gradual death:

I said goodbye to her a lot of times when she was still alive. The model I had because my father had dropped dead of a heart attack, where I talked to him the night before, drove out to see him, and by the time I got there he was gone, that was completely different grieving. This is that gradual attrition of personality.

This woman further went on to explain how she grieved during the caregiving process, noting,

At the nursing home, I made sure everyone knew what a fascinating, smart person my mother was, how well traveled she was, how many languages she spoke. None of which were particularly important, because she was being herself and they were in the moment. But with my grieving and saying goodbye to that person, I had to make sure that everybody around me knew who she was. That was how I did it, but it was such a long grieving process. Like for each stage of the disease,

what they don't tell you with Alzheimer's, is that no matter what stage and how hard it is, the next stage is going to be worse...So there is a lot of personal grieving for the person I lost and grieving for her and what she lost because she couldn't grieve herself.

A few women referred to certain stages of the grieving process. Participant #8 noted,

Yea, from what I was told, I was going through the grief process because she just wasn't present anymore. Wasn't the person, the mother I knew, and I guess I was grieving her loss, but I didn't know what I was going through. I was angry a lot - I'm told that's one of the stages of the grieving process, so I guess I was going through all of it.

Participant #3 talked about the denial she went through during the caregiving process, stating,

I know initially, even though I had seen my mother deteriorating, I still found it hard to believe. At the assisted living facility, I remember asking questions to the director like "Does it ever get better?" so I still had this fantasy that maybe it was a vitamin deficiency or some other explanation. Denial, bargaining, all of the grief stages I'm sure I went through. I think it had to be part of it.

Lastly, participant #11, who had previously noted how difficult her relationship with her mother was before Alzheimer's, noted mixed feelings regarding the grief and loss process:

Well, yes and no. No because she became much nicer to me and much more appreciative. But then, the loss that I experienced was that I knew she wasn't all there and that it wasn't the same person. So yes, I mourned that, because she literally was not the same person...didn't look it, didn't sound it. But on the other end, she was a lot nicer to me, so it was sort of a strange situation.

Grief and Loss after the Caregiving Process

When asked about grief and loss after their mother's passing, participants' responses contained both similarities and differences. Four women noted that they had already gone through a lot of the grief and loss during the caregiving process, having made statements such as: "When they physically die, you've already gone through a lot

of the grief and loss, because you've already lost most of them" and "I think, obviously, you're never ready, there's definitely a loss, but in some regards, the individual losses might have been harder than the actual last part of it." Participant #1 noted that the grief experienced after a mother's death may depend on the severity of her disease, stating,

I would say definitely the grief happens more while they're still alive. But I'm sure that depends on what stage they die in. In both of my parents' cases, they were both pretty much mentally gone, so I would certainly have had more grief if they had died in the earlier stages.

Contradictory to the above findings, participant #2 did not feel that she lost her mother before she died. She noted,

I hear people sometimes say, "We had been losing her all along, really we lost her five years ago." I didn't feel like that. I don't think anybody in our family felt like that. I know our dad didn't feel like that. There's not a right or wrong way, but we felt like we lost her then.

Several participants expressed feelings of relief after their mother's passing, noting the poor quality of life that is often experienced by individuals with Alzheimer's.

As stated by participant #1,

When they physically die, sometimes it's more of a relief, because you've already lost them, and the only thing that was left was suffering, and even though they weren't really computing why they were suffering, it was obvious they were suffering.

Additionally, participant #5 stated, "It was a relief in some respect, because I really didn't like, well, I actually hated the quality of life she had," while participant #7 noted, "I knew she wouldn't want to live under these conditions." Lastly, participant #11 stated, "It got to the point where I wanted her to be released from this – this was no way to live."

Some participants experienced conflicting reactions at the time of their mother's death, and continued to do so for an extended time period after her passing. As stated by participant #8,

I felt really guilty because when it was all over, I took a deep sigh of relief, “so glad this is over.” But then I felt horrible for feeling that way – my mother had just died! But for maybe about 6 months, I was really glad that it was all over. It was really kind of a conflicting time, but I think that my major response to it was that I was relieved. Then after about 6 months I sort of relived the loss again - I would relive my life with her, as a family, as a child, and it would be very sad. And sometimes I still think of that, have memories of my life with her.

Participant #10 also discussed her mixed reaction to her mother’s death, especially due to the fact that she was caring for her ill husband while also caring for her mother. She noted,

I had a real mixed reaction. One was “its over.” And the other was just heartbreak, having lost your mother...part of it was the relief now that I had time to spend with my husband and I didn’t have to feel conflicted and wouldn’t have to be so exhausted...So there were pros and cons, a real mixed blessing.

Some women discussed their grief surrounding the finality of their mother’s passing. Participant #1 noted, “It’s the ultimate, immediate shock when they call you up and say, ‘Your mother is dead.’ I mean, that’s a very final thing, there’s no hope in that. There’s grief for that.” Participant #10 stated, “It was very profound. There’s no other word that I can use to describe it other than profound.” Lastly, participant #6 noted,

Something terrible had happened. She was never going to be the same; it just felt like, suddenly, it was all over. That was it. Everything that had happened before was what my life with her had been, and now, it was going to be completely different, so I felt a lot of grief about losing her.

After their mother’s passing, some women reflected on the fact that their role as a caregiver had been an integral part of their lives. Participant #6 also stated, “I was stuck with ‘What am I going to do after work? What am I going to do on the weekends? How am I going to live without her?’ And I’m still stuck with that.” Participant #10 described her sadness over the fact that she had “really gotten into a rhythm of seeing her a lot, and that just stopped.”

Others noted the immediate chaos involved after the passing of a loved one, with little time to reflect at that moment. Participant #1 stated, “You have to jump into action and make the arrangements, so you don’t really have time to reflect.” Participant #2 talked about how her family came together at the time of her mother’s death in order to make funeral arrangements, etc. She stated, “That part for people is not the hardest time because you really have a lot on your mind, and you have a lot of people there. Of course when it settles down is when it’s really harder.”

Lastly, it is important to note the special circumstances surrounding some participants’ grieving processes. For a few women, their mothers developed additional illnesses that expedited the dying process. One participant’s mother developed lung cancer, while another passed away in her bed from aphasia. In addition, participant #2 discovered that her husband had been cheating on her for a long period of time in addition to experiencing the grief of her mother’s passing. She noted,

Just a couple of months before my mother died, I discovered that my husband had been having a long term affair and had been seeing this other woman for like a year and a half. The grief from that greatly outshadowed the grief from my mother, so there wouldn’t be any way for me to separate it out.

Coping/Support Systems during the Caregiving Process

Participants in this study used various methods of support in order to cope with the effects of caring for a mother with Alzheimer’s disease. Six participants noted that they used their friends as a primary means of support. Participant #9 stated that she received tremendous support from members of her church. Two women saw a therapist during the caregiving process, and four women identified the Alzheimer’s Association as being very helpful. Lastly, participant #8 and participant #11 noted that they had little

support while caring for their mother. Both women noted that their friends would occasionally assist with caregiving duties and other responsibilities, but that in general, these women did not have supportive outlets during the caregiving process.

Stages Especially Difficult

When asked if any stages of the disease were especially difficult to deal with as a caregiver, the responses varied. In general, most agreed that many stages of the disease were difficult in that every stage comes with different and devastating side effects. For some, both the participant and her mother experienced difficulties in succumbing to beginning stages of Alzheimer's. Participant #1 noted,

In the beginning, when they don't realize there's something wrong with them, and they blame everybody but themselves. They're pretty feisty about it, and that's pretty difficult...It's really hard because you don't want to sit them down and tell them that they have some terrible disease because you don't want to take hope away from them, but on the other hand, you have to make sure that they are knowledgeable enough so they know that there's a problem and that they're willing to make some changes, and that's a really tricky area there.

Other participants noted feelings of denial after their mother's diagnosis. Participant #9 said, "Initially, just accepting the diagnosis was very difficult. I broke down. It was a terrible time" while participant #10 noted, "In the beginning, you don't really know what's going on, and you don't want to believe that it's Alzheimer's disease."

For some women, their mother's behavioral changes were especially difficult to deal with. Participant #10 generalized, "Some of the behaviors got really difficult. I would say that not knowing how to deal with the behavior in the beginning is very hard." A few discussed their mother's anger, with participant #2 noting specifically "the times when things would set her off, and you didn't know what was going to happen or what was going to trigger it."

For many participants as well as for their mothers, there were difficulties in facing the loss of everyday functioning and dignity. Some women noted their mother's incontinence, speech problems and loss of mobility as extremely difficult to watch. Others expressed sadness over their mother's loss of dignity, with participant #2 stating,

That whole personal dignity thing...We got to where we did everything, changed her, took her to the bathroom, helped her take a bath, and she allowed it, and was very sweet with it, she just sort of let you help her, like she almost didn't know...well I think she didn't know, but she was at a place where it wasn't a priority. But that whole dignity thing, that loss of dignity for somebody who was very dignified,

while participant #6 talked about how she would put underwear over her mother's diapers, noting, "I wanted her dignity to be there, and I felt that it wasn't with the diapers." Another woman discussed her mother's loss of independence:

She lost her independence. This originally happened when she was living alone in her apartment. It stripped her of who she was, day by day. She was a really feisty, attractive lady, really into how she looked. You would not believe the transformation this thing caused her! It was horrible to watch it.

Some participants noted their difficulties in dealing with their mother's frequent changes in behavior, as well as with the unpredictability of the disease. Stated participant #1,

You have to realize in the middle that everything you do is going to change. You're reactive to how they are now and you set up a plan, and that plan has to be flexible because they're going to change constantly.

Participant #8 noted,

It's such a tough thing because it's unique to everybody...I would get so angry and frustrated with her, so you have to learn how to respond to the person...One minute they're lucid, the next you don't know what they're saying or if they're just making something up. That was tough.

A few women further discussed feeling unprepared to handle these frequent behavior changes. Participant #8 went on to say,

You have no education; you just don't know anything about the disease so you're right in the midst of it. So you're learning while you're caring for the person and all of these things happen, and you don't know what it is,

while participant #10 stated,

Not knowing what you're dealing with caused tremendous suffering for everyone all around. And no one really trains you in terms of how to deal with people who have memory loss and behavioral disturbances. Once I learned about the disease and became more familiar with it, it got easier, but there's always something in all of the stages that's really difficult.

Lastly, some women talked about the difficulties in dealing with the end stages of the disease. Participant #10 noted that her mother "started to descend the last 6 months of her life, when she started having seizures, and it was really heart-wrenching because I felt like I couldn't help." Others noted their mother's loss of physical and mental abilities in their final months of life to be very upsetting, with participant #6 noting, "It was just heartbreaking to see this very vibrant woman lying there."

Financial Difficulties

For the most part, participants in this study did not experience any major financial difficulties during the caregiving process. Many stated that their parents had enough money left over to pay for their mother's care. Other participants were very grateful in that their husbands assisted in paying for their mother's care.

However, some women experienced financial strain during the caregiving process. Participant #5 noted, "It was a challenge. We basically depleted all of my parents' savings, and then my husband and I paid a significant amount of money." Participant #7 had to take a lower paying job in order to be available to care for her mother. She stated, "It wasn't a difficulty in that I wouldn't do it again, but it was a big drop in salary."

Lastly, two participants discussed the fact that their mother was on Medicare. However, this medical assistance paid for very little regarding caregiving expenses. For example, participant #8 noted,

Oh yea, it was really hard. My mom was on Medicare, and you assume that Medicare will cover everything, but it doesn't – it doesn't cover long-term care. We pretty much had to pay for everything, and it was tough.

Physical Difficulties

When asked about physical difficulties, most participants stated that they experienced minor difficulties, but that no major physical complications occurred. Participant #2 answered, “Exhaustion, when you were in the middle of it. It was very tiring. I learned why they named that book ‘The 36 Hour Day’ because it’s a long, long, day” while participant #10 noted that she had to make occasional trips to the chiropractor after transferring and helping her mother around. However, participant #6 stated that she was not able to maintain her physical health while caring for her mother: “my blood pressure was up, my cholesterol was up, and I didn't care about what I ate and what I looked like.”

Emotional Difficulties

In general, the emotional difficulties that were experienced by participants during the caregiving process are discussed in various sections of this chapter. However, when specifically asked, many participants further elaborated on their emotional experiences as a daughter caregiver.

Participant #1 talked about her experience as a:

Mental, emotional tough time, but I'll say coming out of it the other end, “what doesn't kill you makes you stronger.” It was very frustrating, sort of like having a toddler – you just pick up the house and you go to answer the door and all the toys are dumped on the floor again. You just have to deal with it, and you have to try

not to get so stressed that it affects you, and it does. I mean, there were times when I felt like, 'I'm responsible for the outcome of this situation but I have very little influence on the process.'

Participant #2 discussed occasions in which she had to "go along" with her mother's false beliefs that she had a young child that was missing and needed to be found. She noted,

That was emotionally wrenching, exhausting, and psychologically challenging because first of all, you weren't sure how long you could continue to do it and you know it was going to trigger a lot of anger if you didn't do it.

Other women noted the ongoing, chronic stress that goes along with caring for a loved one with Alzheimer's disease. Participant #5 further described her experience as a caregiver by stating, "Depression just goes along with the disease. It was a bit of a roller coaster."

In general, when asked, participants did not go into great detail about financial, physical and emotional difficulties experienced during the caregiving process. For some women, these issues were addressed in previous sections. Others were fortunate in that they possessed financial flexibility and good health that decreased the risk of becoming burdened by these difficulties. Nonetheless, it is important to note these findings in order to take into account possible limitations within this study's results.

Role Reversal, Family Conflict and Positive Experiences

This section will address participants' experiences regarding potential role reversal within the mother-daughter relationship. Additionally, family conflict and positive experiences as a result of being a daughter caregiver will also be discussed.

Role Reversal

During the interviews, several participants brought up the notion of role reversal prior to being asked about it. As noted in the section that addressed mother-daughter

relationships during caregiving, participants made comments such as “It sort of switched, where I was the parent and she was the child.” and “The roles obviously reversed – I ended up the mother and she ended up the child.”

Throughout the caregiving process, the majority of participants reported that they had experienced some type of role reversal while caring for their mother. Experiences varied from feeling as if the roles had switched in a physical sense as well as in an emotional sense. Still, a few women noted that they didn’t feel as if the roles had reversed. The following paragraphs describe participants’ accounts regarding role reversal and the caregiving process.

Several participants noted that they felt as if the roles had reversed regarding everyday activities. Bill paying, grocery shopping, cleaning and doctors appointments were just a few tasks that were mentioned as having been taken over by participants being that their mother was no longer able to do so. Others referred to their mother as having childlike qualities due to the devastating effects of the disease. Participant #8 noted,

I mean, she would eat and drop crumbs on her shirt, and I would have to dust them off. Like she’s a kid, you know, and I would have to remind her to wipe her mouth...It was like she was a kid again, like she was my child. I would have to watch her, sometimes she would fall – she was fragile...You just have to kind of, it’s like this kid, you know. That’s really bad, you think about your mom, and it’s the person who took care of you, and now you’re sort of having to do the same thing...Definitely, the roles reversed. And sometimes at night she would call out, and it was like a kid saying, “Mommy!” Maybe she was confused because she was in my house and not in her house. And I was like, “Wow, it’s like a child saying ‘mommy.’ Where am I?!”

Participant #7 stated,

Definitely...You certainly are doing behaviors that make you feel that way. Sometimes also getting resistance when you’re trying to help, and it can be a

thankless task. But I also felt much more physical with her – I would cradle her with my arms around her shoulder, kind of like you would with a toddler or little child. To be doing a lot of those behaviors was very much mothering to her.

Many participants referred to general decision-making when asked about role reversal, with participant #9 noting,

Oh yes, that's what I was kind of referring to when I said I was making the decisions. She had always been a strong-willed, decisive person, and toward the end of the course, was more mellow and more, well, it was hard for her to make a decision. And yes, I felt like I was the parent in that role.

In terms of role reversal on an emotional level, participant #11 discussed her experiences, adding,

Absolutely. Absolutely. Emotionally, it was a gradual thing, but she was unable to care for herself, and I was her only advocate. I had to take care of her and make sure that some of her needs were met. She certainly wasn't in a mothering situation with me - that was gone.

Two participants discussed the fact that although the mother-daughter relationship was now different, they still tried to keep their mother's role alive for as long as possible.

Participant #7 noted,

I missed my mom, I missed being able to tell her stuff...Then I realized that I can tell her stuff, so I would tell her about work, all these weird things, and she'd just sit there and smile. So I tried to keep her role alive for a while.

Participant #10 stated,

There were times when she would give me advice, and when she didn't, there were times when I would ask her for it. I sort of sought out and gave her opportunities to be my mother still. But they had to be sought out.

Participant #10 also explained how she felt that the mother-daughter roles had and had not reversed. She went on to say,

You know, both. You do have to take care of the parent with dementia the way you would take care of a child sometimes. You have to tell them what to do because they don't have the judgment they used to have. But my mother was also my mother...And there was always that love between us. It got to the point where

I really wanted to see her, and if I didn't see her for a full week, it was really difficult for me, and I missed her terribly. So we had a love there between mother and daughter; and I don't have children, but it didn't feel like daughter to mother. I felt my mother's love.

Participant #4 did not feel as if the roles had reversed, stating,

Well, I mean, I was her comforter. I was taking care of her, but I never really felt like I was the mother. I mean, as I said, I don't think I felt like her daughter, I couldn't go to her for anything, but I didn't really feel like she was a child or that I was taking care of a child. But I was taking care of her. I didn't feel like there was that kind of reversal. It was different; I was taking care of her.

Lastly, participant #7, who did not have any children, expressed her curiosity as to what it would be like for a daughter caregiver with young children. She said,

It would be a more interesting interview if I had children and was a mother and was a mother to my mother - that just breaks your heart when you think about people like that. I think, and this is me being the objective social scientist, I think people can look to their children for hope and emotional support. There were holidays where I was sitting in the nursing home with my sisters (none of whom have kids) and I was the youngest person there, and I would think, "What does it all mean?" At least when you have little kids running around you have a sense of the generations and the ultimate meaning of life, which gets a little harder when you're with 80 year olds. It would be interesting to know. I mean, the sandwich people are exhausted, but I wonder if they get less depressed...They're probably too tired to do this!

Family Conflict

In general, participants' experiences varied regarding the degree of family conflict during the caregiving process. For two women, family conflict did not occur. Participant #6 stated, "None. My aunt and uncle knew I would do the best. When I needed assurance I would call them, and they would help me out, but none." Participant #9 noted,

No conflict. Our immediate family, like I said, was amazingly supportive. Our parents have been so giving throughout their lives, and our relationship with them was so close. My mother had a sister, and it wasn't so much that we experienced conflict with her, but withdrawal and denial. She just couldn't face it.

Other participants also discussed the initial denial that often hindered family members from agreeing on goals of care for their ailing mother. Participant #7 said,

With my sisters, initially, it was getting everybody on board with the diagnosis. From the reading I've done, that's pretty much a common problem. I had one sister who didn't want to accept that it was a disease. Then we had to decide, 'Does she go into a nursing home? Do we have care here?' It wasn't conflict really, but we weren't in harmony all the time.

Additionally, participant #8 stated,

At the beginning, my family didn't want to admit that anything was wrong, they were sort of in denial. I had an aunt who had had it, so if it hadn't been for that and I had some knowledge of it, I probably would have ignored my mom's symptoms. I knew something was up...But my family pretty much was like 'Oh, there's nothing wrong, you're just exaggerating.' I couldn't even get her primary care physician to acknowledge that something was wrong, he just figured, 'Oh, she's fine.' Nobody really believed me, so yea, it was tough.

Others felt as if their siblings were not as involved as they should have been, with participant #2 saying, "Sometimes there were things with my siblings, feeling that everybody wasn't pulling their weight." Additionally, a few women noted that uninvolved family members would randomly attempt to take responsibility and intervene. Stated participant #1, "My sister was always telling me what to do, 'do this, do that,' but she didn't know how her suggestions were not practical because she didn't really know what was going on." Participant #8, who didn't have family members close by, noted,

I wasn't around my family that much. My cousin (in a different city) didn't resist, he was pretty much on the same page. Only when I was about to put her in assisted living, he thought I should put her somewhere else. He had his wife call me and ask if I felt guilty, he didn't even have the guts to do it himself. "Don't you feel guilty for putting your mother in a residence?" I was like, "I don't need this."

Some women experienced relatively severe family conflict amongst siblings during the caregiving process. Participant #10 said,

My two other sisters were helping out, but that caused real conflict, because one sister of mine didn't help out that much. And I felt like she was being a bad daughter, she didn't do her share, and was expecting us to pick up the slack. That caused some real sort of moral dilemmas. It ruined our relationship for a few years, and it changed after my mother died.

Participant #7 noted,

I had a certain amount of resentment against my brothers. If I were honest, I'd say I was channeling my frustration into hating them, but they deserved it...I've irreparably damaged my relationship with one of my brothers and his children. They lived a lot closer, and they only visited her twice while she was [living in that area]. It was unacceptable.

The remaining participants stated that family conflict was kept to a minimum, in part because they did not seek out participation from other family members during the caregiving process. Stated participant #4,

It was this way because I didn't create any conflict; I didn't insist that they do anything. My sister would come maybe every month, both while my mother was home and in the nursing home. I mean, at a certain point I just decided that if that's the way she wanted it to be, I wasn't going to insist on anything else. Let me make the decisions, and she never questioned anything I did or asked to do it differently.

Participant #5 had similar feelings regarding family participation: "With my other family members, they kind of disappeared; there was no real participation. There were no outward conflicts because it wasn't worth it. Either you participate or you don't." Lastly, participant #11, who's sister had been estranged from the family since 10 years prior to her mother's diagnosis, stated,

There was nobody to have conflict with. I was the only one to do it. There was no one to be in conflict with. I didn't have to deal with 'Is it ok to do this/that?' It was my decision, so in that respect, I didn't have any conflict.

Positive Experiences

In general, the majority of participants noted that something positive came out of caring for a mother with Alzheimer's disease. For example, participant #1 stated, "I got

to know my parents better I suppose. And because I was afraid that once they were gone I wouldn't know anything about the family, we did spend more time concentrating on those things.”

In talking about the different roles embodied by each sibling, participant #7 noted that she and her siblings developed a closer relationship due to the caregiving process. She stated, “We all developed very distinctive roles, and that was sort of neat. That strengthened our relationship. I really came to count on them and appreciate their talents that before, being the smart, spoiled one, I never did.”

Others noted that the mother-daughter relationship was strengthened as a result of being a caregiver. Participant #4 stated,

It was positive between me and my mother, and even when she was angry, it was positive in the sense that I guess I saw what our lives had been like with each other, and that was positive. It really gave me a warm view of our lives together, and that felt good. As I said, she always lit up when she saw me. I really felt like we were very connected. I felt very connected and close to her. That was positive. I tried to make it a positive experience because, I mean, you know, it was my life.

Participant #9 noted, “With my mother, if anything, it drew us closer.” Lastly, participant #11, who described her relationship with her mother prior to diagnosis as “difficult,” greatly benefited from the caregiving experience, stating,

As bad as this scenario was, in the end, there was one time in the hospital at the very beginning and she actually said to me “I really want to say I'm sorry. I really wasn't a very good mother.” And that changed everything how I reacted to her, to the burden of taking care of her, to simply having emotion toward her, to loving her again. Like I said, we had a very poor relationship. When she did that, it was a gift to me, which my sister never had. From whatever unhappiness I had from my upbringing or with my relationship with my mother, that was a profound moment that freed me and freed my soul so that I can look back on that whole horrible experience and say that something seriously positive came out of it. My mother and I were able to connect and I was able to forgive her. So in a way, there was something very positive that came out of it.

A few women noted that they met a “lot of great people going through the same thing,” including support group members and assisted living staff. Others gained knowledge and understanding that could only be learned through maintaining the role of a caregiver. Stated participant #5,

I think, if anything, the disease taught me that life is short – you can’t take anything for granted...I also have more understanding of people who have some sort of handicap or challenge. When you live in a big city, everything is whizzing by you, and you get terribly frustrated when the bus has to stop to let someone on and they have to put the wheelchair lift down, or hold the door for someone who’s struggling. It just made me be more patient.

Similarly, participant #6 noted,

I became a kinder person. I became, it was very strange, a more tolerant person. I look at things quite differently now. Older people - I would do anything for older people. I believe in elder care. I believe that a lot of older people have their rights taken from them, and I would definitely be one of the people to support bills to help get all of their rights back and things like that. It has opened my eyes to the world of elder care.

Participant #7 also benefited from her experiences as a caregiver, saying,

Because I was such a cerebral person, I really did learn how to be more expressive. Something simple, like when someone is ill, someone has died, or something is going on in someone’s life, make sure to say something rather than holding back and thinking, “Oh, I’d be intrusive. They have enough on their plate.” I learned to step out of my shell a little bit, because the little gestures are appreciated. I think, in fact, they’re more important than the big ones. For myself, I learned to do that, and I carried it with me. Also, I think I began to appreciate kindness where I saw it.

Lastly, a few participants noted that their understanding and experience as a daughter caregiver was meaningful in that they can now help others who are going through the same thing. Noted participant #8, who is writing a book about her experiences as a daughter caregiver,

It’s not fun. I can’t think of anything, other than you know, I feel like maybe I can help other people who are going through it. Once you go through it, you can help somebody else and prepare them for what to expect...Maybe that’s the positive

thing – writing my book – that’s come out of this experience. That’s probably the most positive thing, that you can help someone else.

Participant #9 said, “I feel like it’s helped me in that I’m a more understanding person when anyone else is going through the same thing...You understand what they’re going through, and you’re more approachable if they know you’ve gone through this.”

Summary

This chapter summarized the major findings of this study. Efforts were made to address participants’ general experiences as a daughter caregiver. Additionally, special attention was paid to themes surrounding relationships, grief and loss, difficulties, role reversal, family conflict and positive experiences. In the following section, these findings will be presented in correlation with the existing literature. Additionally, implications for future research will be addressed.

CHAPTER V

DISCUSSION

This study retrospectively explored daughters' experiences in caring for a mother with Alzheimer's disease. In particular, participants were asked questions regarding relationships, grief and loss, difficulties, role reversal, conflict and positive experiences. Findings reiterate the uniqueness of embodying the role of a daughter caregiver, with the effects of caring for one's mother depending on a wide variety of factors, including the quality of the mother-daughter relationship (both before and after developing Alzheimer's) and informal and formal means of support. Participants also noted a difference between grief/loss during the caregiving process and grief/loss after their mother's passing. Additionally, the majority of participants noted that they experienced some type of role reversal. Lastly, the degree of family conflict experienced during the caregiving process varied by participant, and the majority of women were able to identify positive experiences that resulted from caring for a mother with Alzheimer's disease.

The following compares the study findings to existing literature. Additionally, strengths and limitations of this study will be noted. Lastly, implications for clinical social work practice will be addressed, followed by implications for future research.

Comparison of Study Findings to Existing Literature

The majority of the existing literature in this area of study focuses on caregiver experiences while the individual with Alzheimer's is living. Although this study sampled

women whose mothers have since passed away, it is possible to compare their experiences with current caregiver research.

First, many participants addressed their experiences of grief during the caregiving process, an idea that has been discussed in several studies surrounding this area of research. For example, a study conducted by Betts Adams and Sanders (2004) concluded,

Each stage of dementia may have a distinct set of emotional tasks for the caregiver...Like the bereaved person, those close to someone with progressive dementia need to work through the grief of each of the losses they are faced with along the way (p. 207).

Similar to these findings, many participants in this study noted that each stage of the disease presented new losses and opportunities to grieve the mother they once had.

Findings from research conducted by Perry (2004) can also be compared to this study. Daughter caregivers from both studies were noted as acknowledging new losses throughout the caregiving process. Additionally, a theme surrounding the findings of Perry's (2004) study included daughter caregivers trying to preserve their mother's dignity amidst their cognitive and physical decline.

Jones and Martinson (1992) interviewed caregivers both during the caregiving process and after the death of their family member with Alzheimer's. The caregivers in this study were not only daughters, but wives, husbands and sons as well. However, the findings can still be compared: Jones and Martinson (1992) found that over half of the study's participants felt as if the majority of grief occurred during the caregiving process while their loved one was still alive. Additionally, it was noted that some caregivers experienced feelings of relief after their loved one's passing, as well as feelings of guilt

and sadness that accompanied this relief (Jones and Martinson, 1992). These findings from the Jones and Martinson study are very similar to those of this researcher's study.

Regarding coping and support systems during the caregiving process, findings from this study can be compared with existing research. For example, McCarty (1996) interviewed both daughters and daughters-in-law who were caring for a parent with Alzheimer's disease to understand daughter caregiver stress. Similar to this study, McCarty (1996) found that "the availability of sibling support and/or spouse support was identified as meaningful assistance to daughters' coping or managing parent care" (p. 801). Furthermore, McCarty's (1996) participants noted positive experiences that occurred as a result of assuming the role of a daughter caregiver, a finding similar to caregivers' experiences in this study.

Lastly, the findings of this study reflect disparities within research that denies the existence of role reversal during the caregiving process. Seltzer (1990) stated, "Role reversal does not occur any more than does second childhood" (p. 5). Furthermore, Brody (1990) noted,

Some caregivers do characterize their changed relationships with parents as "role reversal." Invariably they use that phrase in connection with illness-induced disability and dependency of the parent and most often when the parent is cognitively impaired. Even those caregivers, however, note the differences between caring for a child and for an elderly parent. They recognize that "reversal" represents *deterioration* in the relationship rather than the way things should be (p. 16).

For those participants who experienced role reversal, several women referred to their mother's actions as childlike, but still found ways to focus on positive aspects of the mother-daughter relationship without feeling as if the relationship had "deteriorated."

Integral to the examination of role reversal involves discussing the complexity of this area of research and this study. First, it is important to note that several participants addressed the concept of role reversal prior to being asked about it. Also noteworthy is the fact that the meaning of this term may vary depending on the individual. However, one can argue that caretaking can be described as very parental, and especially when “in the moment.” Because of this, it is not uncommon to refer to the experience as “role reversal,” however it may be defined. Therefore, this is an area of research that requires further exploration while distinguishing between defining role reversal in a literal sense versus as a general experience.

Strengths

This study’s strengths include the fact that findings were obtained in a qualitative, exploratory fashion. This method was chosen in order to best obtain narrative, descriptive accounts of the daughter caregiving experience that would not have been captured had a quantitative study been employed. Additionally, being that this was a retrospective study, participants were able to address experiences both during their time as a caregiver as well as after their mother’s passing, and compare the two. Due to the lack of research in retrospectively exploring the daughter caregiver experience, this study can now act as a stepping stone in this particular area of interest.

Limitations

Limitations of this study include a small sample size, with only 11 women having participated. Additionally, the potential for sampling bias should be noted in that a large percentage of participants were recruited through the New York City chapter of the Alzheimer’s Association. Although this organization strives to serve a diverse population,

the clientele tend to be White, middle to upper-class individuals. In turn, these demographics can also affect physical and financial ability, two key issues which can impact one's caregiving experiences.

Lack of cultural diversity should be noted, with the study comprised of 10 Caucasian participants and one African-American participant. Also, although the question of sexual orientation was not addressed, it was evident that over half of the women were in or had been in a heterosexual relationship, and the single participants never revealed any information that hinted at their sexual orientation.

Lastly, of the participants in this study who had children, all were of adult age during their time as a caregiver. Because of this, this study failed to address issues surrounding the concept of the *sandwich generation*, or caring for an elderly loved one while also caring for young children.

Implications for Clinical Social Work Practice

Findings of this study provided fundamental information that can be used in the field of clinical social work. First, it is necessary to acknowledge the uniqueness of caring for a loved one with Alzheimer's and use clients' experiences as a basis for clinical practice. Additionally, as noted earlier by Sanders and Adams (2005), it is important to understand the relationship as well as the differences between grief and depression. Clinicians should focus on distinguishing symptoms of grief versus symptoms of depression within their daughter caregiver clientele, while also acknowledging that the two may coincide.

Additionally, being that several participants in this study noted the benefit of joining a support group or talking with someone who was also a daughter caregiver,

clinicians working with this population should consider the option of referring clients to outside organizations that cater specifically to individuals caring/who have cared for a loved one with Alzheimer's. As a result, allowing daughter caregivers to work with both licensed professionals as well as peers may allow for a richer, more diverse support system.

Implications for Future Research

As noted above, one limitation of this study included the lack of socioeconomic and cultural diversity within the participant population. Because of this, further research is needed so that daughter caregiver experiences can be examined and compared across various participant characteristics.

Additionally, as noted as a limitation and by one of the women in this study, it would be both interesting and beneficial to inquire about the impact of caring for a loved one with Alzheimer's while also caring for young children. Although this area of research has been addressed while a parent with Alzheimer's is still alive, no studies have looked at this process retrospectively. Because of this, research focusing on *sandwich generation* experiences in a retrospective manner should be conducted. As with this study, the benefit of a retrospective study would give participants a chance to compare their experiences while caregiving to those after their mother's passing.

Lastly, this researcher failed to address issues surrounding the effects of caregiving on other meaningful relationships, such as friendships. Just as several participants in this study turned to partners and family members for support, other individuals may prefer to utilize additional relationships as supportive outlets. Because of the importance of these types of relationships, research in this area would be beneficial.

Summary

This study retrospectively examined the effects of caring for a mother with Alzheimer's on the everyday lives of daughter caregivers. Participants provided descriptive, narrative accounts of the caregiving process in order to address their feelings surrounding relationships, grief/loss, difficulties, role reversal, family conflict and positive experiences. Although many similarities were found among participants' experiences, the findings of this study also addressed the uniqueness of daughters caring for a mother with Alzheimer's, even within the daughter caregiver population.

However, one theme remained constant: Alzheimer's disease is a devastating illness that can have significant effects on everyone involved. Until a cure is found, it is necessary to best serve the physical and emotional needs of both individuals with Alzheimer's as well as their loved ones.

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Appendix A

Informed Consent Form

Dear Participant,

My name is Pamela Rich. I am conducting a study of caregiving and Alzheimer's disease to learn more about the caregiving experience for daughters who cared for their mothers. The data from this study will be used for my MSW thesis, future publication, and presentations on this subject to my colleagues.

I am interested in learning about the daughter caregiving process. You are being asked to participate in this study if (a) you are a woman whose mother suffered from Alzheimer's disease, (b) you were a caregiver to your mother and (c) your mother passed away between one and five years ago. As a subject in this study you will be asked to participate in a face-to-face interview. Questions will focus on your experiences as a caregiver. The interview will take between 45 to 60 minutes. Interviews will be tape recorded, and tapes will be coded numerically to ensure your confidentiality. Tapes will be destroyed after the interviews have been transcribed.

Additionally, demographic information will be requested. This information includes: age, race/ethnicity, city and state of residence, relationship status, number and ages of children (if any), and occupation.

Your participation is voluntary. You will receive no financial benefit for your participation in this study. However, you may benefit from knowing that you have contributed to the knowledge of daughter caregiver experiences of Alzheimer's disease. It is my hope that this study will help social workers have a better understanding of the caregiving process as well as the various emotions that may accompany it. You may also benefit from being able to tell your story and having your perspective heard.

The potential risks of participating in this study are the possibility that you might feel strong or uncomfortable emotions while talking about your experiences. In case you feel the need for additional support after participating in this study, a list of resources for mental health services in your area will be provided.

Strict confidentiality will be maintained, as consistent with Federal regulations and the mandates of the social work profession. Confidentiality will be protected by numerically coding the information and storing the data in a locked file for a minimum of 3 years. If materials are needed beyond the 3 year period, they will continue to be kept in a secure location and will be destroyed when no longer needed. Should a transcriber aside from myself transcribe the tapes, he or she will sign a confidentiality pledge. Your identity will be protected, as names will be changed in the analysis of the data. Your name will never be associated with the information you provide in the interview. The

data may be used in other education activities as well as in the preparation for my Master's thesis.

This study is completely voluntary. You are free to refuse to answer specific questions and to withdraw from the study at any time prior to March 1, 2008 when the final report will be written. If you decide to withdraw, all data describing you will be immediately destroyed. If you have any questions or wish to withdraw your consent, please contact:

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600 North Wolfe Street
Baltimore, MD 21287

Additionally, feel free to contact the Chair of the Smith College School for Social Work Human Subjects Review Committee at 413-585-7974 should you have any concerns about your rights or about any aspect of this study.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

SIGNATURE OF PARTICIPANT

SIGNATURE OF RESEARCHER

DATE

DATE

Appendix B

Interview Screening Guide

1. Are you interested in participating in this study?
2. Did your mother suffer from Alzheimer's disease?
3. Were you involved in the care of your mother? How so?
4. Did your mother pass away between one and five years ago?

Appendix C

Interview Guide

Demographic Information

Name:

Age:

Race/Ethnicity:

City/State of Residence:

Relationship status during the caregiving process/currently:

Number of children and ages:

Occupation:

1. How long ago did your mother pass away? At what age?
2. When was she diagnosed with Alzheimer's?
3. How long were you a caregiver for your mother?
4. What was your relationship like with your mother before she developed Alzheimer's?
5. What was your relationship like during with your mother during the caregiving process?
6. What was your relationship like with your partner and/or children during the caregiving process?
7. Describe any grieving or loss you experienced during the caregiving process.
8. Describe and grieving or loss you experienced after the caregiving process. How did they differ?
9. Were any stages of the disease especially difficult to deal with? If so, describe.
10. Describe any mental, physical and financial difficulties that were experienced.
11. One noteworthy concept in the field of caregiving research is *role reversal*, a term that often refers to "mothering the mother." Do you believe that you experienced role reversal during the caregiving process? If so, describe your experiences. If not, describe how you experienced your role as a caregiver.
12. Describe any family conflicts and/or positive events that occurred because of your additional responsibility as a caregiver.
13. Is there anything else you would like to mention about your caregiving experience?

Appendix D

HSR Approval Letter

November 13, 2007

Dear Pamela,

Your amended materials have been reviewed and all is now in order. We are therefore happy to give final approval to this interesting project and I would think one of considerable current interest as more and more families struggle with this problem.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain signed consent documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your study.

Sincerely,

Ann Hartman, D.S.W.
Chair, Human Subjects Review Committee
CC: Fred Newdom, Research Advisor