LIVING WITH ALZHEIMER’S DISEASE: AN EXAMINATION OF
CAREGIVER COPING MECHANISMS

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by
Mary L. Dolan
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This thesis has been approved by

The Honors Tutorial College and the Department of Social Work

_________________________________
Dr. Richard Greenlee
Dean, Ohio University Eastern Campus
Thesis Advisor

_________________________________
Dr. Karen Carlson
Honors Tutorial College, Director of Studies
Social Work

_________________________________
Jeremy Webster
Dean, Honors Tutorial College
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Introduction

Dementia refers to a group of symptoms and not a specific disease. These symptoms affect “… intellectual and social abilities severely enough to interfere with daily functioning” (CNN Health, 2009). Though memory loss is often associated with dementia, dementia traditionally indicates problems with at least two brain functions. In addition to memory, damaged functions may include judgment and language (Alzheimer’s Association, 2010). The type of dementia suspected is often associated with its cause, of which Alzheimer’s disease is the most common (CNN Health, 2009). As many as 5.3 million Americans suffer from Alzheimer’s disease, a progressive and eventually fatal brain disorder (Alzheimer’s Association, 2010). The disease affects individuals very differently, and symptoms are often unique to the person. Such symptoms may include difficulty-remembering names and recent events, difficulty with daily tasks, impaired judgment, disorientation, confusion, and changes in behavior and mood (Alzheimer’s Association, 2010). The disease occurs in stages, and gradually becomes worse over time. During its final phase, individuals are often left immobile, and unable to perform other activities of daily living (eating, dressing, bathing, and toileting). They may become bedridden, unable to communicate or recognize loved ones, and dependent on around the clock care (Alzheimer’s Association, 2010).

In 2011, the first of the baby boomers, an estimated 70 million people born between 1946 and 1964, will celebrate their 65th birthdays (Alzheimer’s Association 2010; Hassan, 2009). As this generation continues to age Alzheimer’s disease will
remain a challenge for long-term health care facilities and services. The disease already costs more than 100 billion dollars in annual health care spending and the trend is increasing (Hassan, 2009). By 2050, the disease is expected to impact as many as 16 million individuals and half of the population over 80 years old (Hassan, 2009). Growing statistics leave little room for debate, “there is a health care tsunami approaching. It is Alzheimer's disease” (Hassan, 2009).

According to Fred Hassan (2009), Chairman of the board and chief executive officer of Schering-Plough Corporation, “Alzheimer's inflicts cruelty on whole families. It can impoverish the caregivers who must abandon work to look after sufferers, while causing depression and despair in spouses, children and other loved ones.” Thus, such a tsunami would wipe out not only individuals, but also entire families.

Significance of the Problem

The responsibility of caring for a loved one with Alzheimer’s disease often falls primarily on the family, whether that is a spouse, child, niece, or nephew. In 2009, nearly 11 million family members provided an estimated 2.5 billion hours of unpaid care to loved ones with Alzheimer’s disease (Alzheimer’s Association, 2010). However, for the many American families living in rural and impoverished areas, this additional responsibility may come as an extraordinary burden and cause unwarranted stress. In order to limit the negative outcomes associated with high stress levels, effective coping strategies are essential.
One such rural area in the United States is Appalachia. This region consists of 420 counties in 13 states from New York to Mississippi, and encompasses approximately 24.8 million people (Appalachian Regional Commission [ARC], 2010). “Characteristics of Appalachia include lower income, higher prevalence of unemployment, less urbanization, lower level of educational attainment, and numerous health disparities” (Fisher et al., 2008, p. 62). In Ohio alone, the 32 Appalachian counties are home to 13 percent of the state’s population (Fisher et al., 2008; ARC, 2010).

According to a recent study, it is a popular belief that the quality of life for the elderly is superior in rural areas as compared to its urban counterparts (Kosberg, Kaufman, Burgio, Leeper, & Sun, 2007). However, this “. . . romanticized vision of a tranquil and harmonious rural lifestyle is often refuted by the realities of economic deprivation, inadequate housing and transportation, limited access to health professionals and community-based programs, and unaddressed physical and mental health problems” (Kosberg et al., 2007, p. 6). Another study, conducted by Halverson (2004), explained that ones accessibility to medical care is a key element in preventing disease morbidity and mortality. However, according to the same study, there are significant obstacles to receiving adequate health care in much of rural Appalachia. These barriers include, but are not limited to physical distance, terrain, a lack of private and/or public transportation, and a lack of health insurance limiting doctor’s visits and prescription use (Halverson, 2004).
In the case of Alzheimer’s disease, these inconsistencies may likely hinder the rural caregiver’s access to educational programs and essential community connections. Without a sound knowledge of the disease and contact with other caregivers, effective coping strategies are hard to develop. As financial and emotional demands heighten, these caregivers risk their own well-being and ability to provide effective care (Connell, Janevic, & Gallant, 2001).

Purpose of the Study

The purpose of this study is to explore and describe the coping strategies and needs of Alzheimer’s caregivers in the Appalachian region. This information will provide a foundation for future educational and support developments, as the rural caregiver population continues to grow. This is made possible through the use of interviews with individuals who have or who are currently providing care to a relative and/or loved one with Alzheimer’s disease. Families from nursing facilities and support groups in the region will be asked to participate.

Research Questions

To determine the coping strategies and needs of Alzheimer’s caregivers and caregivers of other related dementias, my study will seek to answer the following research questions:

1. Following an Alzheimer’s diagnosis, what initial coping strategies do caregivers employ?
2. What educational and support services are utilized most often, and what additional services would families find most useful if made available?

3. During the progression of the disease in what ways do coping strategies change, and why?
Review of the Literature

Alzheimer’s Disease

Dr. Alois Alzheimer first discovered Alzheimer’s disease in 1906. He examined the brain of a woman who had appeared to die from an undocumented mental illness, and found several clumps (now known to be amyloid plaques) and tangled bunches of fiber (neurofibrillary tangles). Such plaques and tangles in the brain are the main anatomical characteristics associated with Alzheimer’s disease (Alzheimer’s Disease Education and Referral Center [ADEAR], 2008).

“Alzheimer’s disease is an irreversible, progressive brain disease that slowly destroys memory …” and other cognitive abilities (ADEAR, 2008, p. 1). Although an exact cause is not known, damage to the brain can occur as early as 10 to 20 years before any apparent problems surface. As more of the plaques and tangles build up, once healthy neurons gradually begin to work less efficiently and eventually die. As the number of dead neurons increases, brain regions shrink resulting in widespread damage (ADEAR, 2008).

Symptoms associated with Alzheimer’s disease often appear after the age of 60, and progressively become worse. It is common to define the progression of the disease in stages; though different disease models contain a different number of proposed stages (HELPGUIDE.org, 2010). One of the shorter models defines three stages: early, middle, and late Alzheimer’s disease (HELPGUIDE.org, 2010). A loss of memory is the first indication of Alzheimer’s disease; however, the earliest stage may be difficult to detect, as it is normal for memory to decline with age (ADEAR,
It is not uncommon for individuals at the early stage to ask repeated questions, to need frequent reminders, and to experience some degree of depression or other personality change (HELPGUIDE.org, 2010). However, as changes in other cognitive abilities begin to appear Alzheimer’s is more easily detected or suspected (ADEAR, 2008; HELPGUIDE.org, 2010).

Individuals in the middle stage of the disease have impaired reasoning abilities, speech may become incoherent, and accelerated confusion and changes in mood and/or behavior are evident. There is also an increased potential for wandering (HELPGUIDE.org, 2010). These individuals benefit from consistent daily structure and reminders, and need assistance with activities of daily living (HELPGUIDE.org, 2010). By the final stage, individuals are completely dependent on others for care. Chewing and swallowing functions are forgotten; communication ceases, and individuals are often confined to a bed as their body systems fail (ADEAR, 2008; HELPGUIDE.org, 2010). Although the disease is currently not able to be definitively diagnosed and is also incurable, early detection and response is extremely beneficial to both the diagnosed individual and their family (ADEAR, 2008).

An Alzheimer’s diagnosis cannot be determined definite until after death and upon the performance of an autopsy; however, questioning, medical and diagnostic tests, and brain scans are sufficient enough for a physician to make a “probable” Alzheimer’s diagnosis. This means that there are no other reasonable causes for the symptoms found (ADEAR, 2008). However, a “possible” diagnosis infers that the symptoms may be due to another cause (ADEAR, 2008). Having an early diagnosis
allows treatment, most often a drug regime, to begin in the early stages of the disease and can help preserve brain function for months to years (ADEAR, 2008). This buys time for families as well. “Having an early diagnosis also helps families plan for the future, make living arrangements, take care of financial and legal matters, and develop support networks” (ADEAR, 2008, p. 4).

**Characteristics of the Primary Caregiver**

The primary caregiver for a person with Alzheimer’s disease is most often a loved one. This may include a spouse, an adult child or daughter/son-in-law, niece, nephew, or other close friend (American Health Assistance Foundation, 2009). Recent studies have reported similar caregiver characteristics, which may be a good indication of the general caregiver population. For example, two studies regarding caregiver concern and the stress process identified caregivers as predominately married women. The majority of these women reported being a spouse or daughter/daughter-in-law of the Alzheimer’s patient (Farran, Loukissa, Perraud, & Paun, 2004; Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001). Though working and living arrangements differed, the average age of participants from both studies was 62 years old (Farran et al., 2004; Whitlatch et al., 2001).

According to the Alzheimer’s Association (2010), 60 percent of paid and unpaid caregivers are women, and 46 percent are ages 50 to 64. Thus, those in midlife – the so-called sandwich generation – are left to care simultaneously for children and adolescents, aging parents, grandparents, and other relatives as well (Carter &
McGoldrick, 1999). These demands, as well as occupational and financial obligations, pile stress on already vulnerable individuals (Carter & McGoldrick, 1999).

Caregiver Burden and Concern

According to a study by Farran, Loukissa, Perraud, and Paun (2004), caregivers have five major concerns. These concerns include dealing with change, managing competing responsibilities, providing enough care, finding resources, and experiencing the physical and emotional responses to care (Farran et al., 2004). Of these concerns, change is inevitable and may be the cause of some of the physical and emotional stress that caregivers also fear. While dealing with their loved one, caregivers have to also adjust their own daily routines. They may have to put current goals on hold, alter living arrangements, and take on new family roles and attitudes (Farran et al., 2004). Participants in the above study expressed the need to postpone goals such as completing an advanced degree. Both spouses and adult-children also talked about role reversals, from which spouses reported the greatest difficulty (Farran et al., 2004). As one respondent explained, “The kitchen had always been her territory, her kingdom. She prepared the meals, I made money; that’s how it always was. Now I order food everyday because I can’t do any cooking” (Farran et al., 2004, p. 44).

Changing one’s lifestyle also includes managing responsibilities outside of care giving (Farran et al., 2004). Work and conflicting family responsibilities are of great worry to Alzheimer’s caregivers. Most consider reducing work hours or entering an early retirement (Farran et al., 2004). These decisions are made more hesitantly,
however, when the caregivers’ financial obligations include illness-related expenses, such as the possibility of nursing home placement, and other family expenses, such as college tuition (Farran et al., 2004). Though family members may be a source of support for the caregiver, they may also be an additional source of stress. Participants in the study by Farran et al. (2004, p. 45) “… criticized relatives for being unwilling to educate themselves about the disease, for having unrealistic expectations of the caregiver, or for not being more involved in the care giving process.” On the other hand, relatives may criticize the caregiver for being too involved or controlling.

Though these stress factors are very real and commonly experienced, recent studies have identified care recipient problem behaviors as having the greatest impact on caregivers (Robinson, Adkisson, & Weinrich, 2001). A study by Son, Erno, Shea, Femia, Zarit, and Stephens (2007) found that the caregivers who reported experiencing the greatest number and frequency of problem behaviors perceived their own health as poor. As a result, they took less care of themselves and spent the most money on their own health care needs. Another study identified caregivers’ perceptions of the severity of problem behaviors as more important than the actual frequency of such behaviors (Robinson et al., 2001). Regardless, caregivers have less time to pay sufficient attention to their own diet, sleep patterns, and exercise regime. These practices are important in stress management and overall health and well-being, a lack of which will inevitably cause problems (Gruetzner, 2001).
Nursing Home Placement

Additional stress comes with the decision to place a loved one in a nursing facility; however, nearly half of all persons age 65 or older that are admitted to nursing facilities have dementia (Magaziner & German, 2000). Therefore, it is likely to be an issue encountered by Alzheimer’s caregivers (Magaziner & German, 2000). Though a respite for some, caregivers who provided care in the home are just as likely to continue this care after their relatives are placed in a nursing facility (Yamamoto-Mitani, Aneshensel, & Levy-Storms, 2002). This study also found that caregivers who were spouses, lived close to the facility, had a lower education, close relationship with the care recipient, and/or strong negative feelings regarding the nursing home placement were likely to visit most often and for longer periods of time (Yamamoto-Mitani et al., 2002).

A study done by Schulz, Belle, Czaja, McGinnis, Stevens, and Zhang (2004) found that some caregivers reported feeling useful, needed, appreciated, and important. However, the researchers also found that many caregivers remain just as distressed after a facility placement as they were before the move. These individuals are particularly prone to depression and anxiety, feelings of guilt, and an uncertainty about the move in general (Schulz et al., 2004).

Caregivers, distressed or not, can still perform tasks similar to those that were performed in the home, such as feeding, assisting with personal care, and providing transportation. However, new relationships and interactions must be made with facility staff, other residents, and residents’ families (Schulz et al., 2004). Caregivers also
must surrender their role as primary caregiver and accept that others will be watching
after their loved one as well (Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001).
Stress may also result if the caregiver feels that the move was made against the wishes
of their relative, as caregivers often feel responsible for the happiness and comfort of
their loved one (Whitlatch et al., 2001).

Caregiver depression, a result of caregiver burden and stress, is closely linked
to how well both the caregiver and recipient adapt to a nursing home placement
(Whitlatch, 2001). The study by Schulz et al. (2004) found that caregivers generally
had positive experiences with nursing homes and related staff members. However,
findings also suggested that negative interactions played a larger role in determining
caregiver and resident well-being as compared to positive interactions (Whitlatch,
2001). For example, an individual who is met with warmth and a smile upon entering
the nursing facility is more likely to have a positive experience or stay as compared to
someone who felt ignored upon entrance. Therefore, it may be more important to
remove the negative rather than emphasize the positive in regards to family care
giving in the nursing home environment (Whitlatch, 2001).

Schulz et al. (2004) suggest that it is important for those caregivers who do
remain actively involved within a facility to receive support and assistance from
physicians and other health care workers, including social work professionals. It is
also important that they have a network of family and friends to care for them (Schulz
et al., 2004). “… [W]e need to help caregivers who place their relatives,” says Schulz.
“We need to treat their emotional distress, educate them about the nature of long-term
care facilities and their impact on patient functioning, engage them in end-of-life planning, and prepare them for the eventual death of their loved one” (Fisher Center for Alzheimer’s Research Foundation, 2004).

Caregiver Coping Strategies

Several studies have been conducted in an effort to link coping strategies with caregiver anxiety and depression. Such studies have identified three types of caregiver coping, which include emotion focused, problem focused, and dysfunctional coping strategies (Cooper, Katona, Orrell, & Livingston, 2008). Emotion focused coping relies primarily on internal strategies while problem focused refers to efforts made to change a stressful situation. Dysfunctional coping strategies include denial, self-blame, and self-distraction (Cooper et al., 2008). The use of dysfunctional coping is related to higher levels of caregiver anxiety and depression; and this study suggests that services that encourage emotion focused coping and discourage dysfunctional coping be implemented (Cooper et al., 2008).

Findings from Cooper et al. (2008) suggest that emotion focused coping is the most protective strategy against caregiver anxiety, due to the natural course of the disease. As Mitsumoto (2009) describes in his book on Amyotrophic Lateral Sclerosis (ALS), problem-solving coping is best used in situations in which something can be done to resolve a problem. Emotion focused coping, on the other hand, is best used to manage situations that ultimately must be accepted (Mitsumoto, 2009). In the later stages of Alzheimer’s many problems experienced are likely to be obstinate, and
therefore responding to them with problem focused strategies, rather than adapting emotionally, may prove discouraging (Cooper et al., 2008).

Attention has also been focused towards inherent personality traits that reverse the negative outcomes associated with caregiver burden. Two such traits are optimism and mastery. Both traits were linked to positive mental and physical outcomes, while other traits, such as neuroticism, were linked with negative outcomes (Connell, Janevic, & Gallantt, 2001).

Support Group Meetings

In addition to internal strategies, caregivers use external resources as a method for coping as well. Social support, both formal and informal, is an important resource in the caregiver stress process (Connell et al., 2001). One such resource is the support group. Humans are inherently social beings, thus it is not surprising that caregivers indicate feelings of reassurance after attending support group meetings (Larrimore, 2003). Despite this reassurance, caregivers’ needs are unique to their own experiences, and individual caregivers may seek support groups for differing reasons. According to Larrimore (2003), caregivers with care recipients at home viewed the support group as more valuable than those caregivers whose loved ones were institutionalized. Caregivers with institutionalized relatives do not necessarily have the respite need that in-home caregivers cherish. In addition, Alzheimer’s patients in nursing facilities are generally in the later stages of the disease, and these caregivers may have a more
focused need for attending the support group, including a discussion of end of life issues (Larrimore, 2003).

Regardless, both groups expressed an interest in learning more about nutrition, exercise, and current Alzheimer’s disease research. Caregivers also reported that talking with others and hearing from outside speakers were two of the most useful experiences associated with the support group meetings (Larrimore, 2003).

**Education and Skills Training**

While support groups and group counseling may meet the emotional needs of caregivers, they do not necessarily address the physical challenges caregivers encounter in the home. To attend to these issues, interventions that teach families specific skills for in-home care have gradually been implemented and tested. One such intervention is the Environmental Skill-Building Program (ESP) (Gitlin, Winter, Corcoran, Dennis, Schinfeld, & Hauck, 2003).

The ESP was tested as a part of the National Institutes of Health program, Resources for Enhancing Alzheimer’s Caregiver Health (REACH). The REACH project was a six year, multi-site study that was designed to test new, but promising interventions for family caregivers of persons with Alzheimer’s disease and other related dementias (Gitlin et al., 2003). The ESP, specifically, is designed to provide education. It aims to provide education both about the disease and about the impact the environment has on care recipient behaviors. It also aims to provide problem-solving techniques and technical skills to enhance the home experience (Gitlin et al., 2003).
Studies that have examined this type of intervention have found reduced burden and enhanced caregiver well-being in participants, and a sustained affect in those who were enrolled in the program for more than a year (Gitlin et al., 2003; Gitlin, Hauck, Dennis, & Winter, 2005). Caregivers involved in the ESP report less trouble with behaviors and a need for less assistance from others. In addition, women and spouses have been found to benefit the most from skill-building interventions and report increased overall well-being, feelings of mastery, and an increased ability to manage events (Gitlin et al., 2003).

Appalachian Culture

Although support groups, counseling services, and skills training are all studied, effective resources for Alzheimer’s caregivers, it is not certain how these resources will affect the Appalachian community. Geographical location is the first barrier to such services. Health related services are traditionally offered in populous areas, not rural areas (Bauer, College, & Growick, 2003). According to Bauer et al. (2003, p. 21), “… It is not unusual for a big city to have one doctor for every 600 residents, while a neighboring rural community might have only one doctor for every 2,000 residents.” Able Appalachian residents regularly travel hours to visit specialists, and many communities lack even a primary care physician (Bauer et al., 2003).

In addition to the geographical barriers, the Appalachian culture itself may discourage some caregivers from seeking assistance from helping professionals. Though not true for every Appalachian family, many Appalachian Americans are
known to guard their feelings, especially those deemed negative. There is a strong belief in doing for one’s self, and help is not commonly asked for (Bauer et al., 2003). In addition, it takes these individuals a significant amount of time to become accustomed to strangers, as their life is family-based and church-based (Bauer et al., 2003). Family obligations and chores take precedence in the Appalachian household. Therefore, it is also more difficult for these individuals to keep scheduled appointments (Bauer et al., 2003). Because of this strong family loyalty, it is likely that most Appalachian spouses and children will experience caregiver responsibilities at some point in life. Therefore, rural support services, deemed reputable by word of mouth, could be extremely beneficial. For the time being, however, the well-being of Appalachian caregivers may be better predicted through personality characteristics and inherent coping tendencies.

**Individual and Family Resilience**

Despite the coping strategies caregivers choose to employ, some individuals are better suited for dealing with stress than others. Resiliency refers to the ability of an individual, family, group, community, or organization to overcome misfortune and resume normal or adaptive functioning (Kirst-Ashman, 2008). It is a combination of two pre-existing conditions: risk factors and protective factors. Risk factors include stressful life events or environmental conditions that weaken individuals and/or systems (Norman, 2000). Alzheimer’s disease is an example of one such risk factor. In contrast, protective factors are features of the person, family, or community that act
against the presented vulnerabilities. Individuals differ in their exposure to misfortune and protective resources; therefore, a person’s ability to recover from such adversity will differ among individuals (Norman, 2000). Regardless, resilient individuals are generally able to triumph in the face of serious trouble, confusion, or hardship (Norman, 2000).

Those qualities most common in resilient individuals include both personality related and interpersonally related characteristics, and are termed “resiliency factors.” Such factors include self-efficacy, realistic assessment of the environment, social problem-solving skills, sense of direction, empathy, humor, and positive relationships and family environment (Norman, 2000). Resiliency, however, is not a static trait. Different circumstances may lead to different outcomes, and as an individual’s stress levels increase, it is more likely that negative outcomes will also result (Norman, 2000). For example, caregivers responsible for the well-being of multiple relatives may have a more difficult time coping than those looking after one loved one. In addition, resilient behavior does not necessarily correlate to good emotional health. Behaviorally resilient individuals may still be emotionally troubled (Norman, 2000).

Though most research has focused on individual resilience in survivors of dysfunctional families, viewing the family as a resilient unit is a more effective approach in relation to Alzheimer’s disease as it effects more than just one individual. Several studies suggest that the personality of the multigenerational family unit affects the way in which a family reacts to the demands of patient care (Fisher & Lieberman, 1996). For example, caregivers who receive support from family members report
feeling less stressed (Zarit, Reever, & Bach-Peterson, 1980). However, a failure to accept what is happening has proven to prevent the family from reorganizing itself and coping effectively (Boss, Caron, Horbal, & Mortimer, 1990). For example, a family in disbelief that their loved one has Alzheimer’s disease will make it more difficult for the primary caregiver to cope, as the family is essentially calling him or her a liar.

Family resilience refers to the family’s ability to confront disruptive events, such as Alzheimer’s disease, manage stress, effectively reorganize, and move forward with life; and family adaptation is dependent on the successful completion of each of these steps (Walsh, 1996). In addition, balance is key to family functioning. Therefore, when an existing family member is lost the family has to establish a new equilibrium based on the circumstances and changes in relationships (Walsh, 1996). This idea relates to homeostasis, the tendency for a system to maintain a relatively constant state of balance (Kirst-Ashman, 2008), a term defined by social systems theory. When the family system is threatened, it will act to regain balance (Cervenka, Dembo, & Brown, 1996). This may be especially difficult in the context of Alzheimer’s disease as progressive loss results in an ambiguity in family roles. The importance and dependence previously placed on the ill relative will also determine the degree of disruption caused by the illness, in this case Alzheimer’s disease (Shapiro, 1994).

The availability of community resources is also essential for family resilience. Such resources may provide financial assistance, home making assistance, social support, and a necessary sense of belonging. As the disease progresses, and family
challenges become greater, resources such as day-cares may become required solutions. Without these outlets, family disruption may be inevitable regardless of balance and strong member relationships (Walsh, 1996).

This component of family resiliency plays into an ecological perspective. The person and environment are in constant interaction, each of which influences the other (Kirst-Ashman, 2008). It has been mentioned, however, that the environment is a barrier to support services in regard to Appalachian caregivers. Likewise, the Appalachian culture is not always receptive towards the “professionally” supportive environment. Because the environment is not meeting the needs of individuals, caregivers are more likely to refer to kin to fulfill this component of family resiliency (Bauer et al., 2003).

Like individual resilience, family resilience is predictive from specific “resiliency factors.” There is an agreement among studies that processes such as cohesion, flexibility, open communication, and problem-solving skills are essential in maintaining family functioning and the well-being of its members (Walsh, 1996). These family variables are similar to those identified in studies of other chronic illnesses as well (Fisher & Lieberman, 1996). Thus the repercussions of family resilience may extend well beyond Alzheimer’s disease.

Learned Optimism

The likelihood of an individual maintaining well-being and effectively coping with the difficulties associated with care giving is not solely dependent on family

As he explains, the pessimist believes that bad events will last forever, that they will tarnish everything, and that he or she was at fault. In contrast, the optimist believes that bad events are simply a temporary setback, they are confined only to a particular case, and that the event or events was not the fault of an individual. To the optimist, these occurrences are a challenge and an opportunity to work harder (Seligman, 2006).

Helplessness, a state in which one believes that their choices and actions have no affect on outcomes, is the foundation for pessimism. Someone who reacts consistently in a pessimistic manner has internalized learned helplessness, and immediately reacts by giving up. Whether an individual is a pessimist or an optimist is related to their explanatory style. Explanatory style is the way in which one explains to themselves the reasoning behind events. A pessimist’s explanatory style would include blaming themselves for an event and reasoning that the matter is out of their control. This kind of thinking fosters helplessness. Optimistic thinking, on the other hand, works to stop helplessness (Seligman, 2006).

Seligman (2006) explains that individuals do have control in choosing the way they think; and thoughts can ultimately diminish or expand the control that person has over a situation. When faced with the fate of seeing a loved one suffer from
Alzheimer’s, it is an inherent human trait to feel depressed and momentarily helpless. The optimists, however, are able to pick themselves up and begin to recover soon after initial shock, while the pessimist’s thoughts only intensify the problem. Optimists are more likely to focus on “good times,” actively seek support groups, and willing ask for help. This tendency in thinking, then, acts as a protection against depression, while pessimism gathers those negative feelings (Seligman, 2006).

An Ecological Perspective

An ecological perspective, unlike resilience theories and learned optimism, considers the ways in which a person is influenced and sometimes changed by their environment and vice versa (Germain, 1991). The concept behind the ecological model is that “neither person nor environment can be fully understood except in the context of its relationship with the other” (Bloom & Germain, 1999, p. 9 & 10). This relationship, between the person and environment, is characterized by continuous transactions, which are not always linear, meaning one entity (person or environment) does not necessarily influence the other exclusively (Germain, 1991). Instead, the term “transactional relationship” is used to refer to “reciprocal exchanges between entities, or their elements, in which each changes or otherwise influences the other over time” (Germain, 1991, p. 16). In this case both entities are changed or influenced. Therefore, transactions are circular. An event may be a cause initially and later an effect “… in the ongoing flow around the loop of social, cultural, emotional, psychological, biological, and physiological processes” (Germain, 1991, p. 16).
Life stressors, such as Alzheimer’s disease, may result in either positive or negative person:environment relationships. To some stress is viewed as a challenge, and an opportunity to improve; therefore, positive relationships result (Germain, 1991). However, in other situations life stress results in negative relationships, most often when perceived harm is greater than the capacity one has for dealing with it (Germain, 1991). This type of stress “… arouses negative and often disabling feelings, such as anxiety, guilt, rage, helplessness, despair, and lowered self-esteem,” all of which have been observed in Alzheimer’s caregivers (Germain, 1991, p. 19). In addition, what is perceived as stressful varies among individuals with different life experiences. Therefore, the same situation may be perceived as stressful by some, but not others (Germain, 1991).

Individuals who experience stress must adapt to their situation. Adaptation refers to an individual’s active process of self-change, environmental change, or both. Stress, however, evokes a special adaptation termed coping (Germain, 1991). When effective, coping eliminates or improves the demand and/or harm caused by stress. Unsuccessful coping, however, may result in physical, emotional, and social disruptions, which result in additional stress that is more difficult to overcome (Germain, 1991). Germain (1991) describes two functions of coping previously discussed, problem solving and regulating negative feelings. Each, however, is explained to be a requirement of the other. Problem solving results in increased self-esteem and management of negative feelings. Similarly, regulating feelings allows the individual to work successfully on problem solving (Germain, 1991). Further,
Germain (1991) suggests that those who cope most effectively with severe stress do so by partially ignoring reality and negative feelings, in order to maintain some hope. This allows for the initiation of problem solving; and as this proceeds, self-esteem is increased and original defense mechanisms are needed at a decreasing level (Germain, 1991). Regardless, both methods of coping require supportive personal and environmental resources, such as social support systems (family, friends, neighbors, church congregation, etc.) (Germain, 1991).

Germain (1991) also describes a process by which individuals decide upon a stress reaction and means of coping or adapting. This process consists of two questions. The first is, “How am I doing” (Germain, 1991, p. 20). If an individual evaluates their person:environment fit as stressful, they then ask a second question, “What can I do about it” (Germain, 1991, p. 20). A person who overestimates their stressor as more harmful then it is, may experience inappropriate physiological, emotional, and behavioral responses. However, a person who underestimates stress, viewing it as not harmful, is less likely to act and as a result increases their potential for harm (Germain, 1991).

Similarly, individuals who believe a stressful situation warrants no action or who maintain feelings of hopelessness and helplessness run a risk of increasing stress levels because resources are not accessed (Germain, 1991). Therefore, those individuals who accurately rationalize stress levels and seek assistance will restore the person:environment fit, whereas those who do not may make the relationship even worse (Germain, 1991).
The functionality of the person:environment fit will result in varying degrees of human relatedness, competence, self-direction, and self-esteem; and experiences of relatedness, competence, and self-direction help maintain positive self-esteem, or positive feelings about oneself (Germain, 1991). Human relatedness refers to the ability of human beings to form attachments with others. Competence is an individual’s perception of their ability to influence and/or change the environment; and self-direction is a concept related to autonomy, a person’s ability to maintain some degree of independence when faced with pressures from both internal and environmental forces. Self-direction also refers to the ability to take responsibility for managing one’s life while respecting others’ rights in the process (Germain, 1991). These attributes develop throughout the life course. Positive experiences that result in positive self-esteem may protect individuals from life stressors and/or increase an individual’s coping resources (Germain, 1991). Negative experiences, however, may diminish self-esteem and coping abilities as a result (Germain, 1991).
Methodology

Focus of the Study and Research Design

Qualitative research differs from quantitative research, in that it focuses on individuals lived experiences and the meaning they denote to such experiences (Royse, 2008). In conjunction with this goal, this study explored and described the coping strategies of Alzheimer’s caregivers in the Appalachian region, specifically counties in both rural Ohio and West Virginia. It identified educational and support services available to caregivers in this region and patterns of coping strategies used by the individuals.

These counties both have access to active Alzheimer’s support groups that meet once a month. Group facilitators gave their approval for this researcher to ask for participation from its members. Individual semi-structured interviews followed. Using this design, the study sought to answer the following research questions:

1. Following an Alzheimer’s diagnosis, what initial coping strategies do caregivers employ?

2. What educational and support services are utilized most often, and what additional services would families find most useful if made available?

3. During the progression of the disease in what ways do coping strategies change, and why?
Respondents and Sampling

Upon obtaining approval from the Institutional Review Board at Ohio University, the researcher contacted two Alzheimer support group facilitators. At that time the facilitators presented the proposed research to their group members and requested their participation on behalf of the researcher. Willing group members provided the facilitator with their name and phone number, which was passed on to the researcher for continued communication. The researcher also requested participation from families at a nursing facility located within the Appalachian region.

Phone calls were made to those who had indicated an interest in the research, from which nine individual and/or family interviews were scheduled at a time and location convenient to both the researcher and interviewees. During the phone conversation the researcher introduced herself, further explained the purpose of her research, and answered any questions. At the time of the interview participants indicated their informed consent by reading and signing a form. A copy of this document can be found in Appendix A.

Respondents used in this study made up a purposive sample. A purposive sample is one in which participants must meet basic criteria for inclusion in the study (Royse, 2008). In order to qualify for participation in this study, individuals had to have been or currently be a primary caregiver to a relative with Alzheimer’s disease or related dementia and reside in the Appalachian region. This study defined primary care giving as any individual who lived with and/or provided care to a relative with Alzheimer’s disease. Caring responsibilities needed to include assistance with
activities of daily living, such as dressing, bathing, and feeding. Though nine interviews were conducted, twelve respondents participated in the study, nine females and three males. This was made possible through two group interviews, one that consisted of a husband and wife, and the other consisted of three siblings.

Data Collection

Data collection occurred throughout February 2010 and March 2010 for a period of approximately eight weeks. During this time individual, semi-structured interviews were conducted to gain information on participants use of coping strategies and educational and support services. Pre-planned, open-ended questions, produced by the researcher, were used as a guideline to initiate discussion, though most questions were tailored to the individual interview. Pre-planned questions can be found in Appendix B. The responses to these semi-structured interviews were recorded and kept in a file, in the researcher’s home, for further analysis after all of the interviews were completed.

Instrumentation

The researcher was used as a human instrument to interview individual respondents throughout the study. The human is the instrument of choice for qualitative methods, as the human is the only instrument suitable to cope in an undetermined situation, such as the interview (Lincoln & Guba, 1985). The human-as-instrument has the ability to respond to environmental and personal cues that may or
may not exist; researchers can adapt to changes quickly and collect information on
multiple factors and at multiple levels simultaneously (Lincoln & Guba, 1985). The
human also has the distinct capability of summarizing data and clarifying information
with respondents. Researchers can pick up on unusual responses, allowing for a more
in-depth understanding of the problem at question (Lincoln & Guba, 1985).

The human instrument was best suited for this study, as this method allowed
the researcher to collect the most detailed data, which allowed for a thick, rich
description when answering research questions. Through interaction with the
respondents, the researcher used nonverbal cues as well as verbal responses to better
understand the hardship endured by each individual.

**Strengths and Limitations**

Qualitative interviews are designed to be flexible and less structured than a
survey interview. The respondent is acknowledged as the expert, therefore more
detailed and in-depth information can be collected: the greatest strength of qualitative
research. Qualitative interviews also allow the researcher the opportunity to pick up on
nonverbal responses, which may negate or reinforce verbal responses. This
interactional dynamic allows the researcher to better understand the problem as a
whole. From these interviews the researcher can obtain a rich description of the
problem, as opposed to a statistical description that could be obtained following a
quantitative protocol.
Limitations, however, include the possibility of researcher bias. The researcher may have been subjected to biases developed through personal experiences with Alzheimer’s disease. Her biases may have caused her to misinterpret information provided by respondents. The researcher tried to remain objective by discussing her research and interviews with her thesis advisor and instituting member checking at the completion of data analysis. Member checking is a technique used by researchers in which participants of the study are asked to review researcher analysis and check for its accuracy (Royse, 2008). Member checking allowed the researcher to validate her interpretations with the respondents’ intentions. Two respondents were randomly selected and contacted. They were asked to review the researcher’s analysis and provide feedback regarding the representation of the information they provided. Misinterpretations were noted and discussed until an agreed upon interpretation was devised.

The small sample size is another limitation of qualitative research. Though the small sample allowed the researcher to spend more time with individuals, it is possible that their responses are not representative of every Appalachian Alzheimer’s caregiver. All of the respondents were also using either a nursing facility or support group at the time of the interview, indicating that participants were already knowledgeable in regard to available resources. Given a different criteria set, or purposive sample, it is possible that responses would differ.
Reliability and Validity

Due to the distinct nature of qualitative research, traditional definitions of reliability and validity do not necessarily apply. Instead, Lincoln and Guba (1985) have defined four terms that better fit the methods underlying qualitative research. These terms include credibility in place of internal validity, transferability instead of external validity, dependability instead of reliability, and confirmability in place of objectivity.

Credible data must be believable from the perspective of the research participants (Research Methods Knowledge Base, 2006). Prolonged engagement with participants, multiple sources of data collection, peer debriefing, and member checking are all ways in which researchers can ensure credibility. This researcher used peer debriefing and member checking as two main means of ensuring credibility. The researcher met with her thesis advisor weekly to review progress.

Qualitative data must also be transferable. Transferability refers to the degree to which qualitative research results can be applied to different situations (Research Methods Knowledge Base, 2006). It is the responsibility of the researcher to describe results using a thick, rich description so that readers can transfer the findings into their own contexts. Though qualitative research assumes that each researcher holds his or her own unique perspective, confirmability, or the degree to which others can verify a study’s results, must be considered (Research Methods Knowledge Base, 2006). Again, the researcher’s thesis advisor was used to ensure confirmability. He oversaw
the means by which the researcher collected and analyzed data, bringing to attention any potential for bias or distortion of data.

Though not prominently used in this study, dependability is the last means by which qualitative researchers can ensure reliability and validity in research results. Dependability refers to accounting for changes in setting that occurred while research was conducted (Research Methods Knowledge Base, 2006). Lincoln and Guba (1985) suggest the use of “overlap methods,” again using different forms of data collection and examination by an objective researcher.

Protection of Research Participants

Prior to the conducted interviews, the researcher contacted the potential respondents by telephone to introduce herself and to provide a description of the study and its purpose, benefits of participation, the risks involved, and what their involvement level would be if they chose to continue with the interview. At the time of the interview respondents were asked to read and sign a form indicating their consent to be a participant in the research study. Participation was completely voluntary, and respondents were assured that there would be minimal risk through their participation, and that they could choose to end the interview at any time should they begin to feel uncomfortable.

In order to protect the confidentiality of respondents, the interviews took place at a location within the community convenient to the participants. The interviews were recorded using a cassette tape; however, the names of participants were altered during
the reporting of data. The tapes were stored in a file, at the researcher’s home, during the duration of the study. Only the researcher and her thesis advisor had access to them. After the completion of the project, the tapes were immediately destroyed.

Data Analysis

The researcher analyzed interview responses using grounded theory. Grounded theory is a method by which theory is developed from the data (Royse, 2008). Therefore, the research process began with data collection rather than a developed hypothesis. The following are steps the researcher followed in the grounded theory process:

1. Transcription: Interview recordings were transcribed by extracting key quotes as determined by the researcher. Though the majority of each interview was transcribed, unrelated comments were not included in transcription.

2. Coding: After the audiotapes were transcribed, the researcher coded lines of text using appropriate labels.

3. Development of Categories and Themes: Through the comparison of labels, noting similarities and differences, the researcher grouped coded lines of text into categories. Themes were then developed through the elaboration of and relatedness of categories. Refined themes are the beginnings of analysis and theory development.

Categories and themes are the basis for creating theory, as resulting theory is an explanation of categories and the relationships among them (Calloway & Knapp, n.d.).
Data was continually collected and coded until no new ideas or categories emerged from new material. At this point themes were integrated to form the final piece of literature or theory.
Findings

Introduction

These findings are derived from the interviews with the research participants and seek to answer the following three research questions:

1. Following an Alzheimer’s diagnosis, what initial coping strategies do caregivers employ?

2. What educational and support services are utilized most often, and what additional services would families find most useful if made available?

3. During the progression of the disease in what ways do coping strategies change, and why?

In addition, other important topics emerged from the interviews as well. Topics included the care recipient’s behaviors, conflicting responsibilities, and the psychological effects of care giving. These topics will be presented first, followed by a discussion of the research questions.

Care Recipient Behaviors

The need for effective caregiver coping strategies arises from the multiple problems caregivers face during the progression of the disease. These issues vary among individuals and include both personal and intrapersonal conflict. Additionally, most caregivers experience and must work through a combination of the various presented problems.
One such problem is the care recipient’s behaviors deemed difficult by caregivers. These behaviors often referred to as problem behaviors, commonly increase in occurrence and severity as the disease progresses. The problem behaviors described by the research participants include agitation, wandering, incontinence, disturbed sleeping patterns, and delirium or paranoia.

He was always clean about himself and he started going dirty and not wanting to dress. He would go around the house in the nude and if I’d tell him to do anything he would start to cuss and he never cussed before. He never wanted to go to the bathroom; if he had to go he would just go on the floor. It’s a good thing I had linoleum on the kitchen floor cause he would sit on the kitchen table and instead of getting up he would just relieve himself in the kitchen. He was wandering off from the house and the neighbors would have to go find him and bring him back home. It was a lot.

I got very little sleep, maybe four hours. Cause I am a poor sleeper, and I would just get to sleep and he would want up again.

She kept thinking that everybody took everything. She still hides her billfold; even up here (nursing facility), her bingo money.

He stopped taking food I would cook. He started saying I was poisoning him and I would have to eat out of the pot before he would eat anything out of the pot. I would have to eat first cause I was putting something in his food. That’s why he was going to McDonald’s all the time. I got called out from several people for not cooking for him and I says well he just won’t eat the food that I fix.

He would imagine he’d see things. Like he’d say, “Did you see that person lying on the floor over there?”

One caregiver, whose loved one suffered from paranoia symptoms, described feelings of being a prisoner in her own home:

He never was jealous before. I’d have to keep my doors locked, windows closed, and blinds pulled. If I would go to look out the door, “Who you looking for?” I would tell him nobody; I’m just looking out the window. He even nailed some of my windows shut. He had to have everything locked up tight. It was like I was a prisoner in my own home.
Behaviors and moods also fluctuate daily, which leaves caregivers never knowing what they are going to experience on a given day.

It used to come and go, which I think is strange. But, I suppose it’s like that for anybody. Sometimes you can see her or talk to her and almost make sense, but other times it’s like she’s not even aware of the world around her.

I think that, you know, you never know. You never know how things will develop and sometimes they get to the point that they are very difficult to deal with and you need someone 24 hours, and it may get to the point that it would not be practical to keep him at home.

The hard part of Alzheimer’s or dementia is that you expect them to behave a certain way and there is no certain way. Up one day, down the next, yelling, and hollering, and cussing.

Mom now will say give me a kiss, and she never did that. Oh, it was just about two weeks ago, I leaned over and she kisses me and she said she loved me. I mean when she does that it just takes your heart. And you think well I’ll take her home, and then reality hits and you think no in a few minutes she’s going to be gone again.

It was everything in the book and then all of a sudden it would change and he would be sweet as can be.

Managing behaviors is often a 24-hour activity.

Well, I mean I didn’t get much else done, the housework and taking care of him and even at night he was up two or three times in the night and I was lucky to get my rest.

I asked this caregiver if she had help from family or friends. She replied:

My daughter came to see us, but she works so she didn’t have time. No, I’m the only one.

Leaving the care recipient, for any period of time, is a production that many caregivers choose to avoid.

Every time we’d go somewhere we’d have to make a bigger plan. We’d have to have somebody to check on them, and you know, we really couldn’t go anywhere.
When we would get ready to go somewhere a big crisis would happen. Even though we had everybody coming in the morning and the evening to check on her, it still wasn’t enough. She was worried that we were going; she was afraid that something would happen to us while we were on vacation. It was really, you couldn’t enjoy going away cause you knew she was worried and you were worried and it was just stressful.

Well, I used to go away sometimes for the weekends. I don’t go away over night now, and I don’t try to stay away too long during the day.

**Conflicting Obligations**

Caregivers also have other work and family obligations that they must tend to in addition to caregiver responsibilities.

When he was at home it was difficult to maintain the outside work, meals, cleaning, laundry; it was difficult to do that and keep an eye on him too.

She didn’t want to come and stay with any one of us. She wanted us to come and stay with her. Of course, you’ve got a home and a family and a husband. It was hard for everybody, when you’re trying to cope with something that you don’t understand. And then you have your family to deal with too, and your children, grandchildren, and great grandchildren.

For many these duties lead to an early retirement, though often considered a blessing.

It was so wonderful that I was retired through all of this. I retired in ’02 and it was like they gave me an early out where I worked, I got my same retirement I would of at 60, and I thought boy this is going to be neat, but I never dreamed my retirement would be what it was. But, I was glad.

It’s so much easier if you’re not working. I don’t know how people who have a job can cope with this. It must be really stressful for them and I don’t know what advice I would give them. They better have some people helping them. They can’t take care of somebody and work. I don’t think we could do what we’re doing.

I have been retired eleven years. I retired so that I could provide care for her, because she couldn’t stay by herself.
We were going through a terrible time at work, and the company that I worked for offered a buyout of employees, and I saw a need for that. We had just put mom in the nursing home, and we knew that we were going to have to fix her house up and get it ready for sell. I took the buyout at the end of March, and was able to work on the house and we sold it that fall without ever putting it on the market. That was just a miracle. That gave me a chance each day to go to the nursing home and see her.

Psychological Effects of Care Giving

The demands of care giving, in most cases, have some negative psychological effects on the caregiver, though the duration of this experience differs among individuals. The majority of caregivers in this study voiced feelings of guilt, loneliness, resentment, frustration, and states of depression and constant worry and/or fear.

Once problem behaviors escalated beyond occasional forgetfulness, most of the caregivers experienced an initial state of endless worry and fear.

Even when you’re not there physically, you’re there. You’re worrying and you’re responsible.

It was that constant not knowing what might be happening. You didn’t know when she might decide to take a little walk or something.

We always check our messages at home, at least two or three times a day to make sure that nothing’s lost in-between. We still worry when we’re away, probably more than when we’re at home cause we feel more reachable.

I was constantly in fear, every time he would leave the house cause he was still driving. I was always having to call around to find out where he was at. And if he thought I was calling around I would get it when he got home.

We never knew what she was really wanting to do. When I would go in she would tell me that neither one of my sisters had been there, but I knew that they had been there because I saw the food that was left. When she was in the house we asked her not to go upstairs, we were afraid she was going to fall
down. And, we would come in some mornings and find her at the foot of the steps. Her bedroom was on the main level so there was no need for her to go upstairs. We got to a point where we just couldn’t trust her. We were afraid for her health sake that there was going to be a problem.

You just always feel tied, because you’re afraid to leave. You’re afraid, you know, that something’s going to come up.

Another psychological effect that caregivers faced early in their experience was depression. Of the three research participants who admitted to experiencing bouts of depression, each also acknowledged the use of antidepressants.

Well it makes me sad. I’ve been somewhat depressed and the doctor has offered me antidepressants and I did try that for a while, and then I think I have always been affected by winter weather and when spring came and I could get out and work the garden I was feeling good and I didn’t renew the prescription because I was fine. But, since then I guess I have tried to think a little bit more about what makes me feel good and try to do those things.

At first when I was coping with it after he got in here (nursing facility), I cried all the time I came to see him, and I thought I can’t be doing this I have to be supportive to him. So, I got a … I asked my personal physician to give me something to cope with, and that has helped.

You feel so helpless when it’s long distance; I became quite depressed. I would wake up in the morning crying, knowing that I couldn’t take care of her. And my dad was so resistant to letting me do things.

I became depressed. My blood pressure went up, and I went to my family physician and he said I’m a licensed professional clinical counselor, and he said why don’t you do a session with your therapist, duh. You know, and I started an antidepressant too. I found that, you know, the research shows that anywhere from 25 to 50 percent of people who are caring for dementia patients become clinically depressed. I completely agree with that number, and perhaps it is that I work with those people who are most depressed and most involved and having the most difficult time. It’s a hard, hard, hard job.

Other caregivers described feelings of resentment and frustration. A daughter described feelings of resentment associated with her mother’s memory loss.
I’ve kind of resented that I was pretty active and I haven’t had the time to do a lot of things that I used to do. That would be one of the things I need to deal with is the resentment. Mom tells us that she needs us and she doesn’t acknowledge that we’ve got children and grandchildren who need us. In this past 20 years my grandchildren have grown up. I would like to have spent more time with them then I have.

She described another experience that exemplified similar resentment:

A couple weeks ago my son was going from Muncie, where he lives, to Pittsburgh on a business trip and I was up with mom. I told her, I said mom I’m going to have to go. Bill’s coming through and he’s going to stop at our house, and she didn’t say anything. A little bit later I said well mom I’m going to have to go, Bill’s going to be there. She says you call Bill and you tell him not to come. I need you here. I had a lot of resentment over that because I thought, you know, she’s in her own world and she doesn’t acknowledge that we’ve got anybody but her. Her world is very small right now; it’s just each one of us. That’s about her world.

New emotions are experienced after making the decision to place loved ones in a nursing facility. According to research participants, these emotions include guilt and feelings of loneliness. Guilt is often felt during initial placement.

That was the hardest thing to get rid of, and I’m not really completely rid of it yet, because when she says take me home I should just pick her up and take her home. I can’t do that. I know physically and mentally I can’t do it. And you just have to deal with it.

It is hard; it is the hardest thing I have ever done is to leave here (nursing facility). The guilt, you know, she’s my mother why can’t I take care of her?

I felt like I had sold him down the river, because he trusted me. I was telling him your doctor says you need to go here, but he didn’t get it.

This same participant continued:

They put him in a sitting room, and the look on his face. He took one look around, and this one lady, she was a tall thin, kind of witchy looking lady, and she just kind of reached up at him as we’re walking through the doorway and it was kind of like it hit him, “oh yeah.” And I was feeling like, you know, I’d led a lamb to slaughter.
Her husband added:

In some ways that was even worse than the day he died.

Another caregiver expressed feelings of guilt associated with taking over responsibility.

One thing that has really bothered me has been a feeling of guilt when I have done things behind his back. I think that I have able to bring that out in the (support) group.

Loneliness too, is just as common an emotion following a nursing home placement.

I wondered if it was the right thing. After being married 43 years it is still hard for me to go there and have to leave him and come here to an empty apartment.

When the patient is admitted to the nursing home it is difficult for the caregiver to accept that she is alone and now must take on everything.

The loneliest part, when he first came up here, was in the evenings. Knowing when he first came up here that he was probably never going to come home.

Research Question One

The following section will describe the answers participants gave to the three research questions, beginning with the first: Following an Alzheimer’s diagnosis, what initial coping strategies do caregivers employ? Initially, multiple participants reported a lack of understanding regarding Alzheimer’s disease.

Misunderstanding of Diagnosis

Alzheimer’s disease is not easily detected, and initial denial often arises from a misunderstanding of the disease itself.
We think she had Alzheimer’s for quite a while before we realized what was happening. We called it dementia, senility, and I didn’t myself realize what Alzheimer’s was.

The wife of a care recipient explained the round about way in which she discovered her husband’s condition:

Well I didn’t really know what was happening until he had his open-heart surgery, and they discovered in the hospital that he had the first stages of Alzheimer’s.

The initial signs of Alzheimer’s are also easily ignored when caregivers are unaware of the disease.

We ignored a lot. We ignored, or took symptoms in stride. Looking back we should of said, “Oh my gosh, this is what it is!” And we just kind of, we didn’t disregard it, but we made up for deficiencies that were there, because it was easier. If you see problems, it makes life a whole lot easier if you just aren’t paying attention.

Others, however, choose to keep suspicions private due to the difficulty of discussing the condition.

Oh yeah, I knew. I knew there were changes coming, I knew it. But, we didn’t talk about it.

The caregiver is not always the only person confused by the diagnosis or left in denial. The care recipient is also likely to experience some degree of denial after learning of his or her irreversible condition. A son described the way in which his father, an educated psychologist, learned of his prognosis:

And, so little by little it just crept in, and probably about ten years ago we did a neuropsych exam and dad was a psychologist so very intelligent, knew what was going on, had done many, many, many testings over his decades of career and when the diagnosis was of an Alzheimer’s type dementia he was irate that the student and the doctor didn’t know what they were doing and it was the wrong diagnosis. So that was difficult because he was essentially in full denial even though he was a textbook case all the way through the better than ten
years of deterioration. You could almost turn the page and go yes, yes, yes, as he progressed.

Similarly, another son explained the ways in which his mother hid her forgetfulness:

Not only did we deny it, but the Alzheimer’s or dementia patient themselves denies it. That hides the certain things that she was doing. She was hiding things from us so that we would think she was normal. She was having problems for sometime before we realized she was having problems. She was in denial.

This ability that the care recipient has early in the course of the disease, to hide their difficulties, leaves some second-guessing the Alzheimer’s diagnosis.

The patient always puts on a good face, you know; when his siblings come around and ask him how are you, “Oh I’m ok,” you know, and then that leaves them to thinking that you’re trying to pull something over on them when you say well he’s not ok.

Now I’m All Alone

Care recipients in denial are more reluctant to give up household roles and responsibilities, however most participants talked about taking over chores that their care recipient once did. They gradually became the sole provider in a relationship that was once mutual. Added tasks include activities such as making repairs, taking out the trash, paying bills, driving, and completing yard work.

I started taking over doing the little, you know, tasks with the hammer and nails or screwdrivers around the house, but I’ve tried not to be too obvious with that.

I have found that when it comes to the point that I have to take over something sometimes I can just gradually do, like the little handy man jobs around the house. And taking the compost out and relining the compost bucket, if I can just find the time when he doesn’t see me I can do it and gradually get to the point that I’m doing it all the time and he sort of forgets about it.
I would find bills in the van that wasn’t paid, wasn’t even open, and I would have to go and try to find out how to pay the bills. To keep the electric going and the telephone, I was taking my check and paying all the bills. If they wasn’t being paid we would of lost everything.

I’ve finally got to the point that I try to pull anything out of the mail that has to be paid and be sure that a check is sent. I haven’t wanted to take over the check writing a hundred percent, but I’ll make out the check and give it to him and let him sign it. Any repairs that have to be made around the home, any small things, either I have to do or I have to get someone to do it.

I took over most of the driving.

I would allow him to mow the front part of the yard, but I would mow the rest of it.

He has always wanted to do things his own way; he’s always been that way. Very early in our marriage I decided if I wanted something done a certain way, if that wasn’t the way he thought it should be done, I better do it myself. So, I’ve been dealing with this problem to some extent, but until now it has never been something where I really had to say that I was taking over and doing it my way. I don’t know if it’s the dementia, or his feelings of incompetence because of the dementia, that is making it worse.

I gradually had to take over more and more things that he used to do.

I have more to do, because there are things that he used to take care of that I have to take care of.

Caregivers faced with opposition from their loved one cope by devising ways to disguise necessary, but important decisions.

The driving was a concern for a while, but we convinced him to donate his pick up truck to a private school and then we filled in with other people to take him places. So, we actually got the vehicle clear out of the situation, and since it was his idea, which we kind of planted the seed, to get rid of the vehicle and help the school we didn’t hear too much response about we took his vehicle away. But, we did a little bit.
However, not all care recipients are easily coerced. One wife described her husband’s reluctance:

It was harder on him, I think, to accept the fact that he wasn’t able to do what he had always done. And it was hard for him to realize that he had taught me well enough that I could do those things and it was hard for him to give up mowing the yard and you know doing things.

She continued with her own opinions:

It’s devastating to you as a caregiver that your spouse isn’t able to do the things that he normally would do and that was so natural to what he did. I think for a man it is hard to accept the things they cannot do that they have done so well in their lifetime.

Another wife shared similar feelings.

And yes, he was sad I guess because he couldn’t do things. He always wanted to help, but he just couldn’t.

Though denial is sometimes an initial response for both caregivers and care recipients, the disease becomes harder to ignore as problem behaviors increase in occurrence and severity. Though not employed directly following a diagnosis, other coping strategies used early in the care giving experience include physical activity, self care, planning for the future, the use of humor, and relying on faith.

**Physical Activity**

As caregivers sort through responsibilities, they rely on physical activity as a way to relieve stress as well.

I have been taking Tai Chi through most of the time. That has helped me a lot to even just come back to center.

I like to walk everyday.
I go to Curves and try to keep moving.

I play the piano and I would a lot of times go to the piano and just start playing some music. I play for church and he’d like to hear me play.

Taking Care of Self

Physical activity is also a way in which caregivers remember to take care of themselves. A support group facilitator reminds her members of the importance of self care monthly.

At the end of the group I always ask the group members what they’re doing to care for themselves. So it’s a reminder to me too, to do that.

A wife, who is now an active volunteer, described the lesson she had learned from her sister-in-law who also cared for a husband with Alzheimer’s disease.

She has been a good role model in that she allowed her health to be deteriorating at the same time his was. And I have learned from that that you have to take care of yourself. That if you don’t then you’re in trouble and the patient is in trouble too. So, I have learned to accept the fact that things aren’t going to change and that I have to take care of myself, and I’ve done that.

Another caregiver described her own battle with health concerns.

When I got type-2 diabetes it scared me to death. I thought gee my brother has it, my sister’s had it for thirty years probably, and she has type-1, and I thought I have heart trouble and all this stress and here we’ve all worked this for twenty years with dad being gone, and our families going and coming and jobs and our kids are all about the same age. But I said nope, and I did I lost 42 pounds, and I did exactly what they said and I felt good. And then all at once it all came back.
Planning for the Future

Caregivers who care for themselves, and take time for themselves, are planning for the future.

Well, it hasn’t been too bad yet, and one thing that I have been doing, I have realized that the time is going to come when I am going to be a lot more confined. So while I can still get out I try to take advantage of that.

At the very first it really didn’t change my life too much, but I’m thinking I better do things I like to do while I have a chance. And another thing, not let friends drift away cause a time is going to come when I’m going to especially need friends, I don’t want to let them drift away because I am too busy doing other things.

Completing advanced directives and discussing end of life issues is another way caregivers plan for the future, before their loved one is too far progressed.

If you could ever give anybody any advice I’d tell them to get the medical power and the power of attorney while they’re still able to do this. Cause if you get in a crisis you’ll have to go to court and get a lawyer and it’s expensive and it tears you up cause your having all this other stuff going on.

You must talk about how to be cared for before Alzheimer’s sets in. You have to talk about funeral arrangements and we did. You have to talk about do you want a feeding tube. You have to talk about do you want an IV. Do you want to be resuscitated? You have to talk about all those things, and we did. Shortly after I retired, I called Will into the room and I said Will we have to talk about this stuff. I think we spent about a half a day talking about things. And it’s been easier because we did do that. I know that I’m doing the things that he wanted done. If you don’t talk about that I don’t know how you could get through all that. It would be very difficult.
Humor

Among the seriousness of each individual situation, caregivers also employ humor as a means to remain upbeat in a possibly overwhelmingly grim process.

The collating was incredible, how that occurred, and it caused some good humor and also some frustrations for us.

Sometimes to survive you just had to laugh and go home, and then come back.

Faith and Humility

In addition to the coping strategies mentioned above, caregivers display a tremendous amount of faith and humility in dealing with their situations. A son, who has watched both of his parents battle Alzheimer’s disease, said:

Yeah, most people have it worse then we do. We know that. We’re really lucky.

He and his wife live their lives following two brief mottos.

Our two mottos are it’s always something, always. Somebody always has something worse then we got.

Caregivers unanimously expressed help from a more divine individual.

I still think that the Lord had to help us, or we wouldn’t of made it.

When I’m walking down the road I say, we need your help. All of us need your help. I said, we can’t tell you everybody who needs your help. I said, everybody needs your help whether they ask or not. They need your help and you got to tell us what to do. We don’t know.

I don’t know how I could of gotten through this without a good spiritual life and the support that I have gotten from the church family.

I became more religious. I have read the Bible more.
When I asked what it was that made faith an important aspect of coping, one caregiver responded:

I guess knowing that he will, when he’s gone, be in a better place, and accepting that. He will not be in this world of whatever it is he’s in.

Collectively, one participant described caring for the initial stages of the disease as you would a child:

It’s sort of like with a child who is old enough that they can do a lot of things on their own and they’re going out running around the neighborhood, but you still have to …

“Keep an eye on them,” I asked.

Yeah. Yeah.

Though an honest analogy, caregivers are still very much concerned with maintaining the dignity of their loved ones and treating them as an adult.

Every three months I would go down to Florida and go with them to the doctor. I would take my mother to the hairdresser. I would make sure that all of her clothes fit, and that they were in outfits that matched. My dad was never a slave to fashion and he’s also color blind, so he just didn’t get it. My mother was a pretty fastidious dresser when she was of her right mind and this was hard for everyone.

But you can’t imagine how scary that must be for a person, to know all these things are going on and they don’t understand what’s happening to them. I’ve said to her, “Mom it must be terribly scary not to remember.” And she’ll say yes. And we just don’t say anything more.

Research Question Two

The second research question asked participants about educational and support services available in the region: What educational and support services are utilized most often, and what additional services would families find most useful if made
available? Participants noted using formal and informal support services and various reading materials. They also offered three suggestions for improvement.

Support Group and Other Formal Support Systems

Five of the twelve research participants reported using a support group at least once during their experience. The benefit of attending support meetings varied among participants. Responses to this question included:

Well I know about the disease now and I know it wasn’t anything I said or done that caused him to change.

I’ve got a lot of practical suggestions there. I found the atmosphere and the practical suggestions helpful. I think that there are resources if it gets to the point that he really needs a lot of care.

A son described his involvement in a support group as one of his most significant coping mechanisms.

One of the most significant probably was the communication I had with not only family, but friends, and just to be able to call and vent or tell a funny story. I was involved with the caregiver support group here in the Athens area. And as time went on, since I have had so many years of care giving interaction I found that I was able to help other people with their current situation more than what the group was actually helping me. And still at this point I am involved with that group even though I am not care giving anymore, and I enjoy it.

In addition, participants sought help from health care professionals: physicians, nurses and social workers.

I’m here when the doctor comes; I know which day he’s going to be here. And I’m here for his visit just to see him and let him know that I’m surviving. He’s good about asking the girls, you know, how’s Debbie doing? And I appreciate that. I really appreciate that.
I called the welfare office and I have friends that work down there and I’d talk to them. They helped me quite a bit. Now that he is down there at the nursing home I have the support group, and the nurses down at the care center, where he is at, they help me cope with it.

I depend a lot on social contacts here (nursing facility) and my niece is one of his nurses on the floor, and we’ve talked a lot and she’s very supportive.

**Informal Social Support**

Of the multiple means of coping caregivers reported in this study, informal social support was reported the most useful, most frequently. Informal social support systems included family, friends, neighbors, and church congregations.

Whenever I needed help, as far as outside activities yard or whatever, I had family that I could depend upon and were there to do that if I wasn’t able to do it.

I had a good support group in that the minister where we went to church, his father had died with Alzheimer’s. I would go talk to him a lot and he would tell me what I was going to experience.

Talking to other people, that’s probably been the most helpful.

All of her family lives in North Carolina, so I was just glad when they came to visit. And they have periodically, twice a year; they’ll come to visit. It takes a little bit of burden off of me, to feel like I have somebody there to talk to.

My strongest family ties are with my family, they are very supportive. I have a sister who is very supportive; we do a lot of things together. I have a niece and a nephew who live close to me and if I need anything all I have to do is call them and we get out of our entanglements, whatever we get into.

I also had a wonderful marriage, a great husband. We traveled a good bit. I have fantastic friends. I’m really blessed.

You get to talking to people and everybody’s got somebody that’s been through it in the family or with friends and they don’t talk about it normally, but if they find out what you are going through, they’ll talk. And I think that sometimes helps them too a little bit.
I was getting a social security check off of his social security and that wasn’t leaving me very much after paying all the bills. I have to ask, I hated asking people for help. Good thing our church has a friend that helps people out. God bless them they really stuck by me and helped out quite a bit.

Like I said I had church and good friends.

A lot of times he was saying he was going to end it all. He couldn’t walk very good and he was always falling. He said, “If I can’t walk anymore I’m just going to end it all,” then he would take off. With me having to use the walker I would have to call the neighbors and they would have to go hunt him down and it was just too much.

Caregivers who share care giving duties with other family members reported doing so most effectively by employing teamwork.

I guess our system is just teamwork, whatever needed done we would do.

All three of us got along very well and my two brothers were very happy to have me be in the overseeing, in charge position. I did keep them informed with at least one or two phone calls per week, sometimes daily, as it got more intense. They were willing to pitch in wherever they needed, but they’re not in positions to drop and go like I was necessarily. But they were thankful to have me do this so that they didn’t have to.

The three of us did so much communication it was almost like a group effort anyway and we all agreed.

My youngest sister is a businesswoman and then the other sister is an accountant, so I said you guys do the money, I’ll do the mom.

I worked with families that not understanding the dynamics or the limits of the abilities of folks and people get really mad sometimes at their sibs about it. I’m blessed in that I understand those dynamics. But lots of people don’t. I think it’s just so important that for our family I said to the girls we need to decide this, talk to your husbands, this needs to go forward.

Caregivers also find benefit in helping others. A son described informal support sessions at the local Burger King:

There is another family that comes to Burger King, and this lady is taking care of her husband at home, he has Alzheimer’s. He still gets around, he can still
talk and make sense, but they have to go to Burger King everyday. At 10:30 he
looks at the clock and says, “We going to Burger King?” And they got to go. I
told her, I said, “Now you be careful,” I talk to her away from him of course.
And I said, “You be careful. You have to look out for yourself.”

His wife added:

We know how stress worked on us, and to live with it 24/7 like she does, it has
to be terrible.

Though caregivers hope for the support of family and friends, not all
participants received this social support.

Our older sister lives away, and she probably came home once every three
months sometimes longer. But anyway, we couldn’t get her to understand that
caregiver. She did

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she don’t like her. It makes you feel like ok you’re the only one, and you’ve

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I do.

I’m sure they (the care recipient’s family) have blamed me for putting him in
the nursing home, which I don’t have much contact with them. He has one
sister that comes to see him occasionally. The younger sister that doesn’t like
me, I don’t even call her. I can’t afford to have a conflict, especially a conflict
of being called a liar and so on and so forth. I just can’t handle that.

We have all come a long way. What bothers me a lot, it bothered me in the
beginning when we first brought her up here (nursing facility), was people
would come in and they would say well I saw your mother and she knew me,
like there wasn’t anything wrong. Like we had just put her up here to get rid of
her.

The wife of a care recipient described her initial battle with her daughter:

My daughter has a family of her own and she wasn’t always around him. She
didn’t realize all the changes and she didn’t see the violent side of her dad.
She continued:

I asked her one day if she was calling me a liar and she says, “Well mom, dad’s not violent.” I says you don’t see him everyday. I says you don’t know what it’s been like, him waking up sometimes in a good mood and then other times he just shakes his fist at me or throws something at me, and the verbal abuse.

This lack of support is an additional grief the caregiver must own. Though now very close with her daughter, the same wife explained these emotions:

It’s just hard on the loved ones if they don’t have the support of people in the family. The family members that don’t know what’s going on, they blame the spouse for the change and it isn’t.

Reading Material

Though not as personal as social support systems, books were also noted as an important tool in coping. Each of the caregivers in the study mentioned reading *The 36 Hour Day*. One of these caregivers found great relief in the book.

Dr. May gave us a book to read, and the name of that book was *The 36 Hour Day*. And reading that book I thought well this is mom, this is exactly mom. You know she thinks that we’re taking things and she’s hiding her mail, and just telling one of us one thing and one of us another. But now I realized she didn’t remember. Before that I really had a resentment toward mom, because boy she was telling us all this stuff and why is she lying to us and why is she doing all this. But as I read the book and went to some Alzheimer’s classes I realized that it wasn’t that she was doing it on purpose. So it made it easier for me because it relieved that burden.

Caregiver Suggestions

As was previously mentioned, the caregivers interviewed enjoy helping others. Therefore, it was not surprising that they had several suggestions for future programs supporting future caregivers. The first of these ideas is an Adult Respite Center.
Though these facilities are not uncommon, according to the caregivers that participated in this study there are not any conveniently located in the region.

Our community doesn’t have an Alzheimer’s respite really, and they don’t have a day program. I wasn’t in a position where I felt like I could care for my mother all by myself, that she would not get the level of care from me that she would with a staff. But if there had been an Alzheimer’s unit that I could have taken her to in the morning and resources to be able to get some additional reliable care there’s a possibility that I could have had her come home at least in the beginning. She had the money to do it, but those services aren’t available here.

Some of the ideas that I thought of would be if there were some kind of senior gathering places that someone could go for a few hours or a day as a release for caregivers or if nobody could go in for a day.

A son who described the effort it requires to schedule services in a remote area proposed the second suggestion.

I think since we all are aware of the possibilities of what’s out there I think we probably were well informed regardless of living in a remote area. Sometimes getting assistance in a remote area is a little more time involved.

He suggested a caregiver network.

I started to talk about having the caregiver network that could pass names to the next round of families that need care giving because I have done that myself with a number of people in the care giving group (support group) and some of the caregivers have found more jobs and have moved on.

The final suggestion was one involving regularly scheduled physician visits. A few caregivers praised one on one time with physicians prior to check-ups, while others wished for that time.

I found it beneficial to spend a few minutes with the doctor ahead of time so they could kind of get up to speed without feeling like I was trying to talk about my parent in the same room. And that is something I would still like to see improved in most geriatric visits, is to have five minutes to have either a caregiver or a family member be private with the doctor and I have yet to see that occur. What the patient is actually telling the doctor is very different then
what reality is. And it’s not fair to constantly correct a patient in that setting I don’t think.

Every time I went to visit, I went with them to the doctor. But before I went I wrote a letter, or I brought a letter with me and said that I’ve seen that there’s a change in her ability to dress, there’s a change in her ability to, you know, whatever it was.

In addition to respite centers, networking, and personalized visits with physicians, participants voiced a wish to have had earlier access to resources and Alzheimer’s information. The benefit of this being an earlier understanding of the problem, a problem that according to one caregiver is not going away.

It’s going to be a big problem, and people better pay attention to it.

Research Question Three

The last of the research questions asked: During the progression of the disease in what ways do coping strategies change, and why? Though a distinct pattern of coping was not found, participants described a “learn as you go” process. In addition, as the disease progresses caregivers reported relying on memories and acceptance as coping strategies. Many too must cope with the loss of responsibility.

“Learn As You Go” Progression

Most of the caregivers described their coping method as “learning as you go,” or more formally on the job training. They changed strategies, as they found necessary, sticking with those that worked and stopping those that did not.

I have done some Internet information, but a lot of it we just sort of plotted our way through.
We sort of just stumbled along, and tried to do the best we could.

We know we’re not perfect, and we’ve asked a lot of questions during this process. We tell people we don’t have any idea what we’re doing. Help us, give us advice, or whatever. And we try to listen, you know. That’s what we try to do with other people.

We’d leave her notes on what she was supposed to do. We got books on Alzheimer’s, care giving and stuff, trying to figure out what we were supposed to do.

I think you don’t really understand until, even if the resources had been there, it wouldn’t be the same until you’ve dealt with it. I think dealing with it is the best teacher.

A wife provided an example of such a strategy:

He would sit and look at people and people would come up and say something to him because he was a parts man and everybody knew him, and after they were gone he would say, “Who was that?” And a lot of times I didn’t know who it was, then I got into the habit of asking, “Sir I’m not sure what your name is,” you know and they would identify themselves then so that I could tell him who it was. You have to kind of learn that I guess.

A daughter, educated in gerontology, employed this strategy as well.

When she was first in the nursing home we could go out for ice cream, she came to our house and we went for walks, she helped me plant flowers, it was a really interesting transition because, you know, I worked as a geriatric social worker for years and years and years and I had her come in and I got her a chair and sat her down and I started cooking. Well she got bored, you know, she had always been involved in the kitchen, and I went duh, you know. Pretty soon I had her washing the lettuce and ripping it up and you know. In the end what I would do when I would cook, I would wash the pans and give them to her and she would dry them. She needed to be involved, and it’s the same thing I’ve told caregivers over and over, but it’s interesting how different it is when it’s actually your parent.
Key Transitions

Caregivers reported using the “learn as you go” coping process in addressing the changes in their loved ones. These changes, some of which were previously described as problem behaviors, are transitions characteristic to Alzheimer’s disease. Those reported included ignoring household responsibility, denial, wandering, the inability to drive, handle money, bathe, dress oneself, maintain conversation, feed oneself, a disinterest in hobbies, disrupted sleeping, obsession with order and detail, agitation, paranoia or delusions, and often the move to a nursing facility.

The same way with her bills, she would have them out on the table in front of her but she couldn’t figure it out.

I think for a man it is so hard to accept the things they cannot do that they have done so well in their lifetime.

How would we have felt if we had hesitated to make a decision and all of a sudden one night she heard a voice and she went to see what it was and got out on the train track or walked into the riverbank?

We was always finding him down along the river or road.

He also enjoyed hiking and he would sometimes get himself into a difficult position out in the woods and so that was a concern.

The driving was a concern for a while, but we convinced him to donate his pickup truck to a private school and then we filled in with other people to take him places.

Cash, he couldn’t handle cash.

He was always clean about himself, and he started going dirty and not wanting to dress.

You can’t have good conversation because he can’t keep the train of thought, he doesn’t understand what I’m saying even though it’s something simple.
He never wanted to go to the bathroom, if he had to go he would just go on the floor.

Then he would have toilet accidents, and you know, you didn’t know to use depends.

When their eating ability is affected, that is a major, major, major concern. You’re deciding whether they live or die.

In the last five, six years we noticed that she always loved crafts. You never knew what she was doing, but she had her own paint by numbers sets and she did different things. She would have the stuff on the table but she couldn’t put them together anymore.

I can go to bed at 10 o’clock, but he might go to bed at 8, 8:30, 9 o’clock. Well then his sleep was over with or it was interrupted and he was ready to get up.

The organization skills are fascinating with the Alzheimer’s brain. He wanted to put all round objects together, all triangles, and all similar colors.

She kept thinking that everybody took everything.

One family provided a painstaking description of their transition to the nursing facility.

I can’t get that … The day we brought her, we all Frank and Sally and I went over to her house that morning. She thought we were just coming for coffee like usual. Dr. May had given us an anxiety pill to give her and so instead of giving her …

Her brother continued:

Her thyroid pill, we gave that one to her and she sat there in the chair and she was sleepy. Otherwise she would have thrown a royal fit if she thought we were going to take her someplace she didn’t want to go.

Participants also discussed the recognition of a need for additional assistance as the disease progressed.

We hired a girl who came in and would be three days a week for eight hours. So, for those three days of the week for eight hours I could go anywhere I wanted to or go outside and work.
I guess one thing that is different part way through was the option of calling somebody else and having them come in and fill in. You know with mom we were trying to do it all ourselves, just my family. And it really wears on a household.

**Relying on Memories**

In the present, caregivers rely on memories to replace what is no longer, including intimacy.

After being married 43 years it is still hard for me to go there and have to leave him and come here to an empty apartment. What keeps me going is just to see his picture. I keep his pictures all around, wedding pictures and then his picture of him now, and I remember all the good times we had together. That’s what keeps me going; I remember the old Ned and the jokes he used to play on me.

One thing too, and you didn’t bring it up but I will bring it up, sex. You have to learn that they are unable to perform anymore and you have to learn that it’s over and not only for you but for them. And you rely on the memories that you have. A kiss and I love you has to be, you know, how you get along. We’ve had a good life, but it all comes to an end. Life doesn’t last forever.

**Acceptance**

Of the coping strategies mentioned by caregivers, acceptance was overwhelmingly an important approach in dealing with the disease, and often a final phase of the care giving process. For some acceptance was an inherent reaction to the Alzheimer’s disease, while for others the process occurred gradually. One of the wives described a desire to have had the opportunity to accept things gradually.

It was so sudden that he got worse, that I was just hoping that we could get along for a few more months, you know. But, it was so sudden; it came on so fast that he was immobile that I just blew up all at once instead of gradually getting ready. It was just happening right now, and that was hard to accept because you couldn’t believe that it was happening.
Regardless, acceptance is a multifaceted concept and process that is addressed with time. Caregivers must come to terms with the disease, associated changes in daily living, and death.

Before an individual can accept change or death, they must accept the fact that their loved one has Alzheimer’s disease, and that they will for the remainder of their life. As one of the caregivers, a wife, explained:

His brother had had Alzheimer’s and his wife had told me, “It will be a long, long time before you say goodbye.” And I have come to realize that very much.

The caregiver must also accept that behaviors are a result of the disease and not due to intentional laziness or spite.

Another thing that I feel certain is because of the dementia is that he doesn’t have the consideration for me that he once had.

We gradually got the hang of it. There is no arguing or rationalizing or trying to make sense of it. You know, that was our theme song. It’s not going to make any sense.

Everybody’s different. Now he’s kind of quiet in his talk, but he was always that way in his life. He was never a person who was aggressive or anything; he was always a quiet person. He loved his customers at the garage when he was a parts’ man, and I’ve noticed that there are so many different ways that they express themselves. So you have to accept that that’s the disease, that’s not the person.

A wife described her route to accepting her husband’s growing limitations:

One of my biggest frustrations was he would never turn a light out. He would go in the bathroom, turn the light on, walk out, and never turn the light out. He’d go in the living room, he’d go down in the basement, he’d never turn a light out, and I would get very frustrated at that. Because I am the one to say well you can turn the light on why don’t you turn it off, no problem. But he couldn’t remember to turn that light out.
When I asked how she handled this situation, she responded:

I should have been more that way. I was frustrated more than anything I guess. I should have been more, oh what the heck leave the light on. But I wasn’t that kind of person.

This same wife also talked about building patience.

It didn’t change it. I just had to be more patient. She (her physician) knows me, and I’m a quick person to react. She says, you’re going to have to be more patient.

I asked how she does this, and she responded:

Just tried to hold my breath and keep quiet. I tried not to talk about it or get upset, but then there’s times when you do.

Caregivers who have a more difficult time being patient are more easily frustrated and or agitated.

In addition to accepting behavioral changes associated with the Alzheimer’s patient, caregivers must accept change in daily roles, their own abilities and inabilities, and consequential transitions, such as a nursing home placement. Caregivers who are able to accept changes in daily living do so earnestly. They are able to also accept the decisions they have had to make, and are generally happy with their efforts.

You can’t keep second-guessing yourself. We thought we did the right thing and the best we could. We did I think.

We made a conscious decision. We made the choice to say this wrecks families if you choose to let it. We didn’t want to do that.

I’m a person who accepts things as they are. Don’t look back; look forward. I just accepted the fact that I had to do it, and I had a good income as well as his income and we managed.

I guess I learned that you have to cope with everyday things and accept what happens.
Maybe there were things we didn’t do that maybe we would have done had things changed. But his stroke kind of changed things, and then you just accept that. If you don’t you drive yourself and everybody else crazy. You complain a lot and nobody wants to hear it after a while.

Though individual’s reasons for acceptance differed, one couple described their route to role acceptance in this way:

They spent a lot of time for us, so we’re spending time for them.

Time spent, however, forces individuals to evaluate what it is they are able and unable to do in terms of care giving. An acceptance of the caregivers’ inabilities in regard to the demands of care giving, in this case, was often the precursor to a nursing home placement.

He had pneumonia and I was worn out. I called his doctor one day and I said, I don’t think I can do this anymore.” So he was brought into the nursing home under the pretense that he was going to get better from the pneumonia. I made up my mind when he came here, I couldn’t take him back home. I would be dead before he was.

I don’t know what the future holds. I just knew I couldn’t take care of him. I couldn’t lift him. He’d fallen a couple times, and he’d broke a lamp in the living room. I mean it was just things that I knew I couldn’t do, and I wasn’t getting any rest.

He would say to me occasionally when he first came, “When am I going home?” And I would say, “I can’t take care of you anymore.” And that bothered you, in that you were unable to do it. But he accepted that and that was a big blessing.

For some, the care recipient is not accepting of the transition to the nursing home. This is often an indication of how well the caregiver will adjust and ultimately accept that their loved one is under the care of the facility. In illustrating this concept, a wife described her husband’s contentment with the nursing home.
Now he is settled in and he don’t even think about wanting to leave there. When they take him out and bring him back he says, “Home.”

When I asked how that made her feel, she replied:

It makes me feel a lot better. I know he is content. He used to beg me to take him with me, and now he just smiles and gives me a good healthy kiss. He is well contented and that makes me feel better that he is contented down there.

Similarly, another wife explained:

I never regretted putting him in the nursing home. He never asked me not to do that, and I never asked him not to do that to me.

Another caregiver, however, described the opposite response and reaction.

I think he thought we were coming here for treatment. One day he said, I didn’t know this is where I was coming, or going to do, or something like that. He let me know that he didn’t know that he was going to stay here very long. He thought it was a short two or three days maybe, or something. He didn’t accept it very well.

Her transition was not as smooth.

I don’t know I was just upset. I went to the doctor and got some nerve medications and sleeping medicines, and just had to wait for it to take its effect. But he was pretty upset when he found out that he was not going home with me.

Regardless, most caregivers, after some time, articulated relief in knowing that their loved one is well cared for.

It’s a relief to know that I don’t have to worry about his care.

You just have to accept the fact that he’s being cared for, getting meals, you know.

I truly appreciate every person in this rest home, all that they do. Whether it be the laundry to maintenance, or whatever, I truly appreciate everybody.
Many expressed feelings of simply not knowing what to do in the home.

How do you get people in and out of a chair, how do you get them in and out of a shower, and out of a car? How do you make sure that their food is appropriately sliced so that they can eat it themselves? As I said, I have been in geriatrics for a long time, but I had never assisted somebody with toileting, an adult with toileting, never. So those are things that you just don’t know.

Then he would have toilet accidents, and you know, you didn’t know to use depends. I’m not sure I could of gotten him into them anyway. Now they were able to do that here, maybe because he was around them more or he saw other people in the same situation. You don’t know a lot of the things to do to make things easier for them and you when you’re doing it on your own.

Like role change and transition, death is also inevitable in the course of Alzheimer’s disease. Most caregivers mentioned having accepted death before its actual occurrence.

You have to accept the stages of the disease. You know it’s not a curable disease. Death is inevitable, and you have to know that death is the release of whatever he’s going through, whatever that might be, we don’t really know.

Just in two weeks time he went from, you know, being in good shape, to ok, and then bedridden, and passed on. So it was wonderful that it could be that quick and painless for him.

For all the years I’ve worked in geriatrics I had never seen a person die, and it was so clear that she wasn’t there, that her spirit was gone. And I was very comfortable with that.

Loss of Responsibility

Despite the difficulty and stress participants associated with care giving, many caregivers feel a void when their care giving responsibilities are lost due to death, nursing home placement, etc.

I was always available for evening times. It was always before supper we’d have our medicines and she’d be ok for the evening. For at least a couple
months five o’clock would come, and it was like I’d need to be somewhere. I was really sad; I had a couple crying jags there. It was like an empty nest or something.

It’s like I’m finally retired now. I didn’t feel like it before, I just sort of felt like I still had a job.

In a lot of ways it created a huge block of time, not only pretty much everyday, but in a weeks time I had space available on the calendar. It was like oh gosh what can I do? What should I do?

Now a way of life, some caregivers prefer to fill time by keeping busy. A wife described how she occupies her time after placing her husband in a nursing facility:

A good replacement is volunteering. I like to volunteer here (nursing facility), keeping busy with church work, getting plenty of rest. If I wake up in the morning and I don’t want to get up, I just lay there. Keeping busy gives you less time to feel anxious and nervous. A lot of times in the summer time I’ll go out on the front porch and just read til dark and that takes up a lot of free time too.
Analysis of Findings

Discussion of Key Transitions

As the findings and previous discussion suggest, caregivers must confront and cope with each of the changes experienced by their loved ones. Table 1 lists some of these key transitions, or changes, that an individual diagnosed with Alzheimer’s disease will likely undergo. These transitions are ones reported by participants of the research study, and have been placed underneath the stage of the disease during which they are most likely to occur. Not included in the table is the diagnosis of Alzheimer’s disease. Though not a physically observed change, it may be considered the initial transition a caregiver will experience.
### Table 1

*Care Recipient Transitions Experienced by Stage of Disease*

<table>
<thead>
<tr>
<th>Transition</th>
<th>Early</th>
<th>Middle</th>
<th>Late</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily Activity</td>
<td>Ignoring household responsibility/paying bills</td>
<td>Innocent wandering</td>
<td>Dangerous wandering</td>
</tr>
<tr>
<td></td>
<td>Disinterest in hobbies</td>
<td>Unsafe driving</td>
<td>Or Immobility</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Trouble handling money</td>
<td>Inability to maintain conversation</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Trouble managing medications</td>
<td>Inability to eat/swallow</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Disinterest in hobbies</td>
<td>Forgetting friends and family</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Disrupted sleeping</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Obsession with order</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Environmental</td>
<td></td>
<td>Need for paid caregiver/family help</td>
<td>Need for paid caregiver/family help</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Nursing home placement</td>
<td>Nursing home placement</td>
</tr>
<tr>
<td>Personal Care</td>
<td>Misplace items (ex. combs)</td>
<td>No longer bathing</td>
<td>Incontinence</td>
</tr>
<tr>
<td></td>
<td>Assistance ironing and folding clothes</td>
<td>Refusal of bathing</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dressing inappropriately/ wearing same outfit daily</td>
<td></td>
</tr>
<tr>
<td>Psychological</td>
<td>Denial Cover-up inabilities</td>
<td>Agitation Paranoia / Delusion</td>
<td>Agitation Paranoia / Delusions</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
As the table suggests, a majority of the transitions occur during the middle stage of Alzheimer’s disease. Like many of the other factors surrounding the disease, however, these transitions and the time at which they occur are not clearly defined. In addition, not every caregiver will experience every transition. Individuals with Alzheimer’s disease show varying symptoms and may progress at a faster or slower rate than others. For example, depending on family structure and value, or the progression of the affected individual, a nursing home placement may occur earlier or later, or not at all.

Regardless of timing, however, it is likely that a majority of the transitions will be noticed during the middle stage of the disease. This is not to suggest, however, that all of these changes in behavior and cognition occur at the exact time. Instead, they are noticed because the individual affected by Alzheimer’s disease becomes less able to cover them up. During the early stages of the disease, individuals do realize that their memory is failing and compromise for this by concealing their problems (Mace & Rabins, 2001). As one family explained:

She was hiding things from us so that we would think she was normal. She was having problems for sometime before we realized she was having problems.

In addition, a daughter explained:

You know the problem with the elderly is that when they’re sick and confused it’s hard to tell what’s actually going on.

Therefore, individuals may have difficulty with tasks long before the caregiver becomes aware of the trouble. For example, difficulty with tasks such as driving and managing medications may be present before they are addressed, putting both the care
recipient and others in danger. This, then, becomes a key issue for social work intervention. By intervening during the early stages of Alzheimer’s disease, practitioners may be able to prevent possible dangerous consequences and also educate family members on the possible future transitions. Family members who are aware of what may be coming, will likely be better prepared to handle these transitions, rather than being shocked by their occurrence. As one wife stated:

It was so sudden, it came on so fast that he was immobile that I blew up all at once instead of gradually getting ready. It was happening right now, and that was hard to accept because you couldn’t believe it was happening.

Three-Stage Transitional Coping Model

The process through which an Alzheimer’s caregiver copes with each transition is unique to the individual. However, there are some similarities among people’s experiences and coping strategies. Using mechanisms repeatedly reported by the research participants, a general coping model can be constructed. This coping process has been divided into the following three-stages:

1. Coming to Terms with Reality

As loved ones began to show the initial signs of Alzheimer’s disease, or related dementia, caregivers reported experiencing one of two feelings. Many reported a misunderstanding of the disease, not recognizing signs due to a lack of education. Others reported an intentional unawareness. Before caregivers could employ effective coping strategies they first had to orient themselves to Alzheimer’s disease and its
implications. Caregivers sought professional health care workers and experienced caregivers for an explanation of the disease, what to expect, and suggestions for coping. Those caregivers who sought advice from a support group or educational reference were likely to do so at this time. Others, however, were left uncertain and unable to grasp the inevitable change ahead. Though they hear the diagnosis, they cannot register its meaning.

2. Development of Effective Strategies
   
   Ineffective Strategies
   
   Once caregivers had some understanding of what their loved one was experiencing they could begin to tailor their day’s work to meet the needs of their family member or friend. At this stage most caregivers have taken on additional responsibility within their households and begin to employ a combination of coping strategies such as physical activity, planning for the future, and faith. Those who were previously unwilling to come to terms with the Alzheimer’s diagnosis, however, may be more likely to employ ineffective coping strategies, such as arguing with their loved one.

3. Acceptance

   Avoidance
   
   The final stage of the coping model is acceptance. Caregivers who have reached this stage understand that there are limitations to their abilities. They no longer experience overwhelming feelings of resentment or frustration. Instead, they know that they, nor a
physician, can cure their loved one, and they recognize both the neurological and psychological effects of Alzheimer’s disease. These caregivers are focused on the comfort and satisfaction of their loved one, and strive to maintain the utmost of each. Though they may never feel completely relieved of feelings of guilt or worry, they can recognize that they are trying their best. These caregivers are also more likely to reach out and help others. Unfortunately, however, caregivers who have not developed effective coping strategies, may not ultimately accept their situation. These caregivers fall towards the opposite end of the continuum: avoidance.

These stages may occur separately, but are not always discrete steps. Instead, caregivers may experience an overlap of the stages. For example, one may continue educating themselves while they begin to employ daily coping strategies and routines specific to their situation. In addition, the stages are a continuum. Caregivers do not necessarily fit only one extreme or the other, but rather fall somewhere between the two. Regardless, caregivers who reported having a greater understanding of Alzheimer’s disease were more likely to continue on the left side of each spectrum during the following stages. Those who have an ambiguous understanding were likely to remain towards the right side of each subsequent spectrum. It is possible, however, that caregivers fall at different spots along each continuum given different stressors.

The model is also impacted by the events of Alzheimer’s disease. The process may repeat itself as the disease progresses, and stages may be especially prone to repetition upon transitions. Change is continuous throughout the progression of Alzheimer’s disease; therefore, this model is also in a continual repetition. As the
findings indicate, acceptance is a multifaceted concept. Therefore, though an individual may have reached the level of acceptance regarding implications of the disease, this does not mean that they have accepted a nursing home placement. As a couple reported:

In some ways that was even worse than the day he died.

Should this transition occur, the caregiver will have to educate themselves about nursing facilities, develop coping strategies to deal with the transition, and eventually accept their loved ones new home. Some, however, may never accept this transition. Other transitions, aside from diagnosis and nursing placement, which may result in the repeating of the coping model include the removal of a driver’s license, coping with incontinence or the need for assistance with activities of daily living, and death. These, and the others listed in Table 1, must each be reconciled separately.

It is also possible for caregivers to regress to the first stages of the model, rather than moving forward through stages. This occurs when caregivers experience “good” days. During these days the caregivers’ loved ones appear to be living in the absence of Alzheimer’s. They are coherent, able to recall information, and converse logically. It is easy then for caregivers to believe their loved one is no longer ill, or that the doctor provided a misdiagnosis. These days are common, but unfortunately temporary. Faced with reality, caregivers must again move through the three coping stages beginning with the first. It is understandable that this constant repetition, false hope, and inevitable reality are all a great source of distress for caregivers struggling through the process of caring and coping.
The ease with which a caregiver moves through the coping model is greatly
determined by one’s inherent resilience. Families that exhibit resilience are able to
manage disruptive events, control stress, and move forward with life (Walsh, 1996),
thus correlating resilience with higher levels of acceptance. Resilience, in turn, is
predicted by one’s general attitude. Caregivers with a generally positive outlook on
life are more likely to be resilient as well. This is not to suggest, however, that
individuals who are resilient will have no difficulty dealing with the many types of
dementia. It is inherently normal for individuals to experience grief in such a situation
(Seligman, 2006), and even those who are positive, resilient individuals do so. These
caregivers will likely, however, have a faster recovery time.

Inherent traits are not the only factors predictive of quick, effective coping.
Environmental factors are crucial as well. The participants interviewed are
representative of a rural, Appalachian population, and many expressed a desire for
earlier information and intervention. However, because these participants are from
rural areas, there may be instances where it is more difficult for them to access
information and specialized professionals; therefore, delaying the time with which it
takes to move through the coping model. Also, as the literature review suggests the
Appalachian culture itself may also be a hindrance in caregivers seeking earlier
assistance. Caregivers, who have developed three of these inherent traits,
individualism, familism, and personalism (Keefe, 2005), may be especially prone to
the refusal of professional assistance.
Individualism refers to one’s belief in self-reliance. Appalachians hold a strong belief that one can solve problems without the assistance of others, and to need assistance is a negative reflection of the individual (Greenlee, 2010). Familism, on the other hand, refers to the Appalachian’s primary source of support during a time of difficulty: the family (Greenlee, 2010). Therefore, because Appalachians hold such a firm belief in supporting family members, they may be more likely to care for ill relatives in the home longer, but without the assistance of professionals.

Further, Appalachians respect individuals who can uphold personable relationships, not individuals who solely hold a higher degree or title. Therefore, professionals working with this population need to treat clients as individuals and not just another appointment in the day. Those professionals who are able to make this connection will have a much better tendency for progress, compared to those who cannot as they will likely be rejected by the population (Greenlee, 2010).

Accepting Assistance

The previous model pertains specifically to the continuous transitions associated with Alzheimer’s disease. While the management and acceptance of transitions is crucial to caregiver well-being, this study suggests that the most successful caregivers are those who are able to identify the need for help, and further ask for and accept assistance from others. In doing so, caregivers appear to move through seven fairly distinct steps. Table 2 lists the psychological, social, and cultural factors caregivers must sort through during the first three stages: not knowing there is
a problem, realizing there is a problem, and realizing that one needs help. A more
detailed explanation of each step follows the table.

Table 2

*Caregiver Psychological, Social, and Cultural Factors associated with Receiving Help*

<table>
<thead>
<tr>
<th>Steps One through Three</th>
<th>Factors</th>
<th>Problem Unrecognized</th>
<th>Problem Recognized</th>
<th>Realize Help Needed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological</td>
<td></td>
<td>Confusion Disbelief</td>
<td>Depression Fear/Worry</td>
<td>Depression Fear/Worry</td>
</tr>
<tr>
<td>Social (Family, Friends, etc.)</td>
<td></td>
<td>Confusion Disbelief</td>
<td>Actively Present Or Disbelief</td>
<td>Present Or Intentionally not Present – Avoidance</td>
</tr>
<tr>
<td>Cultural</td>
<td></td>
<td>Individualism</td>
<td>Individualism</td>
<td>Individualism Familism</td>
</tr>
</tbody>
</table>

1. **Caregivers are not aware that there is a problem** –

The earliest signs of Alzheimer’s disease may likely resemble those of
common aging. As a wife described, she first noticed a change in her husband during a
vacation.

He had three combs with him when we left home and after a few days he had
to borrow a comb from me because he couldn’t find a comb. And he seemed so
slow in making decisions on the highway, like he was not slowing down soon
enough or getting ready to turn soon enough and that bothered me.

Both of these concerns, however, could have multiple explanations, certainly aging,
tiredness, or distraction. Any one of these reasons could be attributed to the incident,
and as a result the problem is innocently overlooked. In addition, caregivers who are not aware of Alzheimer’s disease would not be likely to associate a missing comb with a progressive and fatal brain disease.

Increased occurrences, like the one above, may then cause confusion among family members and friends. Though caregivers may also choose to keep these initial concerns private. Regardless, early incidences will likely not be severe enough to warrant a need for help, especially in the Appalachian community. Individuals in this community are raised to be self-reliant. Therefore, again using the example above and Germain’s ecological model (1991), the caregivers may take over more of the driving or go to the store and buy a few more combs to make up for any deficiency, and to maintain the best person:environment fit for both one’s self and the loved ones. Though a seemingly stable time, this is the best point of intervention for social workers, and other helping professionals. Social workers can educate families and help prepare them for the future, before they begin to experience and must deal with multiple care recipient behaviors, transitions, and family issues. As problems begin to pile on top of one another, it is more difficult for caregivers to manage individual issues.

2. Caregivers are aware of the problem –

As incidences become more frequent and severe, they are no longer easily overlooked. As one caregiver stated:

It cannot be ignored.
The familial relationship, whether that be a spousal relationship or parent/child relationship, is slowly transformed and most often at this step the relationship between the caregiver and care recipient has diverged from one that was relatively equal in that both were independently responsible for their own self and delegated responsibilities, whatever those might entail, to one in which one individual is becoming more and more dependent on the other. In addition, caregivers are simultaneously maintaining their own self and the additional responsibilities no longer manageable by their loved ones.

Understanding that a loved one will not recover from Alzheimer’s disease, in addition to piling demands, appears to be the cause of feelings of depression and fear for the future, which may be heightened or improved by social networks. Those families who were able to share responsibility and work as a team managed transitions most effectively. However, despite this fact, many caregivers reported having family members who did not take on a primary caregiver role. This, however, was not met with opposition when the family members were supportive of the caregiver’s decisions. A son described this concept:

My brother doesn’t want to be involved … But the only upside to that is my brother, he supports everything that I do.

In contrast caregivers chose to limit contact with those who did initiate conflict. Despite family involvement or a lack there of, caregivers are not yet ready to seek help. In an attempt to maintain autonomy, it is often a crisis that propels caregivers to the next step.
3. Caregivers recognize a need for help –

As Germain (1991) suggests, individuals who have underestimated a stressor, and failed to activate resources may increase the potential for harm and persistent stress. Therefore, it is likely that caregivers who have experienced crisis will be the most fearful and depressed. In addition, nearly half of the research participants interviewed were caring for their spouse of several decades. These individuals made a vow to one another; in sickness and health until death do us part. Therefore, requiring assistance may be perceived as a failure, one reason individuals may prolong asking for help. Children too seemed to feel obligated to care for their parents who have done so much for them.

Again this concept plays into the Appalachian cultural belief in familism. The family is the main support system and individuals are responsible for caring for their own. This may become especially prominent in situations in which other siblings or children are unable to assist in care giving responsibilities. One family member may feel obligated to care for a loved one who may otherwise need to be institutionalized.

A continuation of this process is illustrated in Table 3. Table 3 lists the psychological, social, and cultural factors influencing the last four steps caregivers visit before accepting help.
Table 3

*Caregiver Psychological, Social, and Cultural Factors associated with Receiving Help*

<table>
<thead>
<tr>
<th>Factors</th>
<th>Ask for Help</th>
<th>Develop Plan</th>
<th>Implement Plan</th>
<th>Reflection</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological</td>
<td>Depression</td>
<td>Depression</td>
<td>Fear/Worry Guilt</td>
<td>Varying degrees of Guilt</td>
</tr>
<tr>
<td></td>
<td>Fear/Worry Guilt</td>
<td></td>
<td>Guilt Loneliness</td>
<td>BUT ALSO Relief and some Freedom</td>
</tr>
<tr>
<td>Social</td>
<td>Active Assistance Or</td>
<td>Trust in – Family,</td>
<td>Trust in – Family,</td>
<td>Trust in – Family,</td>
</tr>
<tr>
<td></td>
<td>Avoidance</td>
<td>Friends, Paid Caregiver,</td>
<td>Friends, Paid Caregiver,</td>
<td>Paid Caregiver,</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Facility Staff</td>
<td>Facility Staff</td>
<td>Facility Staff</td>
</tr>
<tr>
<td>Cultural</td>
<td>Individualism</td>
<td>Individualism</td>
<td>Individualism</td>
<td>Individualism</td>
</tr>
<tr>
<td></td>
<td>Familism</td>
<td>Familism</td>
<td>Familism</td>
<td>Familism</td>
</tr>
</tbody>
</table>

4. Caregivers ask for help –

When caregivers are ready to ask for assistance they are most likely to talk with those they are most familiar with. Families in which multiple members took part in care giving made many decisions together. Those who were alone in care giving sought advice from individuals such as physicians and ministers. This, however, is more easily done by some than by others. As one caregiver recounted:

I hated asking for help.

And though the Appalachian culture is traditionally more reluctant to seek assistance from professionals, a physician in many situations was the one who not only suggested a nursing home placement but also validated the decision for family members.
A final decision, however, concerning major transitions such as a nursing home placement was often made collectively as a family, even when family members lived out of town or were not overtly active in care giving responsibilities. This decision, regardless of the means by which it was made, leaves a majority of caregivers with feelings of guilt. For reasons mentioned in the third step, guilt is a psychological response that will likely prevail regardless of the caregivers’ backgrounds and knowledge base. Therefore, this is something medical social workers should be particularly aware of.

5. Caregivers develop a plan –

Though an example of a devised plan is to decide to admit a loved one into a nursing facility, caregivers also reported hiring in-home caregivers, and asking family members to come sit with the care recipient while the primary caregiver left the house for a few hours. This, however, is extremely difficult for anyone who has internalized the Appalachian culture, as it goes against nearly all of their values. They have had to admit that they cannot independently take care of their own, and continue by giving someone else permission to provide care, even though this care may be offered in their own home. It is not surprising then that feelings of guilt, fear, and depression are not subsided by simply developing a plan, and that they will continue to linger on even after the plan is implemented. Many caregivers expressed feeling this way.

I wondered if it was the right thing. After being married 43 years it is still hard for me to go there and have to leave him and come here to an empty apartment.
It is hard; it is the hardest thing I have ever done is to leave here. The guilt, you know, she is my mother why can’t I take care of her?

Developing a care plan also refers to the caregiver as well. Until this point the caregiver has been consumed in ensuring the well-being of the care recipient, maintaining multiple household roles, and communicating with family members. Several caregivers, however, voiced the importance of maintaining self-care and not allowing ones own health to deteriorate. This is a convenient time for caregivers to evaluate their own well-being, something else social workers can assist with. Lingering feelings of depression, guilt, fear, worry, and resentment need to be evaluated and addressed, and physical activity maintained.

6. Caregivers act on developed plan –

To develop a plan to receive help is not enough; the plan must actually be implemented. This means allowing strangers into one’s home, or moving a loved one to a new home where 24-hour care will be provided by an array of professionals without the caregivers’ constant supervision, something that is initially difficult for caregivers to accept.

Caregivers in general also run the risk of losing a sense of autonomy and self-direction in the process of care giving. For the sake of the care recipient, activities are often performed at the same time daily. Therefore, tasks become a daily routine, and to some an around the clock occupation. There is no time for the caregivers to reflect on their own needs, and for this reason many caregivers feel lost or alone when their care giving duties are relinquished, usually by a nursing home placement. One caregiver in
particular referred to the transition as living in an “empty nest.” Recognizing these feelings may also be another key point for social work intervention.

This again is a time when the caregivers’ care plans can be implemented to combat feelings of loneliness and continued feelings of guilt. To fill the void caregivers reported relying on friends and family for outings, volunteer work, and other personal enjoyments.

7. Caregivers reflect on the decisions made –

The most difficult part of this process for caregivers, regardless of age, gender, and previous relationship is accepting that the decisions made were needed and beneficial to the care recipient. In doing so, caregivers are acknowledging that they too are dependent on others for help: family, friends, and professionals. They are setting aside a value system that has likely been upheld for decades, and as a result discovering some relief in the end and increased self-esteem. This is achieved primarily through relationships with others. Caregivers reported the benefit in talking with others in similar situations to their own and admitted feeling relief in knowing that their loved one was being cared for. As a wife confessed:

It’s a relief to know that I don’t have to worry about his care.

Caregivers also reported a greater satisfaction with facilities that employed genuinely kind individuals.

As soon as we walked through the door, it was a family type atmosphere. Everybody spoke to us and smiled.
However, not all caregivers are able to accept every decision made, and many reported continued feelings of guilt surrounding issues, particularly nursing home placements. Regardless of outcome, each caregiver goes through a period of reflection, in which they ask themselves if they did the right thing. Again, others may help in validating decisions made: social workers and other professionals, family, and friends. These questions, however, may never be resolved, and caregivers will continue to second-guess past decisions.

Like the transitional coping model the ease with which individuals move through these steps and locate and possibly accept assistance from others is dependent on the individual. Some accept help earlier than others, however, the reasons for this are various. It could be possible that some caregivers experience a premature crisis. Or maybe families that are supportive in members’ decisions, produce caregivers who are less ashamed to ask for help.

Regardless of their situations, caregivers and their loved ones will continue to depend on one another to fulfill a few of their basic human needs: love and appreciation. Both individuals have the need to feel loved and appreciated, and previous studies have indicated that caregivers who do feel appreciated by their loved one report feeling less stressed (Pearlin, Mullan, Semple, & Skaff, 1990). Included in feeling loved and appreciated, is the need to be cared for. While individuals with Alzheimer’s disease rely on the caregiver or caregivers for this attention, caregivers may worry that no one will be around to care for them, especially caregivers who are caring for a spouse. A wife explained feeling grateful for those who worried about her.
My personal doctor has done a lot. When I go he’ll ask how Will is, and he would say, “How are you coping?”

This is another area that social workers and other helping professionals should be aware of. Showing concern for the caregiver may be as therapeutic as assisting them in developing effective coping strategies and outlets for assistance.

Summary

The proposed transitional coping model is a generalized model that many caregivers follow, in some form, each time they cope with one of the transitions outlined in Table 1. The ease with which a caregiver moves through the model is dependent on environmental and personal factors, and caregivers may also regress through the model when given false hope for a recovery. For example, an individual with Alzheimer’s disease may recall a loved one’s name on a good day, leading the caregiver to believe that they are getting better. In addition, caregivers fall along a continuum at each step in the model. Some are ultimately more accepting of a transition, while others choose to be more avoidant, and the degree of acceptance may also differ among transitions.

These transitions that elicit the use of the coping model are characteristic of specific stages of Alzheimer’s disease. Therefore, the stage of the disease can also be approximated by the changes reported by a caregiver. Knowing this approximation allows social workers to better understand where the family is in the progression of the disease, and how they have reconstituted their definition of family. Have they sought out any assistance, and how has this helped? In doing this, the social worker will
evaluate the present psychological, social, and cultural factors and the areas to be adjusted to arrive at an optimal person:environment fit for everyone.

In addition, social workers need to evaluate the level of self-esteem evident in the caregiver or caregivers. If stressors have continued to accumulate, it is likely that an individual’s self-esteem will need to be regained. Positive self-esteem, as discussed earlier, is a combination of three interrelated attributes: human relatedness, competence, and self-direction. However, it is difficult for many to retain these characteristics while caring for a loved one with Alzheimer’s disease.

The first difficulty encountered is that of human relatedness. As an individual progresses through the stages of Alzheimer’s disease their own relationships with others becomes transformed. Therefore, caregivers who are used to sharing a spousal relationship or parent/child relationship with the care recipient must understand that this relationship is inevitably going to change, and the make-up of the original relationship will never be regained. Instead, caregivers must develop new ways to connect with their loved ones, which will inevitably become even more difficult as the disease progresses.

In addition to questioning how one should relate to their loved one, many caregivers also struggle with the many other decisions and adjustments that must be made throughout the course of Alzheimer’s disease. With each of the transitions, some daily modification usually needs to be implemented, and it is common for caregivers to question each of their actions. This questioning diminishes ones sense of
competence. Caregivers may feel obligated to take on the responsibilities of care giving, but not necessarily be prepared.

Finally, as caregivers become consumed in care giving tasks, they run the risk of losing a sense of self. This is their husband, wife, mother, or father; and, therefore caregivers will go to great lengths to maintain their loved ones well-being. In the process, however, many forget to make time for themselves or given a lack of assistance, cannot make time for themselves. This disrupts ones self-direction, the ability to manage ones own life. Caregivers who do not take time for themselves risk their own health, both physical and emotional health, and unknowingly the health of their loved one as well. Caregivers who are emotionally and physically drained will likely have a difficult time maintaining the level of care required by Alzheimer’s disease. Therefore, if social workers can help caregivers rebuild these characteristics first; it will assist them in regaining an optimal level of self-esteem and good person:environment fit. With both in place, caregivers are better prepared to manage future transitions and cope successfully.
Conclusion

The information gathered from this study indicates the variation in coping mechanisms employed by family caregivers of individuals with Alzheimer’s disease and other related dementias. As their loved ones progress through the disease, caregivers are faced with new, but continual transitions and task expectations that must be initially coped with, accepted, and managed. Caregivers reported the use of a “learn as you go” coping process, picking up on effective coping strategies as problems presented themselves. This allowed for the development of a generalized coping model that caregivers follow in gradually gaining some degree of acceptance or avoidance in regards to specific transitions.

The ease with which a caregiver is able to do this is determined by both environmental factors (physical location, cultural traits, etc.) and psychological factors (inherent resilience, personal disposition, etc.). Responses from the individual interviews suggest that individuals, who possess some degree of resilience and a generally positive outlook on the future, are better able to accept the stages of the disease and the change that follows. Regardless, however, it is not uncommon for most caregivers to experience feelings of grief, guilt, frustration, and resentment, especially as their loved ones become more dependent and, as a result, caregivers must assume more independent responsibility. It is those caregivers who are unwilling to work through these feelings and ask for assistance, however, that are most susceptible to caregiver burden, stress, and depression. These individuals are also susceptible to a loss in self-esteem, which must first be addressed before adaptation will result.
Regardless of the caregivers environmental and psychological traits, 10 of the 12 interviewed participants eventually had to place their loved one in a nursing facility, one of the most difficult of the described transitions. Another caregiver employed professional caregivers to come into his father’s home, and the last caregiver interviewed was still caring for her husband in their home, but would ask her daughter to come into the home so that she could leave for short periods of time. In coping with these difficult transitions caregivers praised the comfort they gained in finding social support systems; therefore, implying a need and role for social workers in assisting individuals throughout the coping process.

Implications for Social Work Practice

As the literature suggests, by 2050 Alzheimer’s disease is expected to impact as many as 16 million individuals and half of the population over 80 years old (Hassan, 2009). Therefore, it is likely to be an issue that social workers across disciplines encounter. Geriatric social workers and social workers within health care systems need to be particularly aware of the issues surrounding the disease and caregiver role. In addition, nursing facilities, hospitals, senior centers, and neurological centers would benefit from having a social worker on staff to assist the patients’ family members in managing the physical and emotional demands of care giving.

In assisting clients, social workers should first understand where their client is at in the coping process. Asking about previous coping experiences may be a good
way to determine not only this, but also to determine what should be an initial point of intervention. Clients who described using ineffective coping strategies (denial, argumentative confrontations, etc.) may need initial assistance in coming to terms with the reality of Alzheimer’s disease and managing the negative emotions that may result. Clients who have previously used effective coping strategies may need more specific assistance, for example help coping with particular transitions.

Both groups, however, may also need assistance rebuilding positive self-esteem. Keeping in mind those characteristics that constitute self-esteem, social workers may first offer suggestions on how to interact with the individual with Alzheimer’s disease. For example, many caregivers may not be aware of the technique termed therapeutic fibbing. This term refers to playing into the care recipient’s thoughts, rather than constantly correcting them. So if an individual says he or she is waiting on their mother who has been dead for several years, it is best for the caregiver to concur with this statement rather than putting their loved one through the emotional pain of realizing that their mother is no longer living. This technique may also save the caregiver from several potential arguments with the care recipient.

In addition, social workers may build competence by validating or encouraging appropriate, but difficult decisions. The caregiver should be reminded that these decisions are being made with the care recipient’s best interest in mind. Social workers should also make caregivers aware of the resources available to them in their surrounding area, especially those resources that would allow some respite from care giving tasks. The use of an adult day center, for example, provides time for the
caregiver to run errands or reflect on their own well-being without worrying about supervising their loved one. Though caregivers may need varying degrees of assistance with these issues, increased human relatedness, competence, and self-direction will better the person:environment fit and increase self-esteem.

In targeting specifically the Appalachian population, social workers need to help families understand that their experiences are typical progressions experienced during the course of Alzheimer’s disease. These individuals may need to be assured that they are not any less of a person for needing assistance and for not being able to independently manage the complexity of the disease. Connecting caregivers with community mentors may also be an effective technique in approaching these issues. In addition, social workers need to be personable professionals. Regardless of demographic, displaying trustworthiness and making individuals feel important is key to a successful worker/client relationship.

Social workers understand that there are multiple facets to be examined in every problem. Therefore, keeping internal and external factors in mind social workers can use the proposed models from this study to determine what stage of the disease the client is caring for, what transitions the client is likely to face as a result, and the client’s general coping tendencies: general acceptance or avoidance. Social workers can also evaluate the depth with which families have considered contracting outside help, and assist individuals with future arrangements rather than waiting for a crisis to occur. Considering psychological, social, and cultural factors, social workers can help caregivers match with the best alternative to primary care giving should the need arise.
Social workers with this information can better help clients develop coping strategies in advance, and prepare caregivers for future encounters. This would allow for the gradual preparedness that caregivers had reported that they wished they had had.

**Implications for Social Work Policy**

Social workers can be an extremely important component to a caregiver’s coping process; however, they too need to be trained in managing Alzheimer’s disease. Caregivers may not know how to toilet or bathe an adult, and a social worker that has also not been educated in doing so is going to be of little help.

The Alzheimer’s Association offers a variety of educational and training programs to professional care providers that can be applied toward continuing education (CEU) credits. Therefore, social workers within respective health care agencies (nursing homes, hospitals, etc.) that regularly interact with the geriatric population should be required to complete a set number of CEU credits in programs similar to those provided by the Alzheimer’s Association.

In addition, the start-up of support groups within the agencies described above would also promote effective coping strategies. However, due to the stigma associated with similar groups, meetings should be greatly advertised and the group facilitator should be someone who is visually present within the agency and readily available for questions and/or concerns. Additional adult day services, a suggestion made by research participants, are also needed within the Appalachian region. These services allow caregivers immediate respite, which allows them to maintain their own health
and according to participants would also allow them to keep their loved ones in the home longer.

Many caregivers also reported using informal services through the church, for example, talking with the minister or receiving help from church friends. Therefore, formal church-based services, such as a caregiver network or support groups run by the church, may be more acceptable to Appalachian caregivers and more widely used.

Implications for Future Research

Due to time constraints and the small, purposive sample used in this study, the findings cannot be generalized for the entire Appalachian Alzheimer caregiver population. In addition, all of the research participants had made use of either a support group or nursing facility prior to their interview; therefore, indicating that these caregivers were well aware of their available resources and possibly more motivated to use them.

For these reasons, a larger study that could make use of random sampling would provide a more complete understanding of the needs of Appalachian caregivers. In addition, a study that focused more closely on the emotions attached to specific transitions could be beneficial not only to caregivers, but to the social work profession in general. It would allow professionals to have a complete understanding of both the physical and emotional demands placed on caregivers, allowing for the development of more effective intervention strategies.
Despite some limitation, this study has described two processes by which Alzheimer’s caregivers cope with transition and seek assistance from both formal and informal networks. In doing so, it has also described areas in which social workers and other helping professionals may be of greatest help. These areas include educating the caregivers, assisting in care plan development, validating difficult decisions, and introducing caregivers to other valuable community resources. Adaptive coping relies on the ability of the caregiver to maintain positive self-esteem and an optimal person:environment fit given underlying circumstances. Therefore, the social worker who is able to assist his or her client in doing this will likely observe the greatest progression in caregiver physical and emotional well-being.
References


Appendix A
Ohio University Consent Form

Title of Research:
Living with Alzheimer's Disease: An Examination of Caregiver Coping Mechanisms

Researchers: Mary Dolan, Undergraduate Social Work Student at Ohio University

You are being asked to participate in research. For you to be able to decide whether you want to participate in this project, you should understand what the project is about, as well as the possible risks and benefits in order to make an informed decision. This process is known as informed consent. This form describes the purpose, procedures, possible benefits, and risks. It also explains how your personal information will be used and protected. Once you have read this form and your questions about the study are answered, you will be asked to sign it. This will allow your participation in this study. You should receive a copy of this document to take with you.

Explanation of Study

The purpose of this study is to explore and describe the coping strategies and needs of Alzheimer’s caregivers in the Appalachian region of Ohio. I will do this by interviewing willing caregivers, over the course of approximately eight weeks.

Risks and Discomforts

My research involves little or no risk to its participants, and the decision to be a part of my study is entirely your decision. Even if you choose to participate, you are free to terminate the interview at any time, refuse a question, or eliminate yourself from the study completely.

Benefits

My hope is that this research project will provide a general awareness of the issues and difficulties that Alzheimer’s caregivers face on a daily basis. In addition, through your participation in defining the needs of rural caregivers, initial steps can be taken to construct beneficial programs and resources for future caregivers. If implemented, such programs could have the possibility to decrease the negative health affects often associated with the care giving process.
Confidentiality and Records

All interviews will be recorded; however, audiotapes will be stored in a locked file in the researcher’s apartment and will be played only by the researcher behind closed doors. They will be destroyed immediately following the completion of the thesis by removing the tape from the cassette and burning both items. Audiotapes will have the participants’ names on them, though these names will be altered in the final written thesis. Additionally, while every effort will be made to keep your study-related information confidential, there may be circumstances where this information must be shared with:

* Federal agencies, for example the Office of Human Research Protections, whose responsibility is to protect human subjects in research;
* Representatives of Ohio University (OU), including the Institutional Review Board, a committee that oversees the research at OU.

Contact Information
If you have any questions regarding this study, please contact me at (440) 313-4286, email: md291306@ohio.edu, or my advisor, Dr. Richard Greenlee, at (740) 699-2530, email: greenlee@ohio.edu.

If you have any questions regarding your rights as a research participant, please contact Jo Ellen Sherow, Director of Research Compliance, Ohio University, (740)593-0664.

By signing below, you are agreeing that:
- You have read this consent form (or it has been read to you) and have been given the opportunity to ask questions
- Known risks to you have been explained to your satisfaction.
- You understand Ohio University has no policy or plan to pay for any injuries you might receive as a result of participating in this research protocol
- You are 18 years of age or older
- Your participation in this research is given voluntarily
- You may change your mind and stop participation at any time without penalty or loss of any benefits to which you may otherwise be entitled.

Signature ___________________________ Date ____________

Printed Name ___________________________
Appendix B

Background Information

1. What is your relationship with the care recipient?
2. How far away did or do you live from him or her?
3. Approximately how many hours a week did or do you provide care?
4. During this time did you work outside the home?
5. Was anyone else, family or friends, involved in care giving?
6. Were financial and health matters delegated to specific individuals?

Coping Strategies

1. When did you first notice changes in your loved one?
   - What changes were noticed and how were suspicions confirmed?
2. How did these initial changes affect you and your daily routines?
   - Emotions attached?
   - Largest concerns?
3. How did you manage / cope with initial changes?
4. How would you describe the progression of Alzheimer’s disease?
   - What key changes did you notice in your loved one?
5. During the care giving experience did your coping strategies change?
   - If so, how?
6. For how long did you assume the role of primary caregiver?
7. What event caused the termination of this role?
   - What new issues resulted?
How did you adjust?

Resources

1. Throughout your experience what resources did you find most helpful?
   ➢ Why?

2. Was there anything more you wish you had access to and did not?
   ➢ If so, why? How would this have been beneficial?

3. Is there anything more you would like to share with me?