ABSTRACT

THACKER, HERMINIA SORIANO. The Life Changes that Adult Daughters go through when they Become Primary Caregivers to Parents with Alzheimer’s Disease. (Under the direction of J. Conrad Glass, Jr.)

A case study analysis was used to investigate the changes in the lives of adult daughters when they became primary caregivers to parents with Alzheimer’s disease. This research also explored beliefs, feelings, and perceptions of participants about their role. Based on in-depth and face-to-face interviews with 21 adult daughters and two daughters-in-law, this study argues that although intergenerational caregiving is accepted as a part of membership in families, it is also a source of family disharmony and conflicts. Family nursing is considered a burden based on the length of service. The scope of the changes in the lives of adult daughters/caregivers ranges from living arrangements, family relationships, young children, personal affairs, social activities, employment and economics, health of caregivers to religion. Although caring for AD patients is rigorous, highly stressful, and filled with demanding challenges, the findings of this study show that a majority of adult caregivers would do it all over.
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THE LIFE CHANGES THAT ADULT DAUGHTERS GO THROUGH WHEN THEY BECOME PRIMARY CAREGIVERS TO PARENTS WITH ALZHEIMER’S DISEASE

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DEDICATION

This dissertation is dedicated to mature women everywhere. Education is a source of personal fulfillment and enhancement, as well as liberation from undesirable stations in life.

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FOR MICHELE
BIOGRAPHY

Herminia Soriano Thacker was born and raised in Manila, Philippines. Herminia is one of six children of Igmedio and Arcadia Soriano. Herminia attended parochial schools and Catholic universities. She came to the United States with her husband, an American serving in the United States Marine Corps. After her three children received their college degrees, Herminia continued her quest for higher education. A doctorate in education is the fulfillment of her ambition to teach in institutions of higher learning.
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I wish to offer my thanks to the wonderful staff in the Reference Section of D. H. Hill Library, North Carolina State University. The ladies in that section have made it easier for me to complete my academic journey. In addition, I am grateful to D. H. Hill Library for its extended hours of operation. As a long-distance commuter, D.H. Hill’s hours made it convenient for me to collect resources.

Special recognition goes to my daughter, Gabrielle Thacker Shumate, the best editor there is.
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Chapter I

Introduction To The Study

Americans are living longer as a result of modern medicine, innovative science and technology, improved living standards, and better management of chronic disease. However, this increased life span is also a source of concern for the elderly population and their families. Although many individuals reach their 65th year in relatively good health, the probability of acquiring a chronic disabling condition increases rapidly with age (Aneshensel, Pearlin, Mullan, Zait, and Whitlatch, 1995; Bird, Lampe, Wijsman, and Schellenberg, 1998; Breteler, 2000; Mortimer, 1994; Orodonker, 1991). Ten percent of Americans 65 and older, over four million elderly, suffer from Alzheimer’s disease (AD), and its incidence rises to 20% after age 80 (Castleman, Gallagher-Thompson, and Naythons, 1999). Compounding this situation is the rapid increase of the elderly population age 85 and over. It is predicted that by 2050 there will be 16 million Americans over the age of 85. According to Breteler, the incidence rate after 85 is greater for women than men: one in eight men and one in four women will fall victims to AD.

Family caregiving is a significant issue in this country. Aging parents with Alzheimer's become dependent on family members to care for them in the twilight of their years. With the graying of America, the number of frail elderly being cared for by family members is hitting an all time high. Caring for an individual with Alzheimer’s disease is one of the most serious
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commitments any person can make. The majority of home caregivers are women. In this connection, the focus of this study is the adult daughter, as she becomes the primary source of nursing care to parent(s) suffering from Alzheimer's. It is important to understand how adult daughters face the challenges of dementia, as well as their courage, dedication, and strength to soldier on. A family member who provides care to relative(s) with Alzheimer's disease is considered the hidden or the second victim of the disease (Gruetzner, 1992).

AD is recognized as the most common form of senile dementia and involves the “progressive and global memory loss accompanied by deterioration of other intellectual functions in the areas of language use, perception, motor skills, learning ability, problem solving, abstract thought, and judgment” (Cutler and Sramek, 1996, p. 11). Known as the silent epidemic, AD is a debilitating disease of the brain for which there is no cure. Le Navenec and Vonhof (1996) articulate that the disease assaults not only the body, but also the mind and identity of the patient.

The following are the 10 warning signs commonly associated with AD (Mayo Clinic, 2002):

1. Memory loss
2. Difficulty performing familiar tasks
3. Problems with language
4. Disorientation with regard to time and place
5. Poor or decreased judgment
6. Problems with abstract thinking
7. Misplacing things
8. Changes in mood or behavior
9. Changes in personality
10. Loss of initiative
The onset of AD is so gradual that changes on the part of the victim are almost unobservable (Cutler and Sramek, 1996; Shenk, 2001). Thus, it is not unusual that patient evaluation occurs after a lengthy bout with symptoms, such as forgetfulness of names of relatives, telephone numbers, and misplaced keys. These are often dismissed as a part of the aging process. The first noticeable impairment has to do with language. The AD patient exhibits difficulty in finding words to express himself or herself and is unable to follow up on conversations or details of recent events. As the symptoms progress, the patient is unable to remember the right word(s) and he or she speaks with great reluctance. Attention span is greatly diminished, as well as understanding of reason and abstract concepts. At this stage, the patient is unable to perform calculations, balance a checkbook, and operate home appliances. In addition, a personality change is markedly noticeable (Caring, 1994). A patient who tended to be garrulous before AD may become passive and indifferent, and vice versa.

During the middle phase of AD, the victim’s ability to comprehend written and verbal communication deteriorates further, and the patient resorts to constant repetition of words and questions. As a result of communication impairment, the patient becomes frustrated, argumentative, and angry.

In the most advanced stages of AD, the victim becomes totally dependent on caregivers, having lost mental and bodily functions (Miesen, 1999). This condition may entail incontinence, behavioral problems, hallucinations, wandering, and loss of sexual inhibitions. Because the patient is bedridden, he or she usually dies of complications, such as exhaustion or weight loss due to malnutrition, dehydration,
pneumonia, and urinary tract infection. The average time between the appearance of symptoms and death is 8 to 10 years.

The cause of AD is still unknown and definitive diagnosis is made possible only by a postmortem autopsy. Some of the possible causes that are being researched include genetic predisposition, biological abnormalities, decreased oxygen flow to the brain, environmental toxins, infectious agents, dietary habits, and immune system defects. The advent of high technology equipment, such as Computed Axial Tomography (CAT), Positron Emission Tomography (PET), and Magnetic Resonance Imaging (MRI) has focused studies on the abnormalities in the brain structure and functions of dementia patients, and ways in which these may be modified by drug therapy (Le Navenec and Vonhoff, 1996). Computed tomography measures brain atrophy resulting from loss of brain neurons, which is a hallmark of AD. MRI facilitates images of the brain of living individuals, and detects changes in brain tissues. A PET scan evaluates brain activity and differentiates AD from the normal effects of aging. A German study involving MRI and selected patient groups indicates encouraging results in the diagnosis of AD (Bickell, 2000). The hard reality, however, is the absence of cure in the battle against AD.

Although numerous drugs have been studied in the fight against AD, some have been found to be ineffective or to have toxic side effects. Some of the drugs used in patient management caused involuntary, rapid, uncontrolled, jerky movements, and lips smacking. Still other drugs damaged the liver and, in severe cases, the brain (Mace and Rabins, 1991; Powell and Courtice, 1993).
It is not difficult to envision the magnitude of care involved in AD patient management. The total dependency of the AD victim requires assistance from other family members (Bruchey, 1996; Shanas, 1979). Most victims of AD live at home and are cared for by family members. This may be attributed to the trend that started in the 1980s, which was a departure from institutionalization and toward community care of the elderly and the mentally handicapped. Such patients “are usually not admitted to long-term care facilities until the family is no longer able to care for them at home” (Le Navonec and Vonhof, 1996, p.4). Current literature forecasts the expansion of family caregiving in light of decreased public funding, stringent eligibility requirements to programs available, and the spiraling cost of private care (Biegel and Blum, 1990).

Not unexpectedly, approximately “80 percent of home health care received by elderly in this country was provided by family members” (Barusch, 1991, p.xiii), and three-fourths of the caregivers lived with the carereceivers. Historically, caregiving has been centered on women, just as family support traditionally has been assumed by men; in addition, caregiving is viewed as competing with paid work for women. As in the past, women have continued to assume multiple roles: homemaker, breadwinner, mother, wife, and careprovider to aging and feeble parents (Opie, 1994; Orononker, 1991; Zarit, Pearlin, and Schaie, 1993). Most family careproviders are females, specifically daughters and wives. Adult daughters appear to be the caregivers of choice by relatives with AD, inasmuch as they have greater commitment to render personal care, home health care, and psychological support to their parents than sons. Further, they are more likely than sons to move in and live with dependent parents to
provide care. Adult daughters tend to possess stronger filial responsibility and are more inclined to underscore the intimacy element of caregiving that enhances emotional attachment and linkage with care recipients. According to the literature, adult daughters, as careproviders, are known to quit employment or reduce their working hours more often than sons in order to nurse parents with AD. They assume personal tasks that require concentration on the patient’s individual needs (Abel, 1991; Finley, Roberts, and Banahan, 1988; Miller, 1990; Orodonker, 1991; Walker, Pratt, and Eddy, 1995).

Most adult daughters caring for parents with AD are characterized as the middle generation women, in that they find themselves in the middle of emotional competition for attention between the parents they care for and their husbands and children. Also, they are in the middle of conflict values relating to their own sense of responsibility to care for aged and ailing parents and the newer modern value that it is acceptable for women to pursue careers and other activities outside the home (Brody, 1990; Shanas, 1979). In short, as careproviders, adult daughters are faced with multiple roles and the competing demands of employment, home management, and the care of mentally disabled parents.

According to Berman (1996), this feminine phenomenon may be attributed to feminine characteristics, such as the social construction of women as nurturers, closer relationship to the family, and availability of women as caregivers. That females are more predisposed to sensitivity and caring may be the by-product of socialization. A lifelong process, socialization starts during infancy in the complex attitudes, values, behavior, and skills deemed important in the household and outside environments.
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Other variables—friends, churches, schools, and the media—influence the relationship between parents and child. Infants acquire their first interactions with society through parents’ communication by smiling, touching, cooing, and other gestures of approval/disapproval. Family members, such as siblings, grandparents, and other relatives, aid in children’s development; socially valued traits such as generosity and caring are learned within the home and in the culture (Atkinson, 1989).

Mothers are considered socialization agents in the development of their offspring (Carine, 1998; Chodorow, 1990). Maternal influence plays an important role in the socialization of daughters, in that their gender allows extensive interactions and involvement during the formative years that in turn becomes the bond in later years. Traditional gender role attitudes that center on domesticity, motherhood, and caring are passed on to daughters.

Renzetti and Curran (1995) substantiate the socialization hypothesis. The authors argue that children are socialized through gendered programming of values, norms, and behavior beginning “in utero” (p.90), when the gender of the fetus is known. From infancy gender is color-coded: pink for girls and blue for boys. Gender polarization is carried on throughout the growing period in the form of wardrobe, hairdo, bedroom furnishings, and playthings. Girls are dressed in frills, lace, ruffles, and with ribbons in their hair; their bedrooms are strikingly feminine in window dressings and bed accessories; Barbie dominates the scene. Thus, girls develop in surroundings that impede rough activities and aggressiveness, but encourage femininity, domesticity, and maternalism. On the other hand, boys are enculturated by wearing overalls for freedom of movements and three-piece suits for Sunday
dress. Boys’ bedrooms demonstrate military and athletic orientations that suggest assertiveness and independence. Careproviding is gendered oriented and may be traced from the very beginning in the womb and reinforced through the formative years through the process of socialization.

Purpose of the Study

This qualitative, case study explores the life changes that adult daughters go through, as they become primary caregivers to parents ravaged by Alzheimer’s disease. There is a need to achieve an in-depth understanding of beliefs, feelings, and perceptions of adult daughters as they provide care to ailing and dependent parents. Because of limited past research, it is hoped that this study may be a source of encouragement for future research to illuminate the role played by daughters in the world of family care and dementia.

Research Questions

This study addresses the following basic questions:

1. What life changes do adult daughters go through when they become primary caregivers to parents with Alzheimer’s disease?

2. How do adult daughters perceive their role as caregivers to cognitively impaired parents?

3. What are the beliefs and feelings of adult daughters as caregivers to aging and disabled parents?
Significance of the Study

This study is important and timely because there appears to be a lack of qualitative research on the changing life experiences of adult daughters as they provide care to cognitively impaired parents. The caregiving field has an abundance of literature focusing on the strain imposed on the careprovider and carereceiver; however, most research on caregiving has not addressed the subjective experiences of caregivers, which may offer more insights into the personal feelings and understanding of parental care (Berg-Weger, 1996). According to Abel (1991), research depicting the change to careproviding and how females embrace this role has been inadequate. Intergenerational caregiving is multi-faceted and complex. There is a need to understand the inner feelings and working mechanisms of adult daughters. Most are gainfully employed, managing their own households and families, as well as caring for parents with AD. Descriptive narratives on the nature of the caregiving relationships—the interchanges, interrelationships, intercommunication, and interplays—may offer illumination that will aid in the development of more effective and sensitive approaches to planning and providing familial care.

It is hoped that this qualitative case study may present a cutting edge in intergenerational care. The research focuses on the adult daughter as she functions in the role of nonformal careprovider to a mentally challenged parent. A qualitative paradigm seeks an understanding of a phenomenon from the lens of the participants, known as the “emic” or perspectives of subjects (Merriam, 1998, p.6). The study seeks to lift the veil of clouds surrounding
daughters as caregivers, in order to realize their position and how they view the parental world of dementia through their own voice and experience. According to Denzin and Lincoln (2000), qualitative research is an investigation about human experiences in natural settings in order to make sense of and interpret the occurrence through the meanings that participants convey. In the face of the burgeoning population of elderly suffering from AD, there is a strong interest to mirror the personal activities and perspectives of those responsible for the care of AD patients in the home. In the quest for understanding a phenomenon, Stake (1995) argues the importance to unearth the uniqueness of a case in the field of qualitative research, and through observations by researchers and informants, to present, in thick descriptions and narratives, the dilemma central to the study. To arrive at the uniqueness of adult daughters responding to the demands, fatigue, stress, and exhausting long hours of caring for cognitively impaired parents may well be valuable to policymakers, researchers, federal health agencies, professional practitioners, and familial careproviders.

Stake (2000) declares that a case study is a process of inquiry about some situation that may involve people or programs. In addition, the author offers some categories of case study, two of which will be mentioned here. Intrinsic case study refers to an endeavor that is purely motivated by the interest of the researcher on a particular subject. The researcher is disinterested in developing theories or embracing other cases related to the one at hand. Meanwhile, instrumental case study is the examination of an
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issue to gain insight into a situation or produce a generalization. The process requires an in-depth exploration of the case. My intrinsic motivation may be traced to the time I was a volunteer working with a population in the early stages of AD. Seeing first hand the devastation and tragic progression of AD attracted my interest and curiosity. Instrumental case study orientation may be traced to my academic program: adult education with a concentration in gerontology. Most casualties of AD are elderly. That over four million elderly Americans are on the brink of totally losing their mental faculties; that a great number of them will be dependent on their grown children for care, encourages me to try to understand the phenomenon of familial caregiving.

Naumes and Naumes (1999) posit that the objective of a case study is to discover the relationships within a setting. This research is attracted to the world of adult daughters: how the subjects live, feel, and their own construct of their environment. This study wishes to comprehend lived experiences of participants—their actions, interactions, perceptions, developments, and activities—in the hope of sharing the data with those interested in the experience. The case of adult daughters servicing the needs of their parents engulfed in the midst of AD is a phenomenon in itself that warrants understanding and recognition.

This study offers an understanding of the nature and events leading to the development of adult life changes that turn daughters from non-caregivers into the role of primary caregivers to parents with AD. This investigation may be a source to help guide policy, practice, and professional understanding of
familial caregiving, and could provide more data regarding key support to the role of adult daughters as careproviders. In addition, this study will add to the body of research pertaining to the field of intergenerational caregiving by adult daughters to mentally challenged parents.

**Limitations of the Study**

Findings of this qualitative case study will be limited to a set of particular women caring for AD patients. While caregivers may have similar experiences, beliefs, and feelings, this study makes no attempt to generalize beyond this group. Nevertheless, this study will contribute qualitatively to what is currently known about women who care for their parents, and the struggles and adjustments they go through in the process. Research points out that family members who seek help differ from other caregivers (Berman, 1996). Participants were recruited from Alzheimer’s support groups, area agencies on aging, department of social services, nursing and hospice facilities, training and workshop seminars, and Alzheimer’s organizations in eastern North Carolina.
Chapter II

Literature Review

The advancing age of the baby boomers brings the issue of intergenerational caregiving to new heights (Day, 1996). This subject, however, remains complex and perplexing in spite of the profusion of literature in the field of gerontology, psychology, sociology, nursing, and health related disciplines. Researchers and practitioners strive to define, identify, and clarify the phenomenon that is known as caregiving and its relationship to Alzheimer’s disease. The world of caregiving needs to be explored and examined more, if only to better inform and prepare those who end up carrying the burden of family care.

This chapter highlights some of the literature pertaining to familial caregiving and looks at the nature of intergenerational care, the hierarchy of careproviders, as well as the dominance of women, most especially daughters, in nursing demented parents. Role theory and socialization are reviewed and applied to the development of adult daughters into the role of primary caregivers.

Family Caregiving

The rapidly increasing elderly population and the high incidence of senile dementia in the form of Alzheimer’s disease have highlighted the prominent role played by family members as careproviders. Historically, the elderly are known to seek family members for help in time of need (Berman, 1996; Biegel and Blum, 1990; Shanas, 1979). The literature provides
extensive coverage on family members as the leading source of human service care for ailing elderly relatives. Unexpectedly, familial care is complex in nature and poses implications in intergenerational relationships. For instance, some researchers lament the lack of a precise definition for caregiving in the literature. Although Walker et al. (1995) conceptualize that family careproviding is when one or more family members provide help or assistance to other family members beyond that required of normal everyday life, the authors, nevertheless, present a challenge to other researchers and professionals to arrive at a clear language. This perplexity may be traced to the history and nature of the relationship between the caregiver and the carereceiver. In the hierarchy of careproviders, female spouses are followed by adult daughters, who are faced by multiple responsibilities of caring for the young (their own children) and the old (their aging parents). For this reason, these adult daughters are labeled as the “patron”, “keystone”, and “sandwich” within the context of informal care (Brody, 1990, p.33).

The nature of help provided by family members differs sharply based on gender and generation. Husbands providing care to family members tend to amplify more the care they dispense than wives do (Walker et al., 1995). On the one hand, husbands/careproviders perceive tasks that are not ordinary for them or that are not part of their normal areas of responsibilities as caregiving. On the other hand, wives and/or mothers who routinely perform such chores as laundry, cooking and house cleaning consider such tasks as not in the sphere of caregiving; whereas, husbands engaged in household activities in
the absence of female relatives incorporate them as a part of careproviding. In addition, daughters tend to differentiate the chores they perform in their own households from those that they do in the homes of their parents. For example, house cleaning is considered a task for wives in their own homes, but having to do so in another household is categorized as caregiving. Thus, caregiving perceptions may vary by gender and relationship. In the face of these anomalies, Walker et al., (1995) suggest that caregiving should be distinguished from other aid exchange.

The world of informal caregiving is dominated by women who provide personal hygiene care and household tasks to the feeble elderly (Stone, Cafferata, and Sangle, 1987; Zgola, 1999). The dependency of older Americans suffering from mental illness continues to fall on the shoulders of women in the family. Seventy-two percent of careproviders are women, and even when employed, women carry an uneven share of the caregiving responsibilities. Men tend to reduce their amount of caregiving, whereas women do not (Neal, Chapman, Ingersoll-Dayton, and Emlen, 1993).

Studies on how adult daughters became caregivers to elderly parents suffering from mental illness indicate the emergence of categories such as (a) requests by family members, (b) the absence of other alternatives or resources, (c) family position/structure, (d) duty and/or obligation to provide care. Further, the assumption of adult daughters into the role of caregivers may be linked to (a) love and feelings of family ties, (b) women’s social identity that is built-in with caring, (c) the absence of appropriate public or private care,
and (d) women’s socioeconomic dependency (Berg-Weger, 1996; Guberman, Maheu, and Maille, 1992; Nolan, 1996).

Other aspects of caregiving by adult daughters are traced to stress and strain. In the literature, there is a rich collection of studies covering stress and burden on the part of adult daughters/caregivers. One study claims, “that the reason the caregiver was selected into the role may be related to the strain perceived by the caregiver” (Berg-Weger, 1996, p.97). An examination exploring the consequence(s) of stress in careproviding insinuates that the majority of daughters/caregivers were reluctant to perceive their caregiving efforts in terms of stress. This attitude heightens the complex web of emotions that are inherent components of our humanity, as well as integral parts of familial nursing.

This limited review of literature in the arena of informal caregiving intensifies a need for additional empirical examination of the development of adult daughters into caregivers and the need to capture their experiences within the context of voice and personal feelings.

In summary, there is a need for a clear-cut definition of caregiving. Because of the personal and intimate relationships involved between caregivers and carereceivers, caregiving perceptions may vary by sex and generation. Caregiving tasks and caregiving aids are viewed differently by family caregivers. Women are the dominant role players in nonformal care. Working women are known to reduce their hours or quit altogether in order to assume fulltime caregiving (Biegel and Blum, 1990). Imposition by family
members, and a strong caregiving sense of filial duty thrust women into the arena of familial care. The predominance of women in family caregiving may be rooted to women’s caring nature, as well as their socioeconomic dependency. The absence of alternative public or private care has an influence on family care (Kahana and Young, 1990).

Progress in Alzheimer’s Disease

Alzheimer’s disease has a far-reaching impact on our health care system, on the victims, families, and society in general. Extended life expectancy translates to increased population with AD. In terms of expenditures, AD ranks third after heart disease and cancer. The economics of the disease is staggering. The annual cost of care for one individual with mild AD is $18,000; for a victim with moderate AD $30,000; and a patient with severe AD $36,000. The yearly cost of AD care in the United States is $100 billion (National Institute on Aging, NIA, 2000). The volume of statistics ranks AD in the category of urgent-research priority. Although a cure is still to be found, numerous research and studies funded by federal and private sectors have produced encouraging results as far as diagnosis and prevention are concerned.

The latest progress report of the NIA relative to AD includes scores of research studies that have been made to improve early diagnosis and to develop drug treatments of the disease. Harvard and Massachusetts General Hospital conducted a study involving memory, language, and other neuropsychological factors in order to predict better progression of the
disease. The investigators used a Clinical Dementia Rating (CDR) to determine which individuals with questionable AD had a high possibility of switching to AD diagnosis over time. The “CDR is a semi-structured clinical interview that stages AD from 0 (normal) to 0.5 (questionable), 1.0 (mild), 2.0 (moderate), and 3.0 (severe); based on an assessment of categories of functions (memory, orientation, judgment, problem solving, community affairs, home and hobbies, and personal care" (NIA, p.31). The investigation showed that the possibility of acquiring AD was strongly related to the sums of the individual scores in each category. For instance, more than 50 percent of the participants with a total score of 2.0 or higher at baseline developed AD during the three-year follow-up. Approximately 10 percent of subjects with a score of 1.0 or lower developed AD during the same period. Thus, higher scores from the CDR examination were indicative of progression from questionable AD to acquiring the disease.

A study conducted at New York University School of Medicine investigated whether initial scores on multiple neuropsychological examinations of healthy elderly could identify progression of AD over a span of four years. The results indicated that those who successfully passed a paragraph delayed recall test did not develop Alzheimer’s disease (NIA, 2000).

Dr. David Snowdon, of the University of Kentucky, has been studying 678 aging religious sisters and Alzheimer’s since 1986 (Lemonick & Mankato, 2001). Upon their death the sisters willed their brain to Dr.
Snowdon’s research. This sample has the advantage of fewer differences in lifestyle to confuse the data. Because the nuns belonged to a religious order, the study has the benefit of uniform economic status, health care, and living conditions. Aided by excellent archives belonging to the convent, Dr. Snowdon analyzed the autobiographical essay of each sister when she joined the order. The records contained information pertaining to place of birth, parentage and siblings, and reasons for joining the convent. These data were used as an objective measure of cognitive abilities of the young nuns and the connection to late-life health, functions, and cognition. In addition, other Alzheimer’s studies have shown that the physical destruction wrought by Alzheimer’s didn’t inevitably lead to mental deterioration. The reason, according to one leading theory, was that some individuals might have an extra reserve of mental capacity that kept them functioning despite the loss of brain tissue. Based on this concept, the Nun Study, as the research has been known, reviewed the autobiographies of the sisters, with an eye on that extra mental reserve and language usage. The researchers devised a tool called idea density, which is the number of discrete ideas per 10 written words. Idea density was a good measuring stick for educational attainment, vocabulary, and general information; grammatical complexity was a benchmark of how well memory functioned. Dr. Snowdon’s team of scientists found that the aging nuns who demonstrated signs of AD were those whose writings were low in idea density and grammatical complexity. In short, the number of ideas
expressed in their sentences was a strong indicator of who would develop AD 60 years later.

The Institute (NIA, 2000) continues that the effort to develop drug treatments applicable to the different stages of AD has concentrated on treatments for “short-term maintenance of cognitive functions in patients with AD, treatments to slow the progress of the disease, delay its onset, or prevent it, and treatment for AD associated behavioral problems” (p.31). The Food and Drug Administration (FDA) approved three drugs: Aricept, Cognex, and Excelon. These agents do not change the course of Alzheimer’s disease; however, they “slow down the metabolic breakdown of acetylcholine” (p.33). Acetylcholine is important in the formation of memories and is used commonly by neurons in the hippocampus and cerebral cortex, which are the areas in the brain destroyed by Alzheimer’s disease. Scientists believe that estrogen, anti-inflammatory agents, antioxidants, and nerve growth factors may delay the onset of AD, slow its progression, or prevent it. Agitation, aggression, wandering, and sleep disorders are the common behavioral symptoms of AD (Schulz and Williamson, 1993). Physicians are now treating these behavioral problems with anti-depressants, anti-psychotic drugs, and sedatives. However, the search for better treatments that also include non-drug strategies for AD patients continues at a rapid pace.

Memantine is a new drug that may curtail the progress of Alzheimer's disease in advanced stage. ("Drug offers hope," 2003). Most Alzheimer's drugs currently in the market work only in the early stages of the disease.
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Used in treating brain disorders, Memantine has been available in Germany for two decades, and American families are hoping the federal government would approve its use. Although it is not a wonder drug in the treatment of Alzheimer's, Memantine delays deterioration that gives patients more precious time to live independently.

The Food and Drug Administration approved, on October 17, 2003, the use of the drug Memantine in the United States ("FDA Approves," 2003). Distributed by Forest Laboratories under contract with Merz Pharmaceutical, the German manufacturer, Memantine will be available in January 2004 under the brand name Namenda. Families of Alzheimer's victims have been buying it through the Internet and by importation from Europe for prices ranging from $147 to $240 a month. Forest Laboratories did not indicate if it would market Namenda within that price range.

Many families in the United States have been demanding the availability of the drug since word of mouth praising the effects of Memantine has been circulating. The FDA cautioned families against miraculous expectations from Namenda. It is not a cure to Alzheimer's disease but Namenda slows down the worsening of AD to the point of allowing patients to perform some routine functions, such as going to the bathroom and dressing by themselves for a few months longer. As mundane as these improvements may sound, they are significant in stress reduction for AD caregivers.

According to studies conducted at the New York University School of Medicine and Indiana University-Indianapolis (NIA, 2000), Memantine has
been found to slow down the deterioration of the mind-robbing malady in advanced cases of AD. Memantime blocks excess amounts of a brain chemical called glutamate that can damage brain cells. AD patients possess abnormally elevated levels of glutamate. AD patients in the research showed marked improvement in their memory and thinking ability.

A study conducted by the University of California-San Francisco reports that cholinesterase inhibitors drugs might improve behavioral problems as well as the ability to perform everyday functions ("Alzheimer's memory drugs," 2003). The study was based on culled data from published experiments involving cholinesterase inhibitors. The results showed that the drugs could help tone down aggressive behavior of patients with mild to moderate dementia. Hostile and violent behavior on the part of AD patients triggers the decision to commit them to nursing homes. Another result indicated that cholinesterase inhibitors could improve memory, and facilitate patients to perform routine tasks such as balancing a checkbook, speaking on the telephone and getting dressed. Although the drugs are approved by the Food and Drug Administration, the cholinesterase inhibitors are not widely prescribed due to minimum memory improvement in many patients.

A study at the University of California-Los Angeles ("UCLA researchers," 2002), reports the discovery of a test to detect the onset of AD. Applicable to a select patient population, the test is a noninvasive examination that includes PET (Positron Emission Tomography) scan and the injection of a chemical traces that identify the brain lesions linked to AD. The study allows
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improved diagnosis that could lead to aggressive and more effective treatment.

A research study involving 5,000 residents of Cache County, Utah, (“Study: long-term aspirin use,” 2002) was conducted to determine the symptoms of AD. The participants, 65 years old and over, were questioned about their former and current use of anti-inflammatory drugs, aspirin compounds or histamine-receptor antagonists like cimetidine and ranitidine. Results indicated that the participants with the longest history of regularly taking the medication (two years or more before the study) did not show symptoms of AD.

Columbia University (“Study: High-fat," 2002) asked 980 Medicare patients with a mean age of 75 to recall their food intake during the first year of the four-year study. The results indicated that diet may play a part in the disease. The study found that most people who consumed the most calories and fat faced double the risk of developing Alzheimer’s. A high diet in calories and fat may increase the risk of Alzheimer’s disease in individuals who are genetically susceptible to AD. Reduction in caloric intake might lower Alzheimer’s risk by curtailing nerve-cell death in the brain. The findings suggested that cholesterol-lowering drugs could reduce the risk of AD.

French and American scientists have mapped chromosome 14 as the location of 60 disease genes, including one linked to Alzheimer's ("Find," 2003). The study reported that scientists have discovered 1,050 genes and
gene fragments that include genes associated with AD. Although the results of the study are significant, they do not represent a cure to Alzheimer's disease. However, scientists hope that this discovery might lead to new avenues in finding the cure for this disease that affect millions of Americans.

**Background and Nature of Role Theory**

The concept of role theory is highly effective in the understanding of the inner experiences of adult daughters as caregivers to the mentally ill. A process of role change occurs as adult daughters assume the care of cognitively disabled parents. In addition, role theory is a vehicle that may illuminate the subjective enterprise relative to the nature of multiple roles that are inherently associated with adult daughters as caregivers. The concept of role theory goes back to when William Shakespeare modeled the characters of his plays after human behavior and attributes. In recent times, however, role theory has been expanded in depth and is widely applied to studies of small groups, families, communities, kinship systems, and informal organizations. The analogy involved between drama characterizations and role theory is the expression of perspectives of human behaviors; players on stage deliver performance based on scripted characterizations. Role players in real life based their delivery on the expectations and demands attached to the role (Biddle and Thomas, 1966).
Perspectives of Roles

Structural perspective on status and role. The concept of status and role is used to identify positions in the social structure, as well as the behavioral expectations linked to those positions. A status is a position within the social structure; i.e., parents, for instance. Role is the behavioral counterpart of a position, an example of which is caring for children. Use of the concept allows the identification of various statuses and the description of behavioral rights and duties associated with them. Achieved status refers to those statuses that people occupy as a result of their own efforts, drive, and ability; occupational status is an example. Ascribed status is socially designated without consideration to efforts or desires of individuals; examples are gender, race, and ethnic memberships (Biddle, 1979).

Interactionist perspectives on status and role. Status and role are structural and objective. Interactionist perspectives stress individual interpretations of social structure and the ability to affect it (social structure), as well as react to its demands. Interactionists argue that the individual relates to the social structure through interpretation and social interaction. Even though social structures provide the context for behavior, people define their relationships to the social structure and help to shape and modify that structure. This perspective allows us to understand the dimensions of social roles, such as when people voluntarily and intentionally choose statuses and the roles they perform, or when roles have wide and flexible sets of behavioral
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expectations, and when individuals conceive informal roles that are compatible with their personal preferences and tastes (Biddle, 1979).

**Socialization**

Socialization refers to the process by which individuals acquire the knowledge, skills, and disposition that enable them to participate as more or less effective members of groups and society (Goslin, 1969). The roots of socialization may be found in the disciplines of anthropology, psychology, and sociology. Each field has its own orientation that at times may appear to be divergent. On the one hand, anthropologists tend to view socialization from the standpoint of the broader culture that helps determine the overall parameters of socialization experiences. On the other hand, psychologists focus on the development of individual characteristics relevant to the social behavior as well as on the basic processes through which these behavioral tendencies are learned (Goslin, 1969.) Meanwhile, sociologists center their approach on characteristics of specific groups or institutions in which socialization occurs and on the common social skills acquired by individuals in varying contexts. Sociologists suggest that individuals are trained or socialized into roles that define caregiving as women’s responsibility. Within the context of socialization, role differentiation is offered in support of the notion that caregiving falls in the confines of womanhood. This argument is buttressed by Walker et al. (1995) with their concept of Instrumental Activities of Daily Living (IADL), which pertains to household tasks–house cleaning, laundry, and meal preparation–mostly performed by females. In addition, complementary instrumental and expressive tasks differentiate the
role of women from that of men. There is a common perception that males are perceived to be breadwinners and mediators for the family and with social agencies. Caregiving literature informs that women are known to take care of the socioemotional needs of family members.

The social role of adult daughters caring for mentally ill parents may be linked to the earlier relationship that was forged between a parent and a child. This early foundation dates back to infancy. Individuals remember the unique intimacy they shared as infant with their mothers and are inclined to imitate it. This unique intimacy is further reinforced by life experiences that are unexpected, traumatic, and, at times, pleasant and detrimental. The intensity and endurance of such a relationship is manifest into the later years of both children and parents, in that the bond between parents and child is abiding (Dwyer and Coward, 1992; Goslin, 1969; Mancini, 1989). In addition, Aronson (1988) argues that women have been socialized to be expressive, caring, and responsive to the needs of others; women have been raised to feel responsible for and sensitive to the well being of others. Such social bonding is demonstrated in the form of intergenerational caregiving. In short, female children usually develop strong maternal instincts resulting from childhood experiences with their mothers. The saying that “mothers beget mothers who beget mothers” is most applicable to this scenario.

In the context of socialization and caregiving, Finely et al., (1989) conducted a research involving 1,760 adult children with older parents or parents-in-law. The researcher investigated why females were more likely to
be involved in caregiving than males. Finley’s study is significant because she was trying to understand if there was a significant difference in the level of the caregiving enterprise between men and women based on available time, gender, external resources, or task specialization. Finley’s far reaching results disclose that time available, sense of obligation, and external resources do not appear to have any difference in the parental care provided by male and female children. The data reveals that the direct relationship between gender and caregiving remains crucial. Women are more prone to role conflict than men, who are less likely to act on the issues. The degree of filial obligation between male and female adult children is similar. Men fall short in certain task specialization, whereas females are more likely than males to provide help in all categories of tasks. Gender is statistically significant in the tasks of daily living and emotional assistance. Thus, Finley’s data accentuates that gender in intergenerational care is considered an institution in United States society. Caregiving appears to be the province of females; the literature has ample documentation in support of this concept. For instance, Hooyman and Goonyea (1995) report that the hierarchy of intergenerational care consists of spouses, daughters, sisters, and nieces over sons, brothers, and nephews.

The family is the dominant force in long-term care in the United States, and women are mostly responsible for many mentally handicapped elderly remaining in the home, rather than being placed in institutions. A survey of 1,168 caregivers to elderly relatives shows 41 percent, or 479, of the careproviders are daughters (Orodonker, 1991). Not unexpectedly, daughters
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are more likely to perform tasks that are considered Activities of Daily Living (ADL), and Instrumental Activities of Daily Living (IADL). Grooming, hygiene, eating, and bed or chair transfer are tasks under the ADL category; while meal preparation, house cleaning, and laundry are considered IADL. Even though there has been a dramatic increase in women’s participation in the labor force, there has not been a decrease in the number of females providing family nursing (Orodonker, 1991).

Role and status are used synonymously to indicate a station in the social system that has its own sets of rights and responsibilities. As mentioned earlier, achieved status is arrived at through ambition, motivation, and the industry of an individual; an example of such is one’s employment position in an organization or ranking in a social establishment. To amplify, ascribed status is a social designation that comes through the accident of birth; i.e., the ethnicity of a person. As an interactionist, the individual’s social relationship within the structure is based on his/her role interpretation. In general, individuals are selected in the role they assume. Behavioral expectations are associated in the performance of a role. Sociologists argue that socialization represents the totality of one’s experiences that influence a person’s outlook, attitudes, and values in life, which makes possible the acquisition of roles. The common assumption is that women and caregiving are intertwined based on social relationships founded in infancy and early childhood. Female children derive their maternalistic traits from their mothers as a result of the social
bond between them that is carried over in the form of intergenerational careproviding.

In conclusion, the increase in life expectancy and its close link to Alzheimer’s disease, as well as the longer life span of women pushes the issue of intergenerational care at front and center of mainstream America. In spite of extensive literature available in the field, familial caregiving and Alzheimer’s disease, however, require further examination and exploration in order to clarify the definition of their interconnectedness. This phenomenon may be traced to the complex nature of alliance between the recipient of care and the dispenser of services. Females, especially daughters, are at the forefront of the expanding army of family caregivers. Caregiving is known to be gender related and a by-product of socialization. Role theory is congruent to the concept of socialization in the transition of females from daughters to primary providers of care to cognitively impaired parents. Although not without discord, the nurturing nature of women is a corollary to the role of careproviders to demented relatives. This characteristic is nourished and cultivated from the earliest time, as in the bonding of daughters to their mothers. Socialization, which is the acquisition of one’s distinct quality, serves as the vehicle that ferries women to the world of caregiving, and assumes the role expected of them.

The perception that women are nurturing by nature may account for their majority in familial caregiving. This feminine attribute is delineated to women’s developmental process. Women’s response to the expectations and
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demands of caregiving is placed to fit within the limits of role and socialization theories. The literature on informal caregiving needs more elucidation on how women assume the transition to careproviders within the family structure and how women see and feel about the role of primary caregivers to parents with Alzheimer’s disease. There is a need in the literature to hear the voices of women as they struggle to meet the demanding challenges of family caregiving. Guided by the framework of role and socialization theories, it is hoped that this research may offer some light and add knowledge to the body of works addressing the issue of women as informal caregivers to frail and mentally handicapped parents.

Theoretical Framework

This qualitative case study research is guided by role and socialization theories as advocated by Biddle (1979) and Goslin (1969). The phenomenon of adult daughters/careproviders is linked to role and socialization theories due to the relevance of patterned human behaviors or roles, their associated properties, and the social and cultural dynamics of the family structure. Individuals in a given society perceive their role according to information transmitted through successive generations. Within this context, role theory is being applied to the social situation of adult daughters as the primary careproviers to parents with Alzheimer’s disease. Biddle (1979) refers to behavioral linkage that is congruent to this study; i.e., two behaviors are said to be linked if the performance of the first (the carereceiver) affects the probability of the performance of the second (the caregiver).
Upon assuming her caregiving status, the adult daughter faces alterations in the role, identity, and expectations surrounding her status. Based on the behavior of the AD patient, the new role of caregiver requires that she consider herself not as a child relative to the parent, but as a form of authority exercising control over parents. Providing care for a mentally disabled parent requires re-configuration of roles, in that the adult daughter/caregiver needs to view her parent as separate from herself and comprehend the reality of her emerging and new persona.

Sociologists argue that individuals are trained or socialized into roles that define caregiving as women’s responsibility, and those women are nurturing in their social ties as a result of socialization. Socialization proposes that female caregivers weigh potential outcomes of the care recipient in their choice of caregiving behavior, in that they anticipate the effect of their caring on the carereceiver (Dwyer and Coward, 1992; Walker and Allen, 1991. Goslin’s (1969) theory of socialization is being applied to demonstrate that socialization results in the gendered nature of care.

Role Theory

Biddle (1979) states that role theory is a science concerned with the study of behaviors that are characteristics of persons within context and with various processes that presumably produce, explain, or are affected by those behaviors. Individuals are conceptualized by the phenomenon of human behaviors and role. Thus, most roles are performed by people and are constrained by our concepts, as well as by the behaviors we observe.
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**Identity.** Identity is akin to labeling, or to put it another way, a symbol that is used to indicate one or more individuals. Usually it is associated with attitudes, motives, and expectations applicable to behaviors of those so designated or of others towards them. As an example, identities may apply to sets of persons; i.e., radicals, left/right wingers, hawks and doves.

**Social position or statuses.** Status refers to a position in the general institutional system, recognized and supported by the entire society. Rights and duties accompany a status. As mentioned before, ascribed status is obtained independent of personal attributes, as in race, gender, and kinship. Achievement status is reached through individual accomplishments, as those who have been successful in economics and politics. Social position may also describe a set of persons sharing common attributes or treated similarly by others.

**Contexts.** Role behaviors are contextually bound by the definition of the situation. A context pertains to any condition or state of affairs that is found to affect behavior; it may also involve time or a complement of persons or position members. The American Heritage Dictionary (1991) refers to context as “the circumstances in which a particular event occurs, a situation” (p. 316).

**Expectations.** They are a standard held for the behavior of a person, or a concept held about a behavior likely to be exhibited by an individual. Other descriptors of expectation are anticipation, norm, or attitude.
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**Functions.** Linked with roles, functions refer to any condition or state of affairs that results from behavior. Stated another way, behavior may be observed to have objective effects or functions. It should be noted that functions do not mean goals or tasks, as they are relevant with roles, activities, and social system. As an example, in football, patterns of behavior are manifested in the form of “plays” for the offensive team, which are only broken when a team member neglects to discharge his or her role or some members of the opposite team cut into the system.

**Socialization Theory**

From a sociological orientation, socialization is the sum total of past experiences a person has had, which may be expected to play some role in shaping his or her future social behavior. It is a process where individuals acquire personal system attributes—attitudes, values, needs, motivation, cognitive, and affective patterns—which mold their adjustment to the physical and sociocultural settings in which they live. This process assists individuals to make role changes and transitions smoothly. Socialization evolves through the life span and is influenced by issues that are properties of each life cycle. In addition, the outcome of the socialization process is tailored by the regular channels of social interaction in the setting.

As a synthesis, caregiving is defined as a role within the broad umbrella of role theory. Family caregiving is perceived as a specific position or a role in society with built-in patterns of behavior and attitudinal expectations from family members, specifically, and society in general.
Intergenerational caregiving is a role transformation spawned by an event, such as the incipience of a family member’s malady (Suitor and Pillemer, 1990). The assumption to this role transforms the adult daughter from a non-caregiver to the role of principal caregiver, and allows her to enter a new world of relationships with her mentally disabled parent. Her new environment changes her social horizon as she takes on a new status, identity, and a role expected of her by virtues of gender, emotional make-up, history of caring, and mainstream beliefs and attitudes.
Chapter III
Research Design And Methodology

This chapter will discuss the design and paradigm employed in the study, as well as recruitment of subjects, sampling procedure, data collection, analysis strategy, and ethics involved in the investigation.

Qualitative Case Study

A qualitative case study was used in this investigation to probe the "particularity and complexity of a single case", in this instance that of adult daughters as keepers of ill relatives (Stake, 1995, p.xi). A case study involves the concentration of interest upon a particular object or person so as to understand the uniqueness of the situation of such thing or person. The objective is to comprehend how the individuals in the study view their world based on occurrences or events in their lives. Qualitative research is a form of investigation that desires to understand and to describe certain happenings to certain things or people in their natural settings (Lecompte and Preissle, 1993). Unlike quantitative research, this method of inquiry does not make use of frequency tables, means, standard deviations, variances and other statistical tools of measurements.

Merriam (1998) posits that a "qualitative case study is an intensive, holistic description and analysis of a single instance, phenomenon, or social unit" (p.27). Qualitative case research seeks to hear the experiences of a certain population from their own perspectives. This study wanted to capture the feelings, reflections, and viewpoints of daughters/careproviders.
Qualitative inquiry allows the acquisition of human expressions in their milieu that will in turn aid in the comprehension of a population that is proliferating rapidly; i.e., familial caregivers. Subjects are portrayed against the backdrop of realism that is life.

Qualitative methodology facilitates visual images and clear definition of voices that are captured in taped interviews. This research was interested in understanding the lived experiences of adult daughters in intergenerational care.

Sample Recruitment

Subjects for this investigation were culled through Alzheimer’s support groups and associations, workshops/seminars, councils on aging, nursing homes and hospice facilities, and the Alzheimer’s Association in Eastern North Carolina. In addition, several were respondents to recruitment flyers posted in hospitals, churches, and malls. Some participants were obtained through advertisements placed in area newspapers. A portion of the sample was obtained by word of mouth among friends and acquaintances. A simple criterion-based selection was used to identify participants for the study. Individuals were daughters of parents who have/have had AD and provided care for a minimum of six months. A part of the criteria was that adult daughters were the primary caregivers to parents suffering from Alzheimer’s. A primary caregiver was defined as a daughter who was also the legal guardian of the AD patient. This research was conducted in accordance with the guidelines, policies, and protocols as set forth by the Institutional Review Board.
Board for the Use of Human Subjects in Research at North Carolina State University.

**Sampling Procedure**

Initially, potential subjects were interviewed by telephone in order to clarify their qualification to join the study. The research interviews were conducted mostly in a private room in county libraries; others took place in the privacy of subjects’ homes as requested by respondents. Some were conducted in public facilities or private offices. Subjects were advised of the confidential nature of their participation, and the protection of their confidentiality. Each participant was informed verbally and through written documentation about possible questions (about herself and other members of her family) that would be asked in the interview(s). The length of the interview ranged from an hour and 30 minutes, or longer; a follow-up interview was possible. Based on interviews, some of the participants were contacted again for clarification on some issues. Subjects’ permission was acquired for tape recording the interviews with the understanding that such tapes would be destroyed at the completion of the study. Participants demonstrated their willingness to join the investigation by signing and dating the consent form, Appendix A. The consent form indicates the nature of the research, as well as names of individuals and their telephone numbers at North Carolina State University in the event participants may have concerns or questions.
The subjects were informed of the possible risks and benefits involved through participation. The risk may appear in the form of personal discomfort and emotional expression of anger, sorrow, or distress. The world of family caregiving may be filled with sensitive and emotional concerns that may have been repressed in the “back burner” of the mind. Under the umbrella of confidentiality protection, daughters/caregivers may seize the moment to release bottled up feelings and emotions. This is beneficial in that concerns, problems, and/or pressure could be addressed, identified, and properly directed for therapy or treatment. Furthermore, subjects may feel better after verbalizing with the researcher, secure in the knowledge that the conversation would remain confidential. Subjects could withdraw from the interview at any time without repercussions. Participants in this study did not receive any kind of remuneration.

Data Collection

Twenty-one (21) adult daughters were interviewed face-to-face and one-on-one basis. Two daughters-in-law participated in the study as well. Although adult daughters/providers were the sample of this investigation, this writer included findings concerning daughters-in-law in an effort to show parallelism that exists in the care of family members struck with AD. Data were collected using participants' observations and in-depth interviewing. The semi-structured interviews were based on a predetermined set of questions, Appendix B. The interview sessions were tape recorded and transcribed on an ongoing basis by this researcher. For the record, each participant was
identified by a number code. Names and other identifying data were changed
to protect the confidentiality of participants. The audiotapes will be destroyed
at the completion of the study. Demographic data gleaned from each subject
included age of caregiver, age of care receiver, marital status, children under
18, employment status, length of caregiving, hierarchical position in the
family of caregiver, and religious orientation.

Participants' Observation

This method of data gathering, which is an essential component of
qualitative research, requires first hand involvement in the social community
selected for the investigation. As a qualitative researcher, this writer used all
her senses acutely in order to capture the sights, sounds, and smells
permeating the natural setting. This researcher was alert to variables relating
to age, gender, social class, and ethnicity. This writer paid closer attention to
body language, gestures and voice of interviewees. Eye contact between
interviewer and interviewee was constantly practiced.

This writer's volunteerism with a council on aging was a source of
advantage to the study in that rapport was established with some potential
subjects. In addition, as a faithful attendee to the monthly AD support group
meeting, as well as attendance in several AD caregivers' seminars in eastern
North Carolina, this writer gained more familiarity and experience in the art of
participant observation. Creswell (1998) posits that participant observation
"offers possibilities for the researcher on a continuum from being a complete
outsider to being a complete insider" (p.123). In this connection, this writer
employed participant observation as one of the tools in the acquisition of data that may be imbedded in the emotions and passion of intergenerational caregiving.

This writer observed that participants in support group meetings developed camaraderie that allowed individuals to be more vocal about their feelings relative to their caregiving role. For instance during meetings, an adult daughter would not hesitate to express aggravation, frustration, and hostility toward her ward. This transparency was not observed in interview sessions. The writer participated by listening to discussions, requesting clarifications, and asking questions concerning issues on the table.

In-depth Interviewing

"Interviewing is a meeting of two persons to exchange information and ideas through questions and responses, resulting in communication and joint construction of meaning about a particular topic" (Janesick, 1998, p.30). An interview not only brings together different persons and personalities, it is also a conversation with a purpose (Glesne, 1999). Interviewing is a vehicle to gain rich and detailed information about attitudes, beliefs, and understanding of participants’ settings. This approach was most applicable in obtaining an individual’s lived experience, as well as capturing the deep meaning of their world in the words of participants. This writer felt that interviewing was the most appropriate strategy in this case study, inasmuch as the focus of the investigation was the societal group of adult daughters and their caregiving efforts. However, the interview process may pose its own limitations. As a
data collection tool, it relies heavily on human interactions (Creswell, 1998). Because of human factors, interviewees may prove to be unresponsive or uncomfortable about sharing some of their lived experiences to someone whom they perceived to be a stranger. To generate rich data from the participants, interviewers should be equipped with the ability to be a good listener, to demonstrate a genuine interest in the subject, and to probe in a calm and placid manner for elaboration. This researcher tried to practice these skills in her interviewing.

Field Notes

Field notes are the "systematic noting and recording of events" (Marshall and Rossman, 1999, p.197). This writer engaged in field note taking during encounters with the subjects and during the actual interviews in order to capture the emotions and sentiments of the hour. Glesne (1999) advocates field notes as a source of "descriptions of people, places, events, activities and conversation" (p.49). This writer's field notes were a source of information that mirrored the venue and scenery of the discussions, as well as the feelings, reactions, and emotions of the participants. Field notes also served as a reminder to communicate with some participants that needed more compassion in their silent struggle as primary careproviders to parents with dementia. This writer communicated with adult daughters as a follow-up and to express concern about their caregiving situation.
Coding

Coding is the process of sorting and defining data obtained through observation notes, interview transcripts, memos, artifacts, documents and other materials relevant to the study (Glesne, 1999). A code is shorthand in representing a collection of words used in sentences or paragraphs of field notes. Codes facilitate retrieval and organization that afford the researcher greater visibility to spot, draw, and group information by concept or themes (Miles and Huberman, 1984). For the sake of efficiency and organization, this writer employed coding methodology on the transcripts and memos. Bogdan and Biklen (1998) offer some coding typology that the writer used in the management of research information:

1) Setting or context codes referred to material, information, comments made by the interviewee alluding to setting, topic, or subject. Included in this classification were descriptive statistics and quantitative data.

2) Perspectives held by subjects were observations, opinions, points of view and conclusion of the participants, using particular phrases or verbiage. An example of this is the statement: "You think that you got your life all figured out."

3) Subjects' ways of thinking about people and objects. In the world of the subjects, they tended to affix labels and descriptive identifications about personalities and objects that were a part of their environment. As an example a subject may describe her ward as a "difficult person."
4) Activity codes referred to pieces of data that pertained to regularly occurring type of action, as in the regularly scheduled intake of numerous medications by the AD patients.

**Memos**

Memos were personal notes of the writer that served numerous purposes. For instance, this writer wrote herself a memo that pertained to some questions that needed to be clarified about some statements on the tape. Some of these questions were about dates that were needed for the accuracy of the study; others referred to chronology of events, locations, and clarification as to the intent of statements. At times due to the emotional state of participants, the writer did not press for further amplification, but instead made a memo entry and plan to re-contact participants involved.

**Data Analysis**

Data analysis "involves organizing what you have seen, heard, and read so that you can make sense of what you have learned" (Glesne, 1999, p.30). It is "the process of systematically searching and arranging the interview transcripts, field notes, and other materials that you accumulate to increase your own understanding of them, and to enable you to present what you have discovered of others" (Bogden and Biklen, 1998, p.157). Narrative analysis was applied to examine the data collected. Through narrative analysis, this study sought to obtain a picture of daughters/providers as they traversed and navigated their way through the undercurrents of careproviding. The transcripts were scrutinized and analyzed for clues to better understanding
Life changes of adult daughters

of the sample’s make-up: language, intonations, and silences, nodding of the head, and extemporaneous expressions or statements. This strategy used in the management of data appeared to fit in the schema of adult daughters and the confines of familial nursing as well. This system complemented the data collection process used in the study, which was semi-structured, in-depth interview. What better way to access the world of adult careproviders than to hear their stories first hand, where "every utterance, even repetition and noises" was considered as a component of the data to be evaluated (Merriam, 1998, p.157). Narrative analysis offered the opportunity to glean the population's construction of their realities, which may have provided answers to the research questions. Qualitative researchers refer to thick description, experiential understanding, and multiple realities in the production of studies. In 1973 Clifford Geertz coined the term "thick description" (Stake, 1995). Since then it has become a part of qualitative research's dictionary. Thick description refers to the direct viewpoint of participants as they verbalize their emic conditions. Experiential understanding is the knowledge gained about the population and locales through direct interactions with the main players, in this case the adult daughters/caregivers. Multiple realities are the various perceptions of individuals that were based on their own experiences.

Interpretation of events and situations is an important facet of narrative analysis. It is imperative to achieve balance in the presentation of interpretations. This investigator is the sole source of data collection and analysis. Over simplification or embellishment of condition(s) could result in
inaccurate conclusions on the part of readers. Readers may assume that the study represents the whole life situation, when in truth it is just a part of the whole. Marshall and Rossman (1999) caution against a pitfall associated with narrative analysis. The authors argue that reliance on participants' recitation of lived experiences may result in selective recall or modified interpretation.

**Ethics**

Ethics refer to the rules or standards governing the conduct of the members of a profession (American Heritage Dictionary, 1991). Constraints on research dealing with human subjects can be traced to the Nuremberg Code, which was a product of the Nuremberg Trial. After World War II, the Nuremberg Military Tribunal was established to confront the atrocities of Nazism (Merriam, 1998). In addition, the development of nuclear energy, as well as research scandals using live subjects, intensified awareness to protect humans from physical and emotional maltreatment during experiments. Since then, most professions have instituted their own principles and policies to regulate field experiments. There are federal laws and directives to protect human subjects from harm, their right to privacy and related matters in biomedical, behavioral, and social research.

This study received approval by the research board governing human subjects at North Carolina State University. Thus, the writer was obligated to perform within the regulations, guidelines, and protocols of the institution. This writer had limited autonomy in the conduct of the research.
At times, interviewing borders on the delicate and personal dimensions of individuals. This writer was faced with the dilemma of how to put the subjects at ease to encourage a more open participation and the concern of coming across as presumptuous in her conduct. This writer made herself more aware of ethics and research issues by reading more on the subjects and was determined to conduct the study with sensitivity. Unless subjects expressed preference to hold the interview in their homes, this writer selected locales that offered the most possible convenience, privacy, and tranquil ambiance. This writer reserved private rooms in county and municipal buildings. This writer conducted the semi-structured, one-on-one interviews with professionalism and respect. In a professional manner, this writer communicated by body language, facial expression, and low-key inflection compassion to the difficult job of providing care to parents with dementia, and respect to participants. Because of the personal nature of some of the questions, it was made clear to participants that they had the option to terminate the interview at their discretion without prejudice. A listing of practicing psychiatrists and psychologists in the area was available for those who may desire such service. Most of the 23 adult daughters and daughters-in-law completed their narratives uneventfully, although a few became emotional during interviews. Given the option to discontinue the conversation, none took advantage of the offer.
Life changes of adult daughters

Granted that this writer stood to gain from the discussion, the sample received the opportunity of voice in a confidential setting. It is common knowledge that intergenerational careproviders may suffer from isolation, alienation, and frustration. The dialogue was a venue for adult daughters/careproviders to express private, personal feelings, and thoughts stored in the recesses of their mind that are associated with the demanding task of nursing. More often than not, individuals experienced feelings of relief and strength to carry on after downloading their innermost thoughts.

As a form of reciprocity, this writer continues to attend the monthly Alzheimer's support group meeting in her county. Most of the participants were recruited through support groups. As a gesture of appreciation, thank-you cards and letters were mailed to administrators, staff, and participants involved in the study.
Chapter IV

Findings

This chapter will report the information gleaned from interviews with daughters/caregivers to elderly parents with Alzheimer’s. As stated earlier, the purpose of the study was to determine the life changes that adult daughters experienced when they became the principal source of care to parents, their perceptions of the caregiving role, as well as the daughters’ beliefs and feelings as family careproviders. The semi-structured interviews were based on a predetermined set of questions, Appendix B. To protect the confidentiality of subjects, names and other identifying data were changed. Transcript of the interviews was coded according to categories that emerge from the data.

Table 1 represents the descriptives of the sample. The racial composition of caregivers consisted of one Asian American, seven African-Americans, and 13 Caucasians. The age range of subjects was between 27 and 72, with a mean of 56. The age range of carereceivers was from 62 to 95, with a mean of 80. Seventeen care recipients were mothers and six were fathers, a total of 23 frail parents because two daughters each cared for both parents. Fifteen careproviders, or 71%, were married, one was single, two were widows, and three were divorced. Nine daughters, or 43%, were employed and at the same time caring for parents with AD. Four careproviders were retired, five quit work to provide fulltime care, and three were homemakers.
Six daughters, or 29%, had children under 18. The age range of children was from 5 to 16 years old, with a mean of 13. In terms of family hierarchy 10 daughters, or 48%, represented the eldest child in a family, four caregivers were the youngest children in a family, four were only children, and three were only daughters. In length of caregiving, the range was from six months to 180 months, with a mean of 58 months or almost five years. In order to qualify for the study, an adult daughter must have provided care to parent(s) with Alzheimer’s for a minimum of six months, and was the legal guardian of her brain-impaired parent(s). In addition to the 21 adult daughters who participated in the study, two daughters-in-law were interviewed as well. The length of caregiving for daughters-in-law was a year, and five and a half years. The research explored the changes in the life of daughters-in-law as they assumed primary care to frail parents, their perspectives on their role, as well as their beliefs and feelings as family caregivers. These two daughters-in-law were primary caregivers and their husbands the legal guardians. One husband was an only son, and the other the eldest in his family. Permission from husbands to participate in the investigation was obtained by daughters-in-law.
Life changes of adult daughters

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Mean 56

Table I Descriptives of Sample

*provided care to mother and father
Life changes of adult daughters

Categories

Analysis of data concerning the changes in the lives of caregivers produced categories such as living arrangements, relationships with parents and young children; personal affairs, social life, family disharmony, employment, day-to-day-routine, economics, personal health, and religion.

The coding categories that emerged under role perceptions of adult daughters as caregivers to cognitively impaired parents were family duty and responsibility, affection, giving back, role emulation, health/estate management; others viewed their role as an infringement in their life.

This research also explored the beliefs and feelings of adult daughters as caregivers to aging and disabled parents. The questions presented to subjects were (a) Do you consider caregiving as a family obligation? (b) Do you consider caregiving as a personal sacrifice? (c) Do you consider caregiving as a burden? The categories that emerged under feelings of daughters/caregivers were aversion to institutionalization, fear, guilt, isolation, loss, regret, maternal attachment, resentment, resignation, and emotional enrichment.
Narratives of Participants

Abigail was Caucasian, 50 years old, and married with two young children. The youngest of seven children, she lived next door to her parents with her family. Her other siblings were scattered all over the United States. She had been married for 15 years when she became the primary source of care to her mother. Her caregiving career stretched to 15 years. Her mother was deceased.

Berneice was Caucasian, 27 years old, and married. At the time of the interview her husband, a U.S. Marine, was deployed in Iraq. Berneice, the eldest child, was a careprovider to her father for 18 months. Her father was in a nursing home at the time of the interview.

Carolyn was Caucasian, 68 years old, and a divorcee. After her mother died of cardiac arrest, Carolyn, an only child, quit her job to take care of her mentally ill father. Carolyn dedicated nine years of her life to family care.

Dana was Caucasian, 56 years old, and married. Dana was sexually abused when she was a young girl attending college. The eldest child, she returned to college at age 45. She was employed fulltime while providing care to her mother. Eleven years of caregiving did not alleviate the deep remorse she felt for placing her mother in an institution. Dana’s mother was deceased at the time of the interview. Her remains were donated to medical research.

Emma was Korean, 60 years old, and married. Emma was an only child and a homemaker. She had two open-heart surgeries while a caregiver to
her mother. Her mother did not speak and did not understand English, although she had been in this country for 30 years. At the time of the interview, Emma had been nursing her mother for three years. Emma’s mother was 82 years old and in good physical health.

Fran was Caucasian, 60 years old, and married. The eldest child, Fran quit her job and took her mother in when her mother could no longer function independently. According to Fran, longevity ran in her family. She had been a caregiver for six years. Her mother was 82 years old and in good physical health.

Frances was African-American, 62 years old, and a recent widow. She was employed fulltime. Her husband and father were ill simultaneously. Her husband died at home while Frances was away caring for her father. The eldest child, Frances was a caregiver for three years. At the time of the interview, Frances’ father was in a nursing home.

Gena was African-American, 56 years old, and a divorcee. Gena was employed fulltime while her mother was ill with AD. Gena was a long-distance caregiver. Gena devoted two and a half years of her life to family nursing. Gena’s mother died at age 80.

Henrietta was Caucasian, 50 years old, and married with two young boys. The eldest child, she and her father operated the family business. Her father recently died and Henrietta appeared fragile during the interview session. She was a caregiver for 24 months.
Isabella was Caucasian, 55 years old, and married. The eldest child, Isabella was married to a minister. While she was employed fulltime, she was taking care of two young children and both parents with AD. Physically abused as a child by her alcoholic father, Isabella held no grudges. She was a caregiver for five years. Her parents were deceased.

Jeane was Caucasian, 63 years old, and a recent widow. Jeane's husband was a heart transplant recipient. A working caregiver for many years, Jeane cared simultaneously for her husband, who was sick with cancer, and her mother who had Alzheimer's. Retired, she relocated to the Southeast to be near her daughter. Jeane’s only sibling, an elder brother, was a millionaire and stayed away from the family. Her mother had been living with her for 15 years. Jeane’s mother was 95 years old and in good physical health.

Kimberly was African-American, 32 years old, and single. Educated as a social worker, she had better understanding of her father’s struggle with Alzheimer’s. The youngest of six children, she moved back home and assumed care of her father, when her mother suddenly died. A caregiver for 18 months, her father was deceased when Kimberly participated in the study.

Lyn was Caucasian, 51 years old, and married. A mother with Alzheimer’s, a teenage son, and an abusive husband were more than enough to send her own business to the ground. Facing Lyn and her little boy, her first husband committed suicide by placing a gun in his mouth and pulling the trigger. Lyn, the eldest in her family, was a caregiver for eight years. Her mother was deceased at the time of the interview.
Madeline was Caucasian, 53 years old, and married. An only child, she spent one Thanksgiving Day transporting her mother from Texas to the Southeast. Madeline felt compelled to give up her high-profile job to be an Alzheimer’s careprovider. It was a rude awakening for Madeline to find out the high cost of nursing homes and assisted living facilities. She was a caregiver for five years. Madeline’s mother was deceased at the time of the interview.

Nancy was African-American, 62 years old, and married. Nancy was the youngest child and the only girl in a family of seven children. Retired, she assumed fulltime care of her mother based on her perception that males were not meant to perform family nursing duties. Fraught with worry over her mother’s safety, Nancy felt that her only option was institutionalization. Nancy provided care for two years. Her mother had been in a nursing home for six years when Nancy was interviewed.

Oprah was African-American, 51 years old, and married. Alzheimer’s struck Oprah’s mother and father almost at the same time. Her children were five and seven years old then. Alzheimer’s forced her to review her priorities in life. The eldest child, Oprah was a caregiver for six years. At the time of the interview, Oprah’s parents were deceased.

Paula was African-American, 72 years old, and married. Her husband just retired from the military when they returned to their hometown to find that her mother was sick with AD. The eldest child and a homemaker, she never lived with her sick mother. In the early stages of AD, her mother lived
Life changes of adult daughters

alone in an apartment. After seven months of looking after her mother, the family decided to commit mother to institutional care. Paula’s mother was in a nursing home at the time of the interview.

Queenie was Caucasian, 62 years old, and divorced. The eldest child, Queenie refused to live with her mother, who was in the second stage of AD. Uprooting herself from the West Coast, her timetable as a caregiver was one year. Queenie was a working caregiver. Queenie had been a careprovider for six months at the time of the interview. Her mother continued to live alone.

Rosalyn was African-American, 69 years old, married, and a homemaker. An only child, Rosalyn was a caregiver for two years. At the time of the interview, her mother was in a nursing home.

Susan was Caucasian, 52 years old, married, and a homemaker. Susan, an only daughter, had four brothers who provided assistance. Susan was the guardian of her mother as well as the primary caregiver. She had been a careprovider for 15 months.

Theresa was Caucasian, 65 years old, and married. Although at retirement age, she continued to work fulltime. The eldest child, she committed her mother to a nursing facility when her six-months leave from work was up. Theresa’s mother was in a nursing home at the time Theresa was interviewed.
Becoming a Caregiver

The road to primary caregiving may be predicated on availability, geography, gender, convenience, and hierarchical position in the family. Eight daughters became primary caregivers because of accessibility and convenience. Compared to other members of the family, it was more convenient for these daughters to nurse their parents because other relatives were preoccupied with spouses, young children, employment, and home maintenance. The following were the comments of some of the participants:

Abigail: “We (husband and two children) lived next door. So whenever my mom got Alzheimer’s, then we moved in with her.”

Carolyn: “They (parents) were living with me. My mother just died…from a heart attack. My father stayed with me. It was that simple.”

Kimberly: “I was in a position where not married, no children, no really financial responsibility, so I could move back (to father’s house), look for a job in the area and care for him.”

Nancy: “I tried to get her (mother) to come into my home to live with me ‘cause I would feel better because you know how boys are (referring to her six brothers).”

Queenie: “I was living in the West Coast and I have four sisters living here on the East Coast. Eventually I became unemployed and I’m divorced. All of my other sisters have jobs and husbands and/or children at home. So I was the obvious choice to come back and help my mother.”
Seven daughters were conveniently located to their parents when they assumed the responsibility to provide care to frail parents. The following were some of their voices:

Dana: “My husband decided to take a job in South Carolina. And she (mother) decided that she would live with us. And I really don’t honestly know how it came about that we were going to share a house. It just happened.”

Fran: “I’m the only one in town. There’s nobody else. …my sister lives in New York and my father’s dead.”

Oprah: “My sister was not here and my brother worked in Chapel Hill. So I was the one closest to my mom.”

Rosalyn: “I was close around and I always had to see about her.” “She stayed at my house for a while.”

The following remarks reflected the assumption of care by accident of birth:

Berneice: “I am the eldest child…there were just two children in the family. It (careproviding) was pretty much dumped on me.”

Gena: “It (caregiving) came about because I am an only daughter. So I began the care for mom in the beginning of her Alzheimer’s.”

Henrietta: “I am the eldest kid and my father always looked to me in helping make decisions. I guess because I was the eldest one it just fell back on me.”
Life changes of adult daughters

Rosalyn: “She (mother) didn’t have any other family and I was the only child that she had.”

Changes in the Lives of Adult Daughters

Caregiving and living arrangements.

Twelve daughters, or 57%, shared households with disabled parents. Dana revealed her experience with her mother who found it convenient to join her family, when Dana and her husband relocated: “We have moved into another house where like one wing of the house–two bedrooms, two baths–and that was hers, the living room in between and our bedroom upstairs.” When Dana’s mother started hearing noises at night she “moved downstairs and slept in the room across the hall.” Berneice elaborated that her father would “put things on (stove), catch things on fire. He buried my driver’s license in the backyard. He didn’t think I was old enough to drive.” Jeane’s mother was living with her and her husband. According to Jeane, her mother “didn’t like Joe (her husband) and I [sic] to go anywhere or do anything and that sort of thing…she got demanding.” Madeline and her husband added a room in their house to accommodate her sick mother.

Nine caregivers, or 43%, lived separately from their parents/patients. Some of the parents living alone were in the second stage of the disease and faced greater risk to themselves and their environments. Queenie informed this researcher that she just could not live with her mother because her “mother was difficult when well and impossible with Alzheimer’s.” Even though Henrietta’s father did not live with her, the demands of her caregiving...
had its effect on her household. “I was getting frustrated sometime about when I came home how my house looked, when I was always used to keeping a clean house.”

**Caregiving and relationships with parents.**

The participants were asked about the kind of relationships they had with parents while growing up and into adulthood, in order to determine if formative affiliation was a factor in caregiving. Thirteen daughters, or 62%, responded with having positive relationships, and elaborated with the following representative comments:

“I was very, very close (to father).” “My father and I did everything together.” “My mom and I were like birdies.” “Loving, caring, well-bonded.” “Very close.”

Eight participants, or 38%, expressed undesirable feelings from childhood and into their later years. Emma’s resentment of her mother was based on physical abuse because “she tells me ‘you eat like your daddy, you walk like your daddy.’ I look like my daddy and that’s why she hit me all the time.” Likewise, Fran’s remarks about her mother maybe traced to her mother’s propensity “to be in the center of your life, running it. And she’s still doing it.” Madeline added that her mother “had high expectations (of her). I could not always fill those expectations.” Gena mused that, “My mother and I were not that close…my brother was always her little boy.”
Caregiving and young children.

During their caregiving years, six subjects had children under the age of 18. Henrietta’s two boys were 14 and 17 years old. She indicated that,

I have one child that has (a) learning disability and it took away a lot of my time that (I) would have spent with him in areas that he needed in school. My boys did not resent any of the time that I was not able to be at basketball or football games because of their grandfather.

Abigail conceded that as primary caregiver to her mom,

it was hard on my children. But on the other hand, I feel that it made them stronger because they depended not on me as much because they knew that I was new in the area (of caregiving). So they became independent.

Lyn’s teenage son was a source of moral support and physical assistance in the care of her mother. According to Lyn,

He (her son) would even entertain her (mother) (by) dancing and all this rap thing. He would sing “Yes Jesus loves me” with her and she would remember those words but she had no idea who he was, what his name was.

He’s very healthy…he’s a big boy and so he could help me with the physical, even though it was very hard (on him) when I had to change her, when I couldn’t get her up and have to start pulling sheets and stuff. He would say ‘I can’t open my eyes, tell me where to put my hands. This is grandma and I can’t do this. It’s not something you’re supposed to do.’

Oprah’s two girls, age five and seven always wanted to go and see her because it was their grandmother. She did not like children and she could not stand to be around children. She wanted them to stand very still, don’t move, don’t say anything.
Dana’s mother showed almost the same symptoms as above. Dana’s children would come and visit their sick grandmother on occasions. Dana narrated that, “unfortunately, towards the end mother got very critical, black and white. She would tell my children that they were not acting properly. She had a very narrow, narrow view. She had very limited tolerance.”

Caregiving and personal affairs.

Fifteen married daughters, or 71%, participated in the study. The study probed how the business of caregiving by a wife could impact on marriage. A majority of the daughters/caregivers experienced favorable response from their spouses, as indicated by the following representative statements:

Madeline: If it weren’t for him as well I don’t know how I got through it. From the beginning…to the very end of her life (mother’s) Tom was involved. He was a wonderful source of support.

Oprah: To let him (father) take a bath took hours to get him into the tub…then you could not get him out. It was like three or four hours…he (husband) could get him out just talking to him. I couldn’t have made it without my husband. I could have lost my mind.

Theresa: My husband was very supportive. He was very agreeable to having her (mother) come to our home.

Rosalyn: She (mother) was real close to my husband. He kinda feel like a son to her more than a son-in-law.

Providing in-home care to an individual with Alzheimer’s could be taxing and could affect most facets of any household. For some marriages, Alzheimer’s and caregiving could be a vehicle of change in the lives of careproviders. Carolyn was a caregiver to her father for nine years. She argued that “definitely” her divorce could be attributed to her caregiving. “He
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(husband) just couldn’t cope with it.” Lyn’s relationship with her husband was not on the best of terms. Nursing her mother for eight years appeared to have provided Lyn with an option to close the door on her husband: "I could not be a caregiver and a wife at the same time but I was able to be a mother and a caregiver."

Madeline echoed the same feeling when she elaborated "there was very little time for Tom (husband) and I to be together.” Fifteen years of caring for a sick mother at home could take a heavy toll. According to Abigail, “She (mother) became my top priority and I didn’t have time for anything and I guess over the years he (husband) became disinterested. He resented it (caregiving) and that made me resent him more. I got out of the marriage.” After three decades, Abigail and her husband divorced. She later re-married.

Caregiving and social life.

Majority of the participants indicated the absence of social activities in their lives. Carolyn declared that she, “didn’t have one. Didn’t go with (anybody). Didn’t know anybody.” Abigail corroborated by saying that, “I had no social life, nothing.” Some of the participants, Frances for example, deliberately stayed close to home, foregoing travel and vacation. Frances “didn’t feel like going away. I felt that if I went away something would happen.” Jeane echoed similar attitude when she explained that she and her husband “turned down a lot of invitations…if we were invited to go out to dinner most of the time we declined.”
For single caregivers like Kimberly, relatives usually became a source of much-needed rest and relaxation. “I had a cousin that would sit with my father during the week and if I needed to stay some extra hours during the week or the weekend, I could get out maybe three or four hours.”

Some subjects would make attempts for normalcy by going on family trips. Dana recalled that, “A number of times we would make plans to do something, or plan to go somewhere. Quite often, if we were leaving or if we were gone and we could get a call and we would come back.”

For others, the nature of the relationship may account for the lack of social activities. Lyn said that, “I really didn’t have any social life at all. I mean we don’t go anywhere together. My husband doesn’t want to go anywhere and if he wanted to go somewhere I wouldn’t want to go there with him.”

For six daughters/caregivers, the church became the focal point of their social life, which was also a source of support for their undertaking. Paula stated that, “My social life is mostly with the church.” Rosalyn added that, “I never really had a social life…just more like I go to church and back.” Emma stated that her friends from the Korean church would stop by for social visits. Active participation in her church was Henrietta’s social scene. Caregiving had put an end to her choir involvement. She elaborated, “I used to sing in the choir. I stopped that a little bit before daddy got sick. I have different priorities.”
Some of the caregivers had learned to substitute activities related to Alzheimer’s, such as attending support group meetings, for their social needs. Fran narrated that she, “come to the meeting once a month. That’s my social life.” Gena did not consider that her caregiving had any impact on her social life, since she “was basically a home person anyway. I enjoyed doing things in my house after work.”

Still for some daughters, social activities were exclusionary to providing care. Isabella nursed both parents and claimed that, “No, I didn’t care about social life. I’m not bragging but I was devoted to my parents. I really was.”

Caregiving and family disharmony.

Abigail’s sister lived “about ten miles away” and “dropped in occasionally. But there was no support system there as a family.” Another drop-in caregiver was Dana’s sister who “would come to visit for a day or two, have tea with her (mother), look at photographs with her. I mean it’s good to do that, but it’s not day-to-day (care).” The inheritance issue played a major factor in Lyn’s caregiving experience. Lyn stated that, “My sister wanted to put her (mother) in a nursing home and then she got mad that I would not do that because there was a large sum of money…she felt like I was throwing away her money. It’s all about money.” In addition, Lyn’s family conflict extended to her “aunts and uncles” who favored institutionalization. Lyn articulated on the issue of institutionalization and her relatives:
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I had the power of attorney so...my sister would have bailed out some money to fight me (in court) and she would not have done that because of the money, not that she didn’t want to.

In addition, Lyn explained that that her sister was right next-door and would not even come over to help.

I could never get over that. Our family wasn’t that close to begin with and it (caregiving) split it wide open. And I was really out there by myself with mama and Alzheimer’s and the whole family against me ‘cause I was keeping her at home instead of putting her in a nursing home. Mama was always scared of being put in one.

When Lyn suspected that her mother was dying, she called her sister on the telephone. “I called her the day before (mother died). It was on a Sunday and I just begged her to come over. I said that mama is in a coma and would you like to please come over and see her one last time?” She said, ‘well, I got to go to the mall’ and mama died at 3:45 p.m. that Monday.”

The youngest in a family of seven, Nancy argued that she received “not much, not very much” help from her six brothers. She found it hard to accept that her eldest brother did not come around because “he just can’t bear to talk, to see her (mother)” in such a debilitated state. Isabella’s parents were victims of Alzheimer’s. At their father’s death bed, Isabella’s only sister informed her that, “If you ever need me, I’m not gonna be there for you.” Isabella stated that, “She did not come around. It’s hard for your own sister to tell you that.” Years after their parent’s death the two sisters were still estranged. This situation applied to two other daughters/caregivers in the study.
Jeane’s only brother had distanced himself from their mother. According to Jean, her brother’s “comment to me constantly is ‘put her in a home. I don’t know how you can stand it, just put her in a home.’” Jeane amplified that, “Honestly, I’m bitter because…I have one brother, he’s got four daughters who all live about ten minutes from my home…they never called my mother. If she (mother) were at their house once a year it was a miracle.”

Carolyn recalled that her father’s relatives “just kept telling me to get a life, put him (father) in a nursing and get a life for myself.”

Unwilling to provide caregiving assistance, Lyn’s maternal aunts and uncles were of the opinion that their sister could receive better care in a professional facility, rather than in-home care, and were quick to share their view with anyone who was willing to listen. Lyn looked back with subdued anger about “the craziness that people said to me, the things that were said" (by her relatives)…but that she “had to keep going, go out and scream, and then come back.”

Isabella harbored annoyance toward her sister because “She didn’t want to be involved a lot, she didn’t want to get involved in the legal stuff, paper stuff and all that.”

**Caregiving and daughters’ employment**

A caregiver’s economics are not spared with the onset of Alzheimer’s. Five participants quit work to care for sick relatives. Nine daughters were employed and at the same time provided care to unwell parents. Dana was
determined to keep her job because “It was so important to me for a lot of reasons to be able to work. I mean I waited until I was 45 when I got my master’s degree. I was using my medical leave (to care for her mother).”

Abigail’s line of work was useful when she assumed care of her mother. Abigail worked as an aide for the county senior services and was assigned on a part-time basis to her mother’s case. “I was working for the county then. I became her (mother) primary aide also.” Under this arrangement, Abigail was able to provide her mother fulltime nursing care and at the same time generated a limited source of income.

Carolyn was working for the Council on Aging at the time her father was sick with dementia. According to Carolyn, her employers were extremely supportive, very, very supportive of the situation…it was like a family over there. I’d get calls from the hospital ‘cause my dad was in the hospital whenever. It was just go, do what you have to do. She (supervisor) was very, very supportive.

Owning a family business provided some latitude in the care of a frail parent, as Henrietta attested: “By working with him (husband) it made it easier for me to be able to leave, or take time out when I needed to. I know that if I have to work a public job it would be difficult.” Jeane, when asked if caregiving affected her work, responded with: “No, work is my sanity.” Kimberly considered herself fortunate to be working for compassionate employers, especially in times when “Dad had a rough night and I don’t know if I can deal with it but got through it. I have a very understanding supervisor.” Lyn had a medical transcription business at home before her
mother’s health forced her to close down shop. According to Lyn, “People were very understanding when I had to let go of contracts. Some of them called me right back after she passed away.”

Oprah’s parents became ill with AD almost at the same time. Oprah tried to continue to work with the help of neighbors. “My mom’s neighbors would call me at work and say, ‘your mom’s just went up the street’…I just had to leave (work) and go find her.” When the neighborhood watch failed, Oprah added that, “I asked to be downgraded.” Shortly thereafter, an economic downturn hit her workplace. Oprah continued: “They were laying off and I asked to be on that list to be laid off.”

Madeline was an executive in a charitable foundation. She loved and enjoyed her position. Before quitting altogether, Madeline tried to balance employment and caregiving. According to Madeline, a typical day would be such that, “her meals were prepared before I left. Then I would come back at lunchtime. I would call her and either she would not answer the telephone because she couldn’t find it, or she would be talking on the phone…place the phone down and she would never come back. I would get scared and I would pick up my pocketbook and go running out of my office and drive home to see if she was alright.” Eventually, Madeline “gave up my career.”

For some daughters, the task of caregiving could also mean significant reduced income. Upon relocating to a small town somewhere in the East Coast, Queenie stated that, “I’m being paid less than half of what I earned in
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California.” Rosalyn found the demands of an AD patient overwhelming: “She’s (mother) got to the point that every time I turn around I had to take her to the doctor. I gave up my job”

**Caregiving and day-to-day routine.**

According to Abigail, “A typical day in the end she (mother) was completely bed-ridden. I was just totally taking 24 hours taking care of her. She couldn’t talk, she couldn’t walk.” A trip to the doctor required Abigail to “pick her up and put her in a wheelchair, take her down the ramp, put her in the van, and here we go.” For Berneice, her father’s mobility kept her hands full: “He’d moved rocks, he’d pick ‘em up–a bunch of rocks and moved them into different places in the backyard. That’s what he did all day.” Emma’s mom’s active energy was a source of distress, in that “she (mother) wakes up at the crack of dawn...(urinates) on the floor and gets back to bed. Then she picks up things, anything, to try to hit me.” At the time of the interview, Emma’s mother was banging and shaking the front door wanting to get out. Emma’s daughter came to the rescue. Aggression on the part of AD patients did not make for a quiet day. Fran indicated that her mother “was hostile. You couldn’t do anything to satisfy her. It was her way or no way.” Rosalyn told how her mother’s paranoia showed, “Sometimes she would get angry, she’d be so mad. She said she knew somebody had been to her house bothering her things. She got angry and she took the (house) key from me.”

According to Theresa, a daily routine went like this:

When I first brought her home, the morning would be very calm. About lunch time she would say, ‘well now, after I have lunch with
you, I’m going to have to get ready to go home.’ She would go home. She was convinced that her home was down the street. At the hospital they actually gave me a straight jacket. And I could hold it up to her and she would come and put it on, thinking that she was putting her coat on. And I would say, ‘mom, let’s sit down and talk a few minutes before you leave.’ And I would tie her arms to the arms of the chair and then she would realize that she couldn’t get up. She would be furious.

Isabella told how her mother’s diet was restricted to soup and milk and “that really hurt me because I wanted to give her something and I couldn’t because…she couldn’t have food in her stomach. She would say, ‘In Hoover’s days I didn’t get anything to eat and I’m hungry now. I was hungry during Hoover’s days and now I’m still hungry.’

Caring for an AD parent demanded a constant state of alert. Dana shared that, “once she (mother) burned the carpet. And she insisted that my sister was in there smoking. And my sister was not even there. She was in Charlotte.” Jeane was so concerned about her house burning down that, “I just told her (mother) she either stop smoking or she couldn’t live with me any longer.” Kimberly’s parents “were married for 45 years, so that was typical for him (father) to continue to ask where my mother was, or in the evening he forget he was not hungry. I mean he had eaten meals.”

Oprah attempted to provide her household a semblance of normalcy, such as going “to the grocery store and do whatever, which was not easy ‘cause you’d say, ‘ok, Dad, stand right here and let me go over just to get some fruit or something.’ You come back and he’s gone. And you try to run trying to find him.” Paula and her husband had gone for a vacation and a
younger sister stayed with their mother. Her sister went out to hang some clothes. “She (mother) locked her outside, locked the door, and stayed down.”

Queenie tried to take her mother out when she was off from work. Queenie narrated how “It would take me two or three hours just to get her out of the house because she’ll start to get dressed, she’ll start to put her shoes on and she’ll spot something on the table and be totally distracted by whatever is on the table. And it’ll take maybe 30 minutes to get her back to put her shoes on again.” Lyn added, “It would take a day just to count the pills. It really would take two, three hours to get her washed which I did every single day…cause I never wanted her to be dirty or smell or be soiled.”

**Caregiving and economics.**

A majority of the participants were reluctant to discuss finance with this writer. A handful readily admitted to the financial burden caused by the disease. Carolyn, who quit her job to take care of her father, admitted that, “we’re slowly going broke ‘cause he (father) had no wealth and there isn’t any kind of aid out there. He fell through every crack there was as far as trying to get any kind of help, you know, for him or for us and finally after two years I was going through all the savings that I had.” To be on food stamps was something Carolyn never expected to happen in her lifetime. “I broke down. I never thought I’d go to Welfare and food stamps you know.” Then “the bank notified me they were foreclosing on the house because I couldn’t pay the mortgage…so we lost the house too. Did a good job, lost everything, lost it all.” “Anyway, my father did finally go. It took me two years to get him back
home to bury him...I didn’t have any money to bring him back home….he only had $2,000 insurance. The Episcopal Church kept his ashes for me for two years. They had a thing on the floor in the altar that you can put things like that.” “And so I waited for two years and my first (Social Security) check I happily got a plane ride home and saw everybody.”

Dana’s desire to keep her mother at home was based on “two incomes” and that, “some things in life would probably have been different if we didn’t have (mother with AD). For one thing we would not have such a large house and such a large mortgage.” Jeane’s only sibling and his family severed relationship with Jeane and her mother. According to Jeane, her millionaire brother has informed her that he was willing to forfeit any and all inheritance from their mother’s estate. Jeane responded that, as the primary careprovider to their mother, she had no plan to make her brother a beneficiary upon the death of the patient.

Madeline brought her mother home to the East Coast from the Midwest, when it was clear that her mother was unable to function by herself. Madeline utilized the community adult day care, assisted living, and nursing home facilities. According to Madeline, “Assisted living ran us about $3700 a month.” After Madeline committed her mother to a nursing home, she ran into a protracted litigation with the state of North Carolina concerning the patient’s legal qualifications for Medicaid. Eventually, the State ruled in her mother’s favor but “for the next six months my husband and I paid out of pocket $4300 a month. We could no longer afford nursing care for mother.”
Lyn advised that, “Medicare would not cover (some expenses) because she (mother) was staying in-home with me. The Aricept was between $300-$400 each month. That was just one medication. And she was on, you know, blood pressure medicine, …osteoporosis and she was hyper thyroid… and they also prescribed Respidot (an anti-psychotic drug). They (Medicare) will cover the toilet, the bedside commode…they’ll let you have a walker but other than that I got nothing else from them.” When her mother became incontinent, Lyn would “just buy her pads and stuff….and keep her changed all the time, you know, like Depends. I changed her so often a lot of money went to that, that’s the thing the insurance doesn’t cover. They don’t cover any of that until Hospice takes over.” Lyn explained that she had been using her own savings for medical supplies and medication. “I knew we were getting close to having to mortgage our house and that was going to be fine, too.”

Fran’s mother had real estate properties that included Fran’s house. Deeds to the properties were transferred to Fran’s name when Fran assumed guardianship of her mother. Three years after the transfer, the assets involved would be secured from state claims, if and when Fran’s mother was institutionalized. According to Fran, her family had a history of extended life span. “My grandmother lived to be 103 and at age 85 my grandmother was still driving around Atlanta, Georgia.” Fran’s mother was 82 and physically healthy.

Assuming full guardianship of her mother, Queenie found out that her mother’s assets were so tightly controlled by the court that, “I have to use my
own money for gas, when I take off from work, to take her to doctors’ appointments, pick up prescriptions and medications.” Kimberly’s situation was different in that, “My father did not qualify for Medicaid because he made too much money.”

Caregiving and health of caregivers.

Of the 21 adult daughters that participated in the study, eight careproviders indicated experiencing some degree of depression. After Frances placed her father in assisted living facility, she recalled “the depression that came with it at the time of my father’s illness that I didn’t have before. It was just like (lack of) sleep and worrying about him whether he was being taken care of or not.” Jeane’s mental health required her to resort to medication while she was nursing her husband dying of cancer and her mother suffering from dementia. She said that, “I was on it for my nerves and I don’t take it now. Maybe I still need it a little bit but I really wanted to be off it.” Henrietta “finally had to give in and started taking anti-depressant because I just lost so much sleep at night worried about him, worried about whether I made the right decision or not, not knowing what to expect the next day and I started having problems with my blood pressure.” As the caregiver to her dad, Isabella declared “when I have arthritis real bad and at times I could hardly go, I’d drag my legs and go.” Kimberly “went to a little bout of depression after I lost my parents.” Kimberly’s mother, who was caring for a husband with dementia, developed cancer and died eight months after the disease was discovered. Her father died shortly thereafter. As a caregiver,
Lyn had “a protruding disc and I have already been diagnosed with chronic pain that could not be fixed. I have osteoporosis degenerative disc disease. I have been told to apply for disability for the last eight years and I haven’t.” Carolyn developed some form of cancer shortly after the death of her father. She was now in remission. Frances stated that during her caregiving episode she also developed gall stone problems.

Caregiving and religion.

Some changes in the lives of adult daughters involved religious affiliations. One daughter severed her association from her church. According to Carolyn, she had telephoned the local Catholic Church and requested that the Last Rites be performed on her dying father. She was asked if her father was a member of the parish. Carolyn’s father was not a member of the local church because “by the time I brought him down here he was too much into Alzheimer’s to become associated (with the church).” A clergy from another denomination came to the rescue. “We’re not even Episcopalians but he came flying down to that hospital. You know, he stayed with us, he prayed with us. So, I was not gonna get over that.” On the other hand, Abigail professed that, “Really, I got religion as a caregiver and I’m glad that I got religion while I was keeping her (mother).”

Fourteen daughters, or 67%, admitted that religion changed their perspective toward their caregiving role. Seven subjects did not consider that religion was a factor in their role as a keeper of sick parents. Henrietta declared that, “I know that God got me through it.” Queenie used religion as
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a rationale to providing care to her mother. She postulated that, “Christianity teaches us that the strong have to protect the weak.” Isabella said that, “The only thing that sustains me …my prayers.” Rosalyn based her decision to care for her parent on her faith “because in my heart it was the right thing to do.” Nancy traced her spiritual revival to the time when, “My mom carried us to church. She didn’t drive but we used to walk (to church) on Sundays. She would put on our regular shoes and when we got to church she changed them and put on socks.”

Role Perceptions of Adult Daughters

Ten participants, or 48%, viewed their family caregiving role as rooted in the meaning of responsibility, duty, affection, giving back, role emulation, and role reversal. Some of the daughters perceived their role as health/estate management. Others viewed it as infringement on life.

Family responsibility, duty and giving back.

Nancy contended that she “just took it on as my responsibility…me and my mother…and I loved her and I just took it on as my job to be there for her because she’s always been there for us.” Fran admitted to being “the dutiful daughter and I’m doing my duty. I don’t know who else would do it.” Paula elaborated on this line when she stated that,
It was her (mother) duty to care for me when I was unable to care for myself. When she is no longer able to care for herself, and so, it is my responsibility and pleasure, I mean I just am thankful that when I am able to and I do. I consider that (caregiving) as a welcome opportunity.

Susan shared Paula’s response about her role as careprovider to her ailing mother. She stated that,

We came from a very poor family. We grew up very poor and my mom worked on the farms around there to make money to feed us. Even though we had a dad, we didn’t have the best dad in the world. But it was really up to my mama. Mama was the foundation of our family.

Berneice was emphatic when she declared that, “It’s family. We’re just raised like that, let a family take care.” Isabella considered caregiving as “serious” because “when mom and dad give me birth [sic] I wanted to do everything I could. That’s the way I felt. I’d give my life, five years and more.”

Role emulation.

Dana linked her caregiving role to her mother’s long experience in nursing her father who suffered from cancer. After seven months in a nursing facility, Dana’s mother brought her father home “because she thought that the care he was getting was terrible.” “She (mother) took care of my father for seven years. And he was on a feeding tube and she took care of him all that time.” When her turn came to service her mother, Dana went through great lengths to provide her mother home care by hiring a live-in caregiver. She described her effort:

We had someone lined up and we stored all of mother’s things within the second room that she had, bought
furniture. We made a bedroom. We had it all ready for the person to come. Twice she postponed the date for various reasons and then finally she just didn’t show up on the day she was supposed to come. It would have been ideal but it didn’t work out.

**Role reversal.**

Five daughters considered their careproviding as role reversal. Abigail’s comment went: “At first I thought it (cargiving) was a downer but then it changed. I became the mother. She began to call me “mom”. It was just role reversal automatically. There was no point in time that it happened. It just happened gradually over the years.” Kimberly, caring for her father, substantiated this occurrence when she said that,

> It’s tricky because you gotta set the role of parents but they’re your parents. I basically felt like I became his mother, his wife, his everything. It became weird.

Henrietta shared the pain of role reversal with her commentary:

> I’ve become the parent. Role reversal. It was really hard sometimes because I felt like I was to take over, take things away from him that he had done most of his life. I felt real guilty about it…but had to do it for his own safety.

Lyn articulated the anguish involved in reversal of roles. She said that,

> “It was hard for her (mother) to accept (as it was) for me to have to say, ‘Mama, you have to do this. Please try to do this, or Mama, we’re going to try this exercise.’ It was hard for me to have to tell her and take over and do things for her.”
Health and estate management.

Lyn’s mother “begged me ‘please do not do anything to keep me alive.’ She put it down and told the lawyer.” Lyn honored her mother’s plea. As the executor of her father’s estate, Carolyn was confronted with a dilemma. This was her voice:

He (father) had a living will. I had a hard time making the decision. He never wanted anything extra to keep him alive. So the hospital gave me the choice of either putting a permanent tube into his stomach because he couldn’t feed himself anymore, or taking him home and let him starve to death. I couldn’t do that.

After some deliberation, Carolyn acquiesced “to put a tube in his stomach and I fed him through it until he died.”

Queenie saw herself as the financial watchdog for her mother’s interests:

I am trying to protect my mother’s money because I’ve heard that there are unscrupulous people who take advantage of the elderly. My mother is comfortably well off. She has enough money to live comfortably if it’s managed properly.

Madeline perceived her role as the administrator of her mother's health care.

She stated that,

My role was one of a manager, managing my mother's doctor appointments, her medical records, and overseeing the medication… watching constantly which medications were working and which medications were not working. If she were on a medication for four months and I didn't see a change, then I would request that medication be discontinued.
One participant viewed her nursing role as an infringement on her life. Jeane told this writer that,

I’d rather not be in the role. I would much rather have my own life. I regret this openly. Let’s face it; I’m 63 years old. I’ve been taking care of her (mother) for 15 years and looking after her.

Beliefs of Adult Daughters

Family obligation.

Fifteen daughters, or 71%, agreed that to care for frail parents was a family obligation; six participants did not. Kimberly posited that, “It was a family obligation but no one forced me to do it. It was my own choice what I’m gonna do for my father or my mother because they have provided for us all those years.” Madeline said that “right or wrong” she considered her task as an obligation to her mother. Oprah conceded that, “Yes, there was no question (about it), like when she (mother) got sick and we realized what was going on, that we had to take care of her. It was just what you do.”

An only child, Rosalyn commented that,

I consider it as a family obligation because I knew she (mother) had no one else to see to her but me and she doesn’t even have any close cousins or anybody in this area. And I knew that if I didn’t do it that I didn’t know where she would wind up.

Personal sacrifice.

Twelve daughters, or 57%, conceded that their caregiving job was a personal sacrifice. Six subjects did not consider caregiving as a personal sacrifice. Three participants had no opinion. Gena, a divorcee, considered
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caregiving as a personal sacrifice because “It changes your lifestyle, so no matter how you look at it it’s a sacrifice.” Henrietta, married with young children, admitted that her caregiving endeavor demanded so much of her time that she “was torn between him (father) and the family because I had two boys. One is a senior, one’s a freshman and I just thought I was torn between the two, trying to make myself available to everybody.” For Oprah, married with young children, her personal sacrifice came in the form of “a lot of things that my family missed because I wasn’t there. My children missed out because I wasn’t there to help them, when you really need to be there to help them read. I wasn’t there at that time.” Kimberly, single, argued that, “Not being married, not having kids, I should be out dating, starting my own family versus taking care of my father.” Madeline, who had grown children, elaborated why taking care of her mother with Alzheimer’s was indeed a personal sacrifice:

Absolutely. That was a time our daughter has just graduated from college and we were finally able to have the freedom and the income…we had a boat down here and we’d come down on the weekends and spend the weekend on the boat. Well, that stopped. Social functions stopped. The position that I held in Raleigh, I took an early retirement. Yes, it was a personal sacrifice.

Queenie, who relocated from the West Coast to the East Coast to care for a relative, accepted that taking care of her mother was a personal sacrifice, “Yes…but I am not a long-suffering person and I am not going to let it (caregiving) go until I feel martyred by it. There will be changes.”
Burden.

Fifteen adult daughters, or 71%, did not believe that familial caregiving was a burden; six subjects disagreed. Henrietta, married with two teenage sons, simultaneously nursed her father for two years and managed a family business. She stated that, “I don’t think ever like it became a burden.” Isabella was married and employed while caring for her mother and father for a total of five years. She claimed that her experience was not a burden “because it was love.” Lyn echoed the same response when she said that,

I loved my mama so much. She was my best friend.
I mean ever since I had my first job when I was 12,
I would baby sit or work in tobacco. I always bought mama things. I just loved her so much.

Madeline was a caregiver to her mom for five years and gave up a lucrative job. This was her voice:

There were times that I was burnt. Did I consider it all to be a burden? No, I just considered it as part of life and probably I kind of welcome the opportunity to take care of mother as she had taken care of me when I was a child. I was adopted. So it gave me an opportunity to really take care of her and show her how much I loved her and how grateful (I was).

Nancy approached the issue of caregiving as not a burden and much along the same line as the majority of the participants when she stated that, “It’s going back again to my mother and I loved her and what I have done for her is out of love.” Queenie and Theresa considered caregiving as a burden based on the length of time involved. According to Queenie, “At this point I don’t, but I could see that if it is 10 or 12 years, yes, it will be.” At the time of the interview, Queenie had been taking care of her mother for six months.
Theresa, who provided care to her mother for six months, added that, “if it has gone on for years, it may have been different, but it was such a short time and my husband was very supportive.”

Berneice considered her task as a burden and amplified that, “Oh yeah because he was dangerous. He got real abusive when he got sick. It was a burden to hang around.” Jeane gave her view that caregiving was a burden when she stated that, “It is a burden. I think anybody who takes care of somebody is a burden. Anybody who says it isn’t got to be a saint from heaven.”

Feelings of Adult Daughters

Almost all of the participants had experienced feelings of aversion to nursing facilities, alienation and isolation, frustration and resentment, guilt and fear, resignation and gratitude, feeling of loss, maternal attachment, and emotional enrichment. These subjects are discussed below.

Aversion to nursing homes.

The participants were asked what would convince them to place their parents in an institutional facility. Nine daughters, or 43%, did not favor placement of their parents in nursing homes. Abigail declared emphatically that,

No, that (nursing home) was never an option. And I just don’t believe in them (nursing homes) I don’t believe in nursing homes. My mother died at home.

Carolyn followed with, “I didn’t. I never did (place father in a nursing home). He was never institutionalized.” Fran indicated that she would “crawl
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first” before committing her mother in a home facility. Frances’ case ran along the same line and said that the rest of the family “didn’t want to put him (father) in a nursing home.” Emma stated that she would “never put her (mother) in a home, no matter what she does” because nursing homes shorten patients’ life span. Lyn said that, “My goal was to keep her out of the nursing home. My dad (who had cancer) didn’t die in a nursing home.” Jeane articulated that, “I figure I raised my children and it should be my turn and now I got another person actually demanding that ‘I have to have my lunch at 12; have to have this done at this time’ and she (mother) does it constantly so, but what can I say? I still wouldn’t. I wouldn’t put her in a nursing home.”

On the issue of institutionalization, twelve subjects, or 57%, were inclined to commit their parents in nursing homes under certain circumstances. The following were some of the decisive situations that may trigger such an action. Berneice argued that there was “absolute chaos in the house…he’d wander down the road…buying alcohol in the liquor store down the street and we couldn’t find him. It was time for him to go.” Dana stated that,

I don’t think that I could have done 24 hours care. It got to the point where it was a little more, a little more and then with the wandering, hallucinations we couldn’t even sleep…doze and wake up, doze and wake up. I couldn’t keep it up and go to work the next day.

Gena contended that, “When she (mother) became very hostile and uncontrollable, it was hard for the family to deal with her different moods. We
knew then that she has to be put somewhere. Madeline added her feelings to this topic when she said that,

When she was living with us…we took her out for a walk. And as she turned a corner, she lost her balance and fell and fractured her ribs…also hurt her back and ended up in a rehab nursing facility. And while she was in that nursing facility…broke her hip and she was very, very osteoporatic.

Nancy stated that it was time to place her mother in a nursing home “when there’s nobody there to watch her or whatever. We don’t know from day to morning that we’re going to see her, if she’s going to be there in the house the next day and stuff.” Queenie declared that she and her sisters “have decided that when mom no longer recognizes any of us and does not know where she is, then we will try to find a home for her.” Rosalyn elaborated that her mother “would get up in the night and try to get out. I just knew if I were sound asleep she’d try to get out. I live beside Highway 17 and if she got on the highway…I’ll never forgive myself.”

Alienation and isolation.

Carolyn expressed her feelings of alienation and isolation when she stated that she “can’t very well ask somebody to come sit with somebody, you know, just because you want to go out and have some fun, have a few drinks with friends and stuff. You can’t do that.” In addition, Carolyn noticed that she wouldn’t get telephone calls for the weekend from anybody. So then somebody would be afraid that I might just say, ‘God, why don’t you come over
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here and give me a break?’ I don’t hear from anybody until Monday morning when I have to go to work.

Nancy related that, “I got two brothers and a sister here (in town) and I hear more from my sister in New York more than from my (siblings) here.

Kimberly admitted that,

caregiving foregoes a lot of relationships. My life would basically be going to work, come home, and take care of my father during the week. Weekends pretty much I was at the side of the house to take my father out (for a drive). I try to make sure we got out of the house some.

Frustration and resentment.

Of her mother, Jeane stated that,

The biggest part is she can be very domineering and demanding and I resent that. And I feel, after working all my life and raising a family and at my age if I would like to do something pleasurable; I feel cheated and can’t do it.

Emma stated that, “It bothers me I can’t do anything with my husband” due to her careproviding. Queenie, who refused to move in with her mother, felt this way:

I am pissed a lot of the time I’m dealing with her. I have no illusion about it. I got to have help. I either got to move with my mother, or to where some of my sisters are living, or I got to be able to hire someone to come in and help. I can’t do this by myself.

Susan added that, “Sure there are Saturdays and Sundays there I mean I’d like to be out doing other things, instead of doing nothing but sitting back and looking after mother.” Abigail felt “resentful because sometime I couldn’t go
to school functions with my kids like I felt I needed to.” Carolyn, an only child, shared her feelings about her parents’ relations:

The family… would come down and visit a lot and they would take him (father) out to eat (but) would never say ‘why don’t you go somewhere for a weekend, we’re gonna be here for three, four days, stay in my house…and go canoeing, sight seeing, and all those things’?

Madeline felt frustrated trying to coax her (mother) into eating. I would tease, joke, sing, dance, be silly, anything that I could to get her to eat. Sometimes I would need to take a break and go downstairs because I would become so upset and tearful… all I wanted in the world was for her to have that nutrition, when the reality was that she was in the end stages of the disease and the body was shutting down.

Guilt and fear.

Jeane elaborated her feeling when she and her husband wanted to go out to social functions. Jeane declared that, “I just always felt guilty because now when I look back I know I felt guilty because she made me feel guilty. It was always ‘I’ll be here by myself, how long will you be gone?’” Of her father’s institutionalization, Henrietta explored her emotions and stated that, “I had to do with a lot of guilt because I did have to place him somewhere (nursing facility).” As a mother, Henrietta stated that her caregiving “affected me probably more than it did them because of the guilt of not being to be there sometimes.” When her mother was being admitted in a nursing home, Nancy stated that,
I could not take it. My sister was the one that carried her (in). I could not bear it...that I had to take my mama there and leave her into a home. I would love to do more for her...but the situation is I feel guilty inside. Like it was a week and a half before I got to see her (at the nursing home).

Expressing fear about the disease, Fran admitted that, “It’s heartbreaking and to think that I could be in this situation, that’s what’s scary.” Frances stated that,

When they (parents) got sick... it was like I had a newborn baby and I couldn’t get but so far away from the baby because I thought something may happen while I was gone.

Acceptance and gratitude.

Queenie amplified that “Someone had to come and help my mother and I was the one who could do it. It required the least sacrifice and the least amount of adjustment to do it.” Berneice said that, “He was still my dad, so I took care of him.” Oprah felt that, “She’s my mom. She couldn’t take care of herself. It’s my turn and I’m going to take care of my mom.”

Feeling of loss.

Fran reflected “on the sadness of realizing that this human being (mother) with love and joy and now everything is slipping away. It is going away.” Dana shared Fran’s sense of loss when she commented that,

My mother started a business at home. She did custom needlepoint...this was quite successful... she made her own decisions on many things... she was good at adding figures. Then she couldn’t write checks anymore, she couldn’t read. And I found her handwriting had become unreadable.
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Maternal attachment.

Some of the participants exhibited the depth of maternal bonding between mothers and daughters. Abigail: “When she (mother) was younger and when I was younger, we had made a bargain…if anything happened to her I would take care of her. If anything happened to me she would take care of me.” Lyn stated that when her mother was still healthy, her mother “would joke, she would say, ‘you know, we have to go together (die together).’”

Emotional enrichment.

Seven daughters reported feelings of renewal and emotional uplift as a result of their caregiving role. Oprah said that, “I learned a lot about Alzheimer’s. I see myself as a stronger person.” Lyn indicated that,

It (caregiving) has been the most enriching thing that ever happened to me. It has made me stronger, how strong I am. My son, even for his senior yearbook thing (when) he had to write a report about someone that he admired, and he said his mom. He said, ‘I never knew how strong my mom was until she took care of my grandma with Alzheimer’s.’

Madeline articulated that, “The wonderful experience have [sic] enabled me to understand life situation…that death could be a beautiful, beautiful experience and one that enriches our life as children.” Oprah admitted that she “learned a lot …and see myself as a stronger person.” Abigail admitted that she discovered spiritual enlightenment and that it helped her in her struggle to provide care to her mother. Carolyn stated that she “was a better person after that.” Carolyn continued that, “I would not be a happy person today if I had $100,000, $200,000 in the bank but I had put them (parents) in a nursing
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home. I would not be, that would not personally do me any good. Lyn felt that it was a “good experience to take care of mama because I felt I got protection from her being there. I felt that God was in the house and that He was with us.” Paula admitted to feeling satisfied with herself and “just thankful that when I am able to and did.” Abigail serviced her mother for 15 years, and ventured to say “that through the years I felt comfortable there. That was my comfort zone with her.”

Feelings after caregiving.

Twenty-one caregivers participated in the study. At the time of the interview, 10 carereceivers were deceased, six in nursing homes, and five were still in the care of adult daughters. This writer explored the perspectives of the subjects after the death or institutionalization of their wards. Abigail stated that,

It was a load off my shoulder, but on the other hand it was like I was lonesome because I’ve been with her for so many years…and I had a time dealing with being lonesome. I was just free. It was like a new life because …I didn’t have to get up during the night and I didn’t have to do that caregiving thing all day.

Dana entertained mixed emotions by saying that it was like “emancipation” when her mother died but that, “the worst thing about it is my sister is estranged.” As a result of her caregiving experience, Henrietta had “more compassion for other people, had more maturity, better perspectives in life.” Isabella reported that, “After they (parents) passed away you have more time to do more things like you want to do.” Kimberly felt that she had “a lot more freedom, a lot different. I’m well satisfied that I did everything possible for
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my parents.” Nancy declared that, “emotionally it changed my life.” Frances enjoyed her new freedom and stated that, “I can go to Raleigh, Durham and I can spend the night there and…I don’t feel like I have to be right there (with parents).”

Would Do It All Over

Asked whether they would do it again, 20 participants answered yes. One subject was unsure. Asked why, majority of the comments reflected the themes love of parents, responsibility/duty, gratitude, and guilt prevention. Most of the daughters’ feelings were expressed in the following commentary:

1. “Because I just loved my parents.”
2. “There’s a certain responsibility that I feel…we should always be responsible for (aging and feeble parents.)”
3. “This is just an opportunity to give back a small portion of what she has greatly sacrificed for us over the years.”
4. “I was there for them. I’m at peace with myself.”
5. “If I had my mom back, I probably would do it all over ‘cause I don’t regret doing that at all.”

Coping

The writer wanted to know how the participants coped with the demanding and exhausting nature of caring for parents suffering from dementia. Five participants sought refuge by going to church and by praying. Abigail declared that, “If I had not been going (to church), if I did not have my faith I probably could not have kept her (mother) ‘cause I would not have
had the patience.” Frances agreed by saying that she coped “with prayers and praying to God and reading the Bible.” Three subjects resorted to prescription drugs and alcohol. Jeane says that she “was on Zoloft for my nerves.” Henrietta “started taking anti-depressant.” Queenie stated that, “I drink a lot…I drink more than I used to. Having a couple of glasses of wine takes the edge off.” Two adult daughters claimed their husbands’ support and understanding as their coping mechanism. Theresa explained that, “My husband was very supportive.” Two caregivers admitted that knowledge of Alzheimer’s disease served as their coping device. Lyn indicated that she “was doing medical transcription for 25 years and I read everything (on AD), heard everything, watched everything, just anything that I could find out about it.” In addition, Lyn resorted to “laughing” when she was faced with some of the difficulties of her task. Lyn was also her “own therapist, I talked to myself.” Carolyn acknowledged that the patient “wasn’t him (father). It was a sickness. His body was there that was it. It took me a long time to accept that and once I did, it was no problem, none at all.”

Fran said that she,

laugh a lot, take a little short nap. I go out on the Internet. I have a friend who lives in Florida and she talks to me very day and we laugh and play games on Pogo. It’s a lifesaver for me.

Isabella coped by going "to the grave and talk to my parents. I know they're not there." Nancy said that she “cried myself to sleep.” Susan coped by “working outside in my yard and flowers and reading.” Berneice, Gena, and Paula coped by being practical about their role. On nursing her father,
Berneice said that, “it was just like caring for a brother that was older.” Gena coped by “keeping my own life on line. I didn’t nearly concentrate on what was going to happen to mom tomorrow…I tried to maintain a pretty even keel.” Paula offered that, “It was just another part of…what I needed to do and what I feel I should do.” For Rosalyn, she coped by committing her mother in a nursing home.

Advice from Daughters/Caregivers

The participants were asked what advice they would offer to potential family caregivers. Eight caregivers, or 38%, recommended membership in Alzheimer’s support groups. Dana urged would-be-family careproviders “to build a support group because there is so much grief along the way and over and over again.” Fran elaborated, “don’t be afraid to go to it. Don’t be afraid to take that first step.” Queenie recommended joining a support group “because there’s a lot you need to know and they have a lot of good information.” Henrietta cautioned that, “you can take care of them up to a certain point in time…for your own physical and mental well being…get in a support group.” Kimberly advised that, “you can’t be too proud or secretive because there are people that care.”

Lyn expressed the need for support from within the family because it was hard for me to even go to the grocery store or the bank. There were a couple of times I had checks bounced because I couldn’t get to the bank. My husband said he didn’t have time and my son was not driving then.

In the case of inadequate time to devote to caregiving and the absence of nursing skills and knowledge about the disease, four caregivers
recommended institutionalization. Berneice stated that, “if they don’t have the
time…try nursing home or someone to come in and help take care.” Frances
explained the rationale for committing relatives with dementia in a care
facility:

   If they are without nursing experience…like they
don’t know what to do…better get someone that
knows what to do or put them in a nursing facility
or retirement (home) where someone knows
what to do because they won’t be getting much rest.

Oprah had cared for both parents with Alzheimer’s simultaneously. This was
her caregiving advice:

   Go ahead and do it (caregiving) for as long as you
can and then when you can’t do it anymore, do the
next best thing…I know that a lot of people say
that you don’t put your loved ones in a facility.
There’s a point in Alzheimer’s where there’s nothing
left to do, unless you have a lot of money, then you could
pay someone to come and stay forever day and night.

One daughter decided not to offer any advice and another caregiver insisted
that caregiving was a family decision. One daughter contended that to become
a family caregiver was a personal choice. Several daughters/caregivers offered
advice that ran the gamut of patience, spiritual guidance, meditation, and
expressions of love. Nancy amplified the theme of patience: “it takes a lot of
patience because the person that you know is not there anymore and it’s really
hard to get with it.” Rosalyn added that, “it takes a lot of patience, maybe a lot
of crying.” Gena offered

   the need to pray for a lot of spiritual guidance for the
moments that will catch you completely off guard when
you have a low day and a high day, to be able to bounce
back. Find ways to give yourself a little bit of relief, if it’s just walking around the yard, tending to the flowers, or cooking, singing in the tub...’cause when you begin to feel sorry for yourself...begin to question yourself--you look at the TV and say ‘why me?’

Madeline advised would-be family careproviders to calm down inside, to take time for meditation...you can’t touch them enough, holding their hands, rubbing their back, massaging their feet, putting lotion on them. Love them and go with the flow...not be a compulsive perfectionist in caregiving.

Daughters-in-Law

Two daughters-in-law were interviewed in connection with this study. Their ages were 47 and 70. The ages of the carereceivers were 83 and 85. All caregivers were Caucasians and married. One husband was an only child in the family and the other one was the eldest in his family. Their length of caregiving was a year, and five and a half years. The same coding categories used in the larger sample were applied to daughters-in-law.

Becoming a caregiver

Anna, 70, and her husband Andrew, 63, retired at the same time and settled in a little coastal town. A year after retirement, Andrew assumed guardianship of his mother. Anna became a caregiver to her mother-in-law. Permission from Anna’s husband was obtained for her to participate in the study. At the time of the interview, Anna had been a caregiver for five and a half years. Anna explained:

My husband is the eldest of four children...and his brother and sisters were still at work. So we were the only ones that were available that could take care of her (his mother).
Brenda, 47, switched jobs from being a dry waller (in building construction) to being an Alzheimer’s caregiver. Her husband had full guardianship of his mother. Permission from Brenda’s husband was obtained for her to participate in the study.

At the time of the interview, Brenda had been a caregiver for over a year. Brenda stated that,

I broke my foot on the job. So I’m sitting around the house, at home, for about eight months. And we’re paying on the nursing home. And Bob said, ‘would you consent to take care of her (his mother), since you’re not doing anything anymore?’ And I said yeah.

Changes in Lives of Daughters-in-law

Anna: We lived and worked in Raleigh…retired and so moved down to the beach. We had a place down there. We got to do what we wanted to do, we were together. If we wanted to go to Raleigh, we did, if we wanted to stay here, we did. And we had a good life. Well, at the end of one year was the (time) she came to live with us.

Brenda: I wanted to learn to play the piano. I have a little room set aside for painting. And I took classes…beginning piano and painting. I had to drop out of both classes.

Role Perceptions of Daughters in-Law

According to Anna, she saw her caregiving role as being very important to her. She elaborated:

I see myself as being blessed to still have her and be able to do it. She’s family. I look at it as an opportunity to help her when she needs help. She helped us a lot when we first got married.
Brenda perceived her role as one “to nurture her and protect her. I’ve been taking her to too many doctors and dentists and stuff that I don’t have time to take care of myself. And as you get older it gets far worse.”

Beliefs of Daughters-in-Law

Anna declared that, she doesn’t see it as drudgery. She’s family and I love her. I took over as the primary caregiver because I was female. He (husband) did not feel comfortable attending to her. I had a lot of time on my hands and I caught myself doing nothing and being useless. And now I feel like my life is useful. I feel that my health may be better by taking care of her, has probably kept me more active and maybe that’s why the Lord let me keep living as good as I am.

Brenda expressed her belief by saying that, “A woman has to pull her weight. You just can’t clean house and expect to be supported. If I’ve taken a caregiver class, I would have been better equipped to do this (caregiving).”

Coping and Daughters-in-law

This writer asked the participants how they coped with bad days and low points in the course of their caregiving. The following were their responses:

Anna: I have thought about the why me…and I realize that there’s no profit in it and I’m only feeling sorry for myself. I try to take a break, get away from it…go to the grocery store, or just visit Dairy Queen and get me a banana split or something.

Brenda: I keep reminding myself that this is a better job than the one I had before (a dry waller), that I finally got off a job that was killing me and this is an easy job.
Would Do It All Over

All two daughters-in-law responded that yes, again they would provide care to parents-in-law with Alzheimer’s. This acceptance was synonymous with that of adult daughters.

The findings in this chapter answered the research questions that guided this study. Through their own voice, adult daughters presented the changes that had occurred in their lives as a result of nursing elderly parents with AD. Through their own words, participants conveyed their perceptions, beliefs, and feelings as family caregivers. These changes, perceptions, beliefs, and feelings are discussed in the next chapter.
Chapter V

Synthesis, Discussion, and Recommendations for Practice And Research

This chapter presents the synthesis of the descriptive data, the conceptual model, and the research questions. Meaningful variables and pertinent findings from the literature are discussed, as well as implications for practice and research.

Synthesis and Discussion

This case study presents a portrait of how the lives of family caregivers were altered with the onset of Alzheimer’s disease. In addition, based on in-depth and face-to-face interviews with 21 adult daughters and two daughters-in-law, this report examined the beliefs, feelings, and perceptions of adult daughters as they provided service to aging and cognitively impaired parents.

What do the findings convey to the understanding of familial care? The narratives of adult daughters parallel what we know about the principal role of women in intergenerational care, as well as the changes and upheavals they encounter. The phenomenon of adult daughters becoming the primary source of care to parents suffering from AD has linkage to linear position in the family. Almost half of the participants represented the eldest child in a family and who was over age 60. This finding is in harmony with the argument presented by Guberman et al., (1992) that birth rank in the family and the age of caregiver serve as a determinant in the role of caregiving, and that, “the gender of the potential caregiver is the most important and most constant indicator of involvement in caregiving” (p.607). Other contributing factors that drove adult daughters into the caregiving service were direct appeals from parents and the lack of alternatives. Frail parents are known to turn to
adult children for assistance; cognitively impaired parents possess strong feelings against institutionalization. The escalating cost of health care and the availability of fewer governmental health programs and assistance are a strong influence in the decision of most adult daughters to assume informal care.

The findings revealed that geography, availability, and convenience propelled most adult daughters of the study in the army of family nursing. Lifestyle in the United States is highly mobile. Mature children seek economic opportunities in distant places. Consequently, adult daughters who lived in close proximity to parents suffering from AD were more than likely to provide care by virtue of location. Further, where some siblings in a family were preoccupied with marriage maintenance, raising children, employment, and mortgage upkeep, others with the least commitment and obligations became the family nurse. Adult daughters who were divorced and preferred not to remarry, widows, the unemployed, and empty nesters found themselves as the most likely candidates to take care of parents with AD. According to Brody (1990) and Mancini and Blieszner (1989), families use a selection process that favors the adult daughter with the fewest competing responsibilities to assume the role of careprovider.

The demand and impact of intergenerational caregiving are felt and observed in almost every aspect of the lives of adult daughters. The pressure of caring for parents who are old and ill weighs heavily on the shoulder of the family caregiver. Based on the findings, these changes range from living arrangements, family relationships to employment, which are discussed below.
Living Arrangements

The findings showed that over half of adult daughters providing care to frail and ill parents either moved in with patients or relocated parents to adult daughters’ homes. Shared accommodations were a source of turmoil for everyone concerned: patients tended to become disoriented and uncomfortable in new surroundings, and family members felt deprived of space and privacy. Co-residency was a source of friction between husbands and wives. These findings support Berman’s (1996) warning that adult daughters who share a household with sick parents provide round-the-clock care. This enterprise is so demanding and debilitating that it is called the 36-hour day. Miller (1989) amplifies that adult daughters’ who share housing with care receivers are susceptible to higher levels of burden and stress.

The narratives demonstrated that nearly half of parents who were in the second stage of the disease lived alone and faced greater risk to themselves and their surroundings. That parents already mired in the quicksand of Alzheimer’s were living by themselves may be traced to adult daughter-parent relationships. According to the findings, some adult daughters who harbored less than ideal experiences with parents felt that they could cope better as family care providers under separate roofs. The findings were consistent with what Mancini and Blieszner (1989) determined that some adult daughters believed in extending assistance to parents when needed but such belief did not extend to sharing household with parents.

Personal Relationships

The findings showed that three daughters in the study paid a heavy price for the role to nurse parents’ suffering from AD. The marriages of three participants
Life changes of adult daughters

disintegrated as a result of family nursing. Slowly and insidiously, the disease chipped away 30 years of married life. The daily stress and tension encountered by adult daughters allowed them to become insulated into their own little world of Alzheimer’s and to develop tunnel vision. Adult daughters became so used to their loneliness that in the long run they found it comfortable enough to call it their “comfort zone.” Unfortunately, this private world was so exclusive that it did not include their husbands. Spouses who were lacking in patience and understanding became “disinterested” and drifted away from marital domain. Others resented the punishing commitment their wives had assumed, and ended the relationship.

The literature on marital conflicts confirms that spouses may be a source of extra load to a daughter who is already weighed down by the burden of caregiving (Brody, 1990). The responsibility of caregiving left no room at the emotional inn and made some adult daughters admit, “I don’t feel like I was a wife.” Being a family nurse meant very little precious “time left over to be a wife.” The extended duration of the disease also took a toll on husbands’ tolerance. There were spouses in the study who could not accept the pressure of continuous care and their cups became full. For these spouses of careproviders, divorce was the next option.

The common thread among adult caregivers with failed marriages was the length of service provided and aversion to institutionalization. Based on the findings, extended caregiving for daughters with spouses requires rock steady relationships. The relentless strain brought on by caring for a parent at home may be sufficient for some marriages to disintegrate.
Reduced Social Life

The findings suggested that to become a caregiver is to spend less time with others. A job that requires twenty-four hours/seven days on site hardly leaves any room for socialization. Majority of adult daughters bemoaned the lack of time and interpersonal contacts that could offer them respite. And even if such temporary relief were available, the fear that something might go awry with sick parents while they were gone prevented them from venturing out. Although some couples in the study deliberately turned down social invitations rather than leave AD victims unattended, others were practical enough to seek camaraderie within the spheres of Alzheimer’s. Fran declared that support groups “were my social life.” Still for some caregivers, church fellowships and activities with parishioners filled the social void. Single/uncommitted daughters missed out on the opportunity to join cohorts in common ambiance and social assembly as illustrated by Carolyn, Frances, Gena, Jeane, and Queenie.

The literature comments that social life is significantly reduced when AD sufferers share housing with families. Keepsake (1998) found that seven out of ten caregivers hesitated to leave their wards alone even for brief periods.

Joining support groups may assuage the brunt of social isolation, as was true of some daughters in this study. A caretaker who shies away from human interactions may be putting her own physical, emotional, and mental health at risk (Greenberg, Seltzer, and Greenley, 1993; Mayo Clinic, 2002). Support meetings afford frazzled daughters a forum to express their thoughts and feelings about unpaid nursing. A support group facilitates exchange of survival skills and strategies.
Support groups may not be for everyone (Mace and Rabins, 1999; Mayo Clinic, 2002; Perry, 2001). Some caregivers may not feel comfortable opening hearts and mind to virtual strangers. Others consider the symptoms being exhibited by AD patients as private information.

**Family Conflicts**

The findings revealed that family disharmony may be generated by the lackadaisical nature of support, the absence of support from other family members, inheritance issues and family squabbles. Dana’s sister would visit her mother infrequently and when she did she would look at family albums with the AD patient. Dana perceived this as an empty and shallow gesture. Abigail’s sister lived close by her house and her sister’s non-participation in the care of their mother was an irritant to Abigail. Jeane’s millionaire brother had distanced himself from his sister and mother with the rationale that he was not interested in any inheritance money. Lyn’s protracted contest with her sister and extended relatives was centered on power struggles and ignorance about the nature of AD. As the primary caregiver, Lyn made the legitimate decision to nurse her mother at home. Her sibling and relatives were of the opinion that the AD victim could be better serviced in a professional facility.

Other research suggests that sporadic help is usually given at one’s convenience and leisure and that it may be viewed as a half-hearted attempt to become involved. Dissociation occurs when a child cannot be counted on to help and this occurrence is applicable to both genders (Walker et al., 1995).

Gruetzner (1992) argues that AD is a form of crisis that is conducive to conflicts involving all family members. Conflicts within the family are a hindrance to
coming to a clear approach to problems. This statement is appropriately applied to Lyn’s situation with her relatives. Long after the death of the AD victim, Lyn, her sibling, and other relatives were not on speaking terms.

**Challenging the Primary Caregiver**

The findings revealed that caregiving and financial decisions of the principal careprovider were often questioned and countermanded by other siblings. Some would go to the extent of surreptitiously coming to town to take the AD victim to a doctor of their choice. Queenie did not find out that her sister, who was based in another state, took her mother for diagnosis until she received the billing statements. Another finding from this study that is in accord with Queenie’s experience involves Fran and her sister, who was a resident of another state. Detached from the daily grind of caring for an AD sufferer, her sister’s infrequent appearance would be full of care ideas and suggestions. Needless to say, the sisters’ reunion would often end in angry confrontations. Principal caregivers often lamented that siblings did not carry their share of the burden and their efforts were unrecognized. Berman (1996) posits that filial hostility is linked to disparity in the distribution of responsibilities among siblings. Although a sibling is designated as the primary careprovider, others are not unhappy about the setup, which leads to ill feelings and resentment.

**Employment**

The findings indicated that as some adult daughters quit work to concentrate on nursing mentally ill parents, others preferred to remain employed. For Dana, her work was important to her inasmuch as she went back to college and finished higher education when she was middle aged. Dana resorted to using her medical leave
benefits in order to keep her job. Jeane juggled her schedules among work, her husband who had cancer after receiving a heart-transplant, and her mother who had dementia. Jeane amplified that her job “kept my sanity.” On the other hand, Queenie found out that due to regional economy, her current earning in retail industry paid less than half of her income in another state. Meanwhile, Carolyn was fortunate enough to be working for an organization that had liberal policies and was solicitous of her situation.

The decision to continue to be a working caregiver is compatible to that advocated by Walker et al., (1995). The authors assert that in spite of possible pressure and tension brought about by employment, working adult daughters find sanctuary and relief in the workplace due to social and financial advantages derived from sympathetic co-workers and income from paying jobs. The workplace offers working caregivers a sense of control as well as professional and personal satisfaction.

Economics

Not enough information was obtained relative to finance and caregiving due to the timidity of most adult daughters to discuss this issue. However, the extended life span and the slow degenerative process of AD eventually put a drain on the assets of many families, as indicated by the findings of this study. It is not uncommon for AD victims to live 12-15 years, during which the level of care changes with the progression of the disease. As indicated earlier, in the face of staggering costs associated with the disease and limited resources, family members on many occasions
opted to take infirmed parents into their homes until the debilitating condition demanded confinement in nursing facilities.

At the onset of the disease, Dana and her husband bought a larger house that they could share with her mother. As with many AD patients, her mother eventually ended up in a nursing home, where she died. Dana admitted the difficulty of maintaining a large home and a large mortgage payment. She considered this a problem brought upon by AD. Madeline and her husband built an addition to their home to accommodate her mother. Complications from AD resulted in her mother going to a nursing rehab, where she quickly deteriorated. Madeline’s mother never came home. From the rehab center, she was admitted to a nursing home where she died.

A number of adult daughters whose parents had real estate properties were knowledgeable enough to transfer such holdings to their names when they started their caregiving career. As an example, Fran and her husband were living in her mother’s house. Her mother owned two more real estate properties in the same neighborhood. Titles to these assets were transferred to Fran’s name. This transaction had to do with eligibility for nursing home admission, finances of the family, and the federal health system.

Three adult daughters decided to keep their parents at home until the very end. Carolyn quit her job to care for her father. She soon depleted her savings, lost the family home through foreclosure, and she went on welfare. Her father was 91 years old when he died. The value of his term life insurance policy was insufficient to cover the cost of burial. Although Lyn’s mother had considerable assets, Lyn had been
tapping her savings to supplement the ever-increasing cost of supplies and medication. Lyn was on the verge of having to mortgage her house when her mother died. Abigail’s mother died at home. She did not discuss monetary affairs with this researcher.

The findings of this study relative to adult daughters who had lost their savings, homes, and had to seek government assistance appear compatible with what the literature offers. According to a survey, a third of caregivers had lost their homes, had gone bankrupt, or suffered major financial losses as a result of caring for relatives on an extended basis. Six caregivers in ten contributed financially to the support of relatives with AD (Lieberman, 2000).

Health of Adult Daughters

The findings suggested that caregivers were subject to a high rate of physical illness and fatigue. Adult daughters experienced health problems ranging from arthritis to osteoporosis. Depression was a common condition with adult daughters, along with lack of sleep, weight loss, elevated blood pressure, and tangled nerves. At times sheer determination made it possible for Isabella to continue taking care of her parents, in spite of her severe arthritic state. Frances discovered she needed surgery to remove gallstones; Carolyn developed cancer shortly after the death of her father. Lyn’s degenerative disc problem was serious enough to qualify her for disability. She did not apply. Because daughters/caregivers continued their duty to serve despite physical limitations and pain the scenario, at times, it appeared like the sick servicing the sick.
Some studies illustrate that elderly, unpaid caregivers (65 and older) who became stressed are 63% more likely to die than their non-caregiving peers (Levine, 2002). Prolonged exposure to stress affects the immune system negatively in the form of infectious diseases, such as the flu. Understandably, the elderly, who may have low tolerance to communicable disorders, may also be slow in recovery.

Religion

The findings disclosed that religion was a strong component of the caregiving experience for many daughters. Although one adult daughter terminated membership in her church due to an unfavorable incident with clerical administrators, another participant admitted to finding religion in the course of her caregiving. Abigail acknowledged that her spirituality played a positive role in the 15 years that she was her mother’s personal nurse. Emma’s only refuge from the exhausting time she spent with her mother was the local Korean church. Emma explained that at the house of worship she prayed and socialized with her fellow Koreans, a situation she considered comforting.

Others drew on religion as a rationale to provide care. The relationship between Queenie and her mother was lukewarm at best. Moving all the way from California, she refused to live with her mother. Queenie believed that in the world of Christianity the able were responsible for those unable to care for themselves. As indicated earlier, Lyn’s caregiving career was laced with mayhem and chaos coming from soured relationships with her husband, sister, and other relatives. With her infirm mother in the house, Lyn “felt protection from her being there. I felt that God was in the house, that He was with us.”
There are some suggestions in the literature that spirituality could be a favorable tool in health care and pain management (Blackwell and Stern, 2001). Commentary on this particular subject belongs to the professionals in the field of medicine and the health industry.

**Role Perceptions of Adult Daughters**

The world of informal caregiving is balanced on the shoulders of adult daughters who are overworked, unpaid, and unappreciated. This study explored how adult daughters in the mysterious world of dementia and elderly parents saw their role. The findings disclosed that adult daughters perceived their nursing role rooted in duty, reciprocity, family value, role emulation and role reversal. In addition, some of the adult daughters’ perceptions pointed to the role as manager of their parents’ health and estate.

Fran’s relationship with her mother was conflicted, but being the “dutiful daughter” that she was, her mother became her ward. As the youngest, Nancy’s sense of giving back discounted her other six siblings. She took a good look at the situation and made the decision that her mother was joining her household because she “has always been there for us.” For some adult daughters the value system in the family was hard to ignore: family members take care of other family members. Berneice was an example of this code. Her father remained in the family home until his condition warranted care received only in a nursing home. When Dana’s mother developed Alzheimer’s, it was her turn to be the caregiver. For a child to be the parent and vice versa was heart wrenching that scarred the psyche. Kimberly viewed it eerily as role reversal nearly engulfed her own personality. Role reversal was painfully stressful for
both caregivers and carereceivers. Caregivers felt uncomfortable and often guilty with their role; parents abhorred loss of autonomy, self-respect, and dignity.

Simultaneously, a person with AD is also a victim of other health disorders. Anxiety, depression, sleep disorder, complications in the form of urinary tract infection, dehydration, malnutrition, and other diseases that accompany the aging process necessitate frequent trips to the doctor and filling mounting prescriptions. At times medication management could be a formidable chore for caregivers. Lyn commented that it would take a good part of a day to count the pills for her mother’s symptoms. Madeline found it necessary to monitor the numerous medications that her mother was taking, and would advise her mother’s doctor as to the effectiveness of prescriptions.

How adult daughters saw their role in intergenerational care was linked to findings in the literature that predisposed women to become suppliers of care to elderly family members. Previous research indicates that sense of duty is a motivating influence for adult daughters to embrace the part of careprovider (Berman, 1996; Guberman et al., 1992). Duty was dispensed in the absence of affection. However undesirable the relations between daughters and parents, adult daughters followed the yen to make things better for the infirm in the family. It is what had been embedded in womanhood and what had been instilled cyclically in the life course: women are nurturers; caregiving is defined as a woman’s role. Most of the women in this study exemplified this attribute.

This study yielded an unexpected result that does not support other research suggestions relative to adult daughters and caregiving. Adult daughters who suffered
physical, emotional, and mental abuse by parents during childhood provided care as well. This finding is inconsistent with the argument posed by Silverstein, Parrot, and Bengston (1995) that early discord in families was an influence in the decision to service aged and feeble parent. The findings argued that past negative experiences between parents and adult daughters were not a factor in the decision to provide nursing care.

In addition, the findings confirmed the literature’s position that most adult daughters do not seek help for themselves in their silent struggle to nurse mentally ill parents. In this connection, adult daughters are considered the victims of Alzheimer’s disease (Gruetzner, 1992).

Another fascinating finding was that education could be a powerful tool for caregivers. Based on this researcher’s attendance in support group meetings, the task of adult daughters could be less stressful if they have an understanding of the disease; what makes a patient do and say. As an example, it is common for patients to accuse their caregivers of some deeds, such as stealing and lying. Instead of being confrontational and engaging in endless arguments, the caregiver should recognize that patient’s accusations are a reaction to the feeling of insecurity caused by memory loss. AD victims mask their fear and disorientation by negative actions and words. Caregiver’s contradictions only fuel victim’s agitated state.

Beliefs and Family Obligation, Personal Sacrifice and Burden

The findings disclosed that a majority of adult daughters strongly endorsed that caring for frail and elderly parents was a family obligation and a personal sacrifice; caregiving was not a burden. As mentioned earlier, adult daughters believed
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that caring for aging and sick parents was what families stood for. Although a good number of adult daughters did not consider caregiving as a burden, a few acknowledged, however, that caregiving was a burden if it extended to ten years.

The narratives of this study confirmed what the literature asserted that women were at the top of the ladder of careproviders. In general, a traditional role attitude is characterized by the inclination to support gender role specialization according to traditional norms, with women attending to care for the home, husband and children, and men attending to paid work. Women are socialized to be nurturing in their social affiliations and relations (Silverstein et al., 1995).

Feelings of Caregivers

Institutionalization.

The findings revealed that 43% of adult daughters did not support placement of parents in nursing institutions. Three daughters remained on the job as caregivers with parents in their homes until the death of patients. With the exception of five participants who were still servicing their mothers at the time of the dialogue, the remainder of the sample eventually placed their wards in nursing facilities. Of the five whose task was still ongoing, three daughters shared housing with AD victims, and two caregivers lived separately from their parents. Questioned, however, if they would place their parents in institutional care, 57% answered in the affirmative.

The literature is clear on the subject of institutionalization: we do not want our parents to end up in a nursing home; parents do not want to be placed in home facilities. The progression, duration, and nature of Alzheimer’s disease all lead towards placement. The high level of stress on the part of caregivers, unmanageable
behavior of patients, and the lack of support eventually precipitate the need for professional care for so many patients. Caregiving has its limitations (Gruetzner, 1992).

**Alienation and social isolation.**

The findings indicated that feelings of abandonment were rampant among adult daughters. The demands and challenges of Alzheimer’s left caregivers occupied most of the day and night. Friends, relatives, neighbors, and co-workers avoided contacts. The telephone did not ring on weekends. Some individuals had a low level of tolerance to the smell of sickness and avoided it at all cost. Others just stayed away. For single caregivers, the alienation and social isolation generated by the disease had deeper consequences in terms of missed social opportunities and potential relationships. In the words of a single daughter: caring for parents with Alzheimer’s had caused her to “forego a lot of relationships.”

**Guilt and feeling of loss.**

The findings demonstrated that most adult daughters constantly lived with the feeling of guilt. Anger over constant repetitions of questions by patients made caregivers “to want to scream” and temporarily lose control, which was followed by deep remorse. In addition, guilt gnawed at adult daughters on the perception that they were not doing enough for sick parents and for neglecting their own husbands, children, and family responsibilities. Additionally, adult daughters felt guilty for harboring impatience over death of parents with Alzheimer’s. The disease robbed adult daughters of the little pleasures in life because they had missed out on their young children’s activities. A caregiver forever missed that expression on her
daughter’s face when she kicked the winning score in a soccer championship game. Reflecting on her non-attendance to her sons’ school activities one participant lamented that, “you can’t go back in time, I mean it’s gone.”

**Frustration and resentment.**

The findings revealed that resentment came in the form of giving up couples’ dream of enjoying the golden years of their lives. Many adult daughters who were middle aged were looking forward “to having the freedom and the income to go and do” that for which they had been working and planning. One adult daughter in the study stated that her “daughter just graduated from college” and she and her husband were planning to go on trips; instead she found herself making trips to the bathroom with her mother. Weeping almost uncontrollably, another caregiver resented the fact that she had been servicing her mother for 15 years; that she “regret this openly,” and “would rather have my own life.” That adult daughters resented their role could be summed up when a participant stated that, “you think you got all your life all set…all of a sudden all that comes to a screeching halt.”

The literature provides ample documentation confirming the feelings of adult daughters, who were overwhelmed by their emotions. The nature of caregiving generates emotional responses such as alienation, guilt, feeling of loss, social isolation, and resentment. Addressed collectively, these powerful emotions are linked to the makeup of AD. Some of the symptoms of AD may be assigned to other ailments, until such time as a clear diagnosis is made. Behavioral symptoms may appear in varying degrees and intensity that are often ascribed to stress or interpersonal relationships. Most importantly, the duration of the disease—10 to 15
years—more than enough to tax the most able-bodied careprovider and drain most resources (Gruetzner, 1992).

**Emotional enrichment.**

The findings indicated that in spite of obliterated marriages, financial and emotional bankruptcies, and the daunting nature of their job, many participants in the study were quick to admit the positive influences of caring for parents with AD. The majority of daughters indicated gaining personal strength and becoming a “stronger person.” Some found themselves “happier, if not materially richer.” Others had found “peace of mind and satisfaction with themselves,” having performed what they considered a filial commitment. One daughter discovered a new dimension in death and mortality. The participant indicated that caregiving “make (her) understand life situation…that death could be a beautiful, beautiful experience that enriches our life as children.”

An interesting finding was that of a participant who suffered from chronic pain before she assumed the care of her mentally ill mother. She disclosed the absence of pain while she was a caregiver. Lyn attributed this to a Higher Power that also gave her a physical sense of security in her home, regardless of the presence of a husband who was physically abusive. The medical and psychological merits of this situation are beyond the scope of this investigation. The literature suggests that caregiving offers positive and negative effects. Undoubtedly, the negative results are easily recognizable. Positive results, such as feelings of accomplishment, satisfaction and elevated self-esteem, are similar to some of the findings of this study (Greenberg, Seltzler, and Greenley, 1993; Miller, 1989).
To Do It All Over

With the exception of one daughter who was unsure, 20 caregivers indicated willingness to assume their caregiving role all over. Asked why, the answers reverted to feelings of affection, duty, responsibility, and reciprocity.

Acknowledging our physical and mental limitations, membership in support groups was highly recommended by participants to potential family caregivers. It takes a degree of humility to join support groups. Joining a support group is a personal choice. This is line with what the literature suggests that support groups are not for everyone (Gruetzner, 1992; Mayo Clinic, 2002; Perry, 2001).

To care for an AD patient is physically and emotionally taxing. An adult daughter who has assumed the role of solitary nurse to an AD sufferer is likely to become more isolated physically and socially. The nature of the disease is conducive to family discords and disagreements, inasmuch as the AD patient, in the course of the illness, is unable to represent herself or himself in the midst of conflicting voices from family members. Some family members may be reluctant to be involved in the demanding care and decide to distance themselves. Other siblings may harbor differing views about the care being provided. In some instances, an adult daughter may be an only child and the exclusive supplier of care. Consequently, social isolation is a frequent companion of family caregivers. The absence of support from within the family unit is demonstrated when an adult daughter had to allow checks to go on overdraft because she could not leave her ward to make a trip to the bank to make deposits. Membership in support groups could alleviate the sense of isolation and reduce the hardships of providing nursing care to elderly parents with AD.
Daughters-in-law

Adult daughters were the sample of this research. However, two daughters-in-law were incorporated within the study and will be discussed briefly. These two daughters-in-law—Anna and Brenda—had been serving as caregivers to parents-in-law from one year to over five years. The findings revealed parallelism between adult daughters and daughters-in-law relative to principal source of care to parents/parents-in-law with dementing illness. The two subjects were not legal guardians of their parents-in-law—they were the primary caregivers—and their husbands were legal custodians. Daughters-in-law assumed responsibility of care through imposition of husbands and for economic reasons. Anna’s husband was the eldest child and only son in his family. He and his wife were retired before his mother came down with AD. As with first born adult daughters who became responsible for primary care due to their availability, this eldest son was designated legal guardian by his family on the basis of convenience, accessibility, and the presence of a daughter-in-law. His siblings were still active in the work force and household management.

Brenda’s husband was an only son. Brenda assumed the role of principal careprovider because of confinement at home as a result of a work-related injury, as well as the son's desire to save on nursing home expenses. Brenda saw dual reasons to assume care: her strong sense to contribute to the household—"a woman has to pull her weight here. You just can't clean house and expect to be supported"—and the welcome relief to quit a grueling job and stay home.
In line with the findings in the literature, caregiving could be a source of positive outcomes as well (Greenberg, Seltzler, and Greenley, 1993; Miller, 1989). In the narrative, Brenda gladly switched from construction work to caregiving. In addition, the lack of other options, a common grievance in the field, was a determinant in family nursing that is also applicable to daughters-in-law.

These daughters-in-law saw their role in multiple dimensions. Whereas one considered their caregiving role as essential to the well-being of patients, another looked at it with feminine sense of caring for the needy.

Beliefs and Feelings of Daughters-in-law

The findings indicated that the two daughters-in-law in the sample considered caregiving as a family obligation. In the absence of blood relationships, there was a common bond running between adult daughters and daughters-in-law relative to beliefs, feelings, and caregiving. With the exception of one participant, love was not a factor in providing nursing care to parents-in-law; however, care was motivated through love of husbands. These two daughters-in-law did not consider caregiving as a personal sacrifice, citing a gamut of rationale ranging from "too many rewards" derived from caregiving to family ties. Participants viewed the burden of caregiving with mixed feelings, alluding to caregiving as an opportunity to serve other family members to plain acceptance.

As with their adult daughter counterparts, daughters-in-law deemed nursing their in-laws as a form of reciprocity for goodwill earned earlier and the striking but almost cliché sounding comment: "because I was female." Others admitted to gaining a purpose in life. Although there was a feeling of resignation between the two
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subjects, in that they did not feel deprived, equally prevalent was the desire to want to get their life back. A daughter-in-law who regarded nursing her husband's mother as a source of respite from a paid job was rather vocal when she stated that caregiving "sucks your blood out of you."

The literature argues that non-blood relatives, such as daughters-in-law, are also products of socialization (Walker and Allen, 1991). Results of the findings in this study complement those in the literature. Only sons assume caregivership to sick parents only in the absence of available female siblings and are more likely to depend on spouses to perform functions of family nursing. In addition, sons as careproviders are likely to provide less extensive support compared to female caregivers. The literature advises that elderly parents who depend on only sons are at a disadvantaged because they do without the extra instrumental aid that daughters provide (Silverstein, Parrott, and Bengston, 1995; Walker, Pratt, and Eddy, 1995). However, this is counteracted by the availability of daughters-in-law stepping in as primary caregivers.

Recommendations for Practice and Research

This study sought to understand the changes in the lives of adult daughters as they assumed the role of primary caregiver to parents suffering from Alzheimer’s disease. The research explored beliefs, feelings, and perceptions of participants as careproviders. There is an immediate need to examine the continued availability of women to provide care for elderly family members. National trends that support this issue are the increasing participation of women in the labor force, women marrying late, declining birth rate, and the burgeoning elderly population.
It is recognized that most women providing long-term home care are reluctant to seek help. It is important to reach these unpaid caregivers before the occurrence of a crisis involving their role as caregivers, their employment, and their wards. Local community health facilities and centers for the aging are urged to initiate more aggressive information campaign by print, radio, and television to make their services known and to persuade these timid careproviders to come forward. It is hoped that other institutions and groups, such as cooperative extensions, organizations of retired persons, libraries, community clubs, and churches, may consider the results of this study as a resource in their efforts to assist, educate, and aid caregivers in the performance of an arduous task, and to provide comfort to elderly parents who are confined to the mysterious world of Alzheimer’s disease.

**Conclusion**

Nonformal careproviders are the foundation of long-term care in the United States. Women continue to subsidize social policies and programs by their availability and willingness to care for frail family members. Their availability and willingness appear to encourage that caregiving is viewed as natural for women and that women are designated family careproviders.
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Appendix A – Consent Form

NCSU Institutional Review Board for the Use of Human Subjects in Research

RESEARCH PROJECT: THE LIFE CHANGES THAT ADULT DAUGHTERS GO THROUGH WHEN THEY BECOME PRIMARY CAREGIVERS TO PARENTS WITH ALZHEIMER'S DISEASE

I, ____________________________ , agree to be interviewed for a dissertation study regarding THE LIFE CHANGES THAT ADULT DAUGHTERS GO THROUGH WHEN THEY BECOME CAREGIVERS TO PARENTS WITH ALZHEIMER'S DISEASE. Notes will be taken during the one-on-one interviews. The interview will be audio taped. I understand that I will be interviewed for approximately 90 minutes, with the option of a second follow-up interview at a later date. I agree that my reflective narratives may be used in the study.

The interview(s) will be confidential. I understand that only Herminia Thacker will have access to this consent form that links my name with my subject number. At the conclusion of the study, the audiotapes, identifiable only by subject number, will be destroyed. Under this condition, I agree that any information obtained from this research may be used for the publication or educational purposes of the researcher only.

There is no anticipated physical or mental risk to me, since my participation is limited to exchanging information through interviews with Herminia Thacker, the researcher. I understand that I am free to withdraw my consent and discontinue participation in this study at any time.

I have been given a description of the study through an initial introductory letter. I understand that if I have any problems or questions in connection with my participation in this study, I shall contact Herminia Thacker, the researcher, at (910) 743-2984, or Dr. Conrad Glass, Jr., faculty advisor for this project, at North Carolina State University, telephone number (919) 515 6238.

_________________________   ______________________________
Date                                                                    Signature of Volunteer
Appendix B – Interview Questions

1. Please share with me how it happened that you ended up as the caregiver to your mom/dad. How did it come about?

2. How was the decision made? Were your sibling(s), husband involved in the decision making process?

3. Share with me a typical day with your mom/dad.

4. How long have you been providing care to your mom/dad?

5. What kind of support do you receive from your sibling(s), husband, children?

6. Who is the eldest in the family?

7. If community services are available, such as adult day care, wheels on meals, support groups, home health care, visiting nurse programs, which of these programs do (did) you use? Why, why not?

8. How do you cope with the stress, pressure and demands of your role?

9. How long do you think you can keep it up?

10. What would happen to your mom/dad/in-law if you become incapacitated?

11. How and when would you consider placing your mom/dad in a care facility?

12. How do you see your role as the careprovider?

13. Which of the following most describes your caregiving situation. Please elaborate on your choice.

   a) family obligation
   b) personal sacrifice
   c) love of parents
   d) religion
   e) none of the above
14. Share with me your feelings about your position as:
   a) wife
   b) mother
   c) career woman (if applicable)

15. If applicable, who looks after your parents while you are at work?

16. When do you consider caregiving a burden? why, why not?

17. Share with me your life before you became responsible for the care of your mom/dad.

18. How is it different now? What are your feelings about the change?

19. What was your relationship like with your mom/dad when you were growing up? into adulthood?

20. What was your relationship like with your sibling(s) when you were growing up? into adulthood?

21. How is (was) your caregiving affecting your:
   a) work (if applicable)
   b) home life
   c) relationship with your husband
   d) children (if applicable)
   e) social life

22. Having experienced first hand what is involved in caring for a sick parent, would you do it all over? why, why not?

23. What advice would you offer to someone wanting to care for a parent with Alzheimer's?