“THE LONG GOODBYE”: UNCERTAINTY MANAGEMENT IN ALZHEIMER’S CAREGIVERS

Sara L. Shaunfield, B.A.

Thesis Prepared for the Degree of

MASTER OF SCIENCE

UNIVERSITY OF NORTH TEXAS

May 2011

APPROVED:

Elaine Wittenberg-Lyles, Major Professor
Brian K. Richardson, Committee Member
John M. Allison Jr., Committee Member
and Chair of the Department of Communication Studies
James D. Meernik, Acting Dean of the Toulouse Graduate School

Caregivers for individuals diagnosed with Alzheimer’s disease (AD) shoulder a remarkably complex burden as compared to other caregivers of elderly individuals. For long distance caregivers, geographical separation further compounds the problems experienced by AD caregivers, as they are isolated from family members and support networks. Both on-site and long-distance AD caregivers experience uncertainty; the findings from this study illustrate how AD caregivers manage the uncertainty of the disease and primary care, as well as how uncertainty differs between on-site and long-distance caregivers. AD caregiver (N = 13) interviews were transcribed and qualitatively analyzed using uncertainty management theory as a thematic lens. The analysis revealed that AD caregivers experience overwhelming feelings of burden, guilt, and doubt; however, these feelings manifest differently depending on caregiver type. The findings of this study demonstrate that sources for obtaining information regarding AD and caregiving were useful for on-site caregivers; however, the sources did not account for the needs of long-distance caregivers or the psychosocial needs of on-site caregivers. Furthermore, AD caregivers did not seek support or information about AD and caregiving from health care professionals. Implications for future research regarding long-distance and on-site AD caregiving are discussed.
Copyright 2011

by

Sarah L. Shaunfield
ACKNOWLEDGEMENTS

First, I would like to thank my advisor, Dr. Elaine Wittenberg-Lyles for her assistance, encouragement, and spirited guidance. I have learned so much from working with you, and without you this thesis would still be a theory.

Second, I would like to thank the members of my committee, Dr. Jay Allison and Dr. Brian Richardson. Thank you for agreeing to be on my committee. Your input was invaluable to the completion of this project.

I would also like to thank the Alzheimer’s Association who graciously agreed to assist me in recruiting participants for this project, particularly Shelly Young the program manager. Her passion for helping others and diligent hard work was a significant contribution to this project.

A special thanks to the selfless efforts of Alzheimer’s caregivers whose efforts are paramount to the well-being of others. Furthermore, I would like to thank the caregivers who readily agreed to participate making this study a possibility.

Finally, I would like to thank my parents Rosemary and Bruce Shaunfield, my grandparents Lane and Harold Albritton, my friends and colleagues namely Damla Ricks, and my boyfriend David Miedzianowski for your endless encouragement, support, and inspiration. I would not have made it through this program without you.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>ACKNOWLEDGEMENTS</td>
<td>iii</td>
</tr>
<tr>
<td></td>
<td>LIST OF TABLES</td>
<td>vi</td>
</tr>
<tr>
<td></td>
<td><strong>CHAPTERS</strong></td>
<td></td>
</tr>
<tr>
<td>1.</td>
<td>INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>AD Caregiver Hardships</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Theoretical Framework</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Alzheimer’s Caregiver Types</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Purpose/Rationale</td>
<td>12</td>
</tr>
<tr>
<td>2.</td>
<td>LITERATURE REVIEW</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Stages of Alzheimer’s Disease</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>Caregiving in Alzheimer’s Disease</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>Burden on the Family</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>Uncertainty Management Theory</td>
<td>23</td>
</tr>
<tr>
<td>3.</td>
<td>METHOD</td>
<td>33</td>
</tr>
<tr>
<td></td>
<td>Approach</td>
<td>33</td>
</tr>
<tr>
<td></td>
<td>Participants</td>
<td>34</td>
</tr>
<tr>
<td></td>
<td>Recruitment</td>
<td>34</td>
</tr>
<tr>
<td></td>
<td>Procedure</td>
<td>35</td>
</tr>
<tr>
<td></td>
<td>Data Analysis</td>
<td>36</td>
</tr>
</tbody>
</table>
4. RESULTS ....................................................................................................................40
   Participants.............................................................................................................40
   Uncertainty Appraisal ............................................................................................43
      Negative Appraisal........................................................................................44
      Positive Appraisal .........................................................................................53
      Neutral Appraisal ..........................................................................................55
      Combined Appraisal .....................................................................................55
   Uncertainty Management Strategies ......................................................................57
      Reducing Uncertainty ...................................................................................58
      Maintaining Uncertainty ...............................................................................65
      Increasing Uncertainty ..................................................................................67
      Adapting to Uncertainty................................................................................68
   Differences Between On-Site and Long-Distance Caregivers ...............................70
      Appraisal Differences ...................................................................................70
      Management Differences ..............................................................................71

5. DISCUSSION ..............................................................................................................74
   Limitations .............................................................................................................83
   Future Research .....................................................................................................83
   Conclusion .............................................................................................................84

APPENDIX ..................................................................................................................85
REFERENCES .............................................................................................................88
LIST OF TABLES

1. Participant Demographics ................................................................. 41

2. On-site and Long-distance Participant Comparison ........................ 42
CHAPTER I
INTRODUCTION

The aging population is rapidly increasing due to life sustaining technological advancements that prolong the average life expectancy. In the year 2010, 40.2 million people were reported as living beyond the age of sixty-five (United States [U.S.] Census Bureau, 2010); the U.S. Census Bureau (2010) projected that the number of elderly will increase to 88.5 million by the year 2050, increasing the total by 3.9 million since the year 2000. Although evolutions in technological, social, and environmental conditions have contributed to the ever-increasing age expectancy, the debilitating illness known as Alzheimer’s disease (AD) is becoming disproportionately endemic (Alzheimer’s Association, 2010). The prevalence of many major causes of death have begun to decrease while AD related deaths have exponentially increased; for example, heart disease has decreased by 11%, stroke by 18%, prostate cancer by 8%; whereas AD related deaths increased by an astounding 46% (Alzheimer's Association, 2010).

The Alzheimer’s Association (2011) estimated that approximately 5.4 million Americans suffer from AD, a number that is projected to increase by 10 million as the baby boomers continue to age over the coming decades. One in eight Americans has Alzheimer's disease. Currently, AD is the sixth leading cause of death in the United States and the fifth leading cause of death for individuals aged 65 and older (Alzheimer’s Association, 2011). AD is unlike most diseases because individuals who are diagnosed with AD live from 2 to 20 years beyond illness identification, however the average individual lives 8 years following diagnosis (Alzheimer’s Association, 2010; Family Caregiver Alliance [FCA], n.d.). Alzheimer’s is a debilitating and gradually progressive disease that is composed of three escalating stages: early, middle, and late. As the disease progresses, individuals suffering from AD require assistance with bathing, eating,
and using the bathroom (Alzheimer’s Association, 2010; FCA, n.d.; National Alliance for Caregiving [NAC], 2004). This study focused on the family caregivers who provide assistance with these daily activities and care for loved ones with AD.

AD Caregiver Hardships

Informal caregivers assume the role of primary or secondary caregiver for individuals with AD, typically working full or part time and either living with the care recipient or at a distance. In America nearly 14.9 million individuals, primarily family members (94%) and occasionally friends (6%), have taken on the responsibility of unpaid caregiver for persons with AD (Alzheimer’s Association, 2010; Alzheimer’s Association, 2011). With the number of AD diagnoses expected to increase dramatically in the coming years, the number of unpaid informal caregivers will also rise. AD caregivers shoulder a remarkably cumbersome burden as compared to other caregivers of elderly individuals. Due to the specificities involved in AD caregiving, individuals who provide care for this population experience increased burdens emotionally and physically; their time is consumed by caregiving tasks that influence their own work and family life (Wilks & Croom, 2008).

People who provide informal care for a person with AD typically experience a decline in overall health. Because of the increased demands associated with caring for a person with AD, caregivers encounter numerous negative consequences that range from physical burdens, emotional stress, social isolation, depression, increased mortality, loss of financial security, and often loss of employment (Alzheimer’s Association, 2010; FCA, n.d.). Informal caregivers are on average women in their late 40s and 50s (Wilks & Croom, 2008); the demands of caregiving, family needs, and the pressures of work that exist for this particular demographic often
overshadow the individual needs of the caregiver (NAC, 2004). The physical hardships associated with providing care for a person with AD continually increases with the progression of the disease (Wilks & Croom, 2008). The laborious physical burdens AD caregivers must cope with include bathing, dressing, shopping, cooking, managing incontinence, and physically transporting the patient (Alzheimer’s Association, 2010; FCA, n.d.). Many AD caregivers report feeling as if they are ‘on-duty’ 24 hours per day, and others report providing 40 or more hours of care per week (Alzheimer’s Association, 2010). The everyday tasks engaged by the AD caregiver are associated with excessive physical strain, which has been found to result in a decrease in the caregiver’s health and increased rates of mortality.

Additionally, taking on the role of informal caregiver leads to stress-related illnesses, such as depression, anxiety disorders, and fatigue, that compromise the caregivers’ health, and substantially increases psychological morbidity (Mahoney, Regan, Katona, & Livingston, 2005), which jeopardizes their capacity to provide care (Bookman & Harrington, 2007; Mitrani et al., 2006). The added dimension of caring for a person with AD is intensified because of the enduring trajectory associated with the disease (Alzheimer’s Association, 2010; Cooper et al., 2008; FCA, n.d.; Wilks & Croom, 2008), and AD caregivers report a greater prevalence of stress, depression, and anxiety than other caregiving populations (Walker et al., 2006).

Providing informal care for persons with chronic and neurological disorders is associated with increased burden and stress that results in a significant decrease in life quality (Bookman & Harrington, 2007; Martinez-Martin, Benito-Leon, Alonso, et al., 2005). For example, people who provide care for individuals diagnosed with Parkinson’s disease experience burden as a result of the care recipient’s depression, agitation, abnormal behavior, mental decline, delusions, and the extensive disease trajectory (Martinez-Martin, Benito-Leon, Alonso, et al., 2005). In a
similar vein, those who care for persons diagnosed with multiple sclerosis report increased levels of fatigue, depression, apathy, and irritability due to the abnormally extensive course of the disease. Generally, multiple sclerosis is diagnosed in young adulthood (between ages 20 and 30) and the symptoms of the disease are unpredictable and include depression, emotional problems, blurred vision, bladder and bowel problems, and difficulty with coordination and balance (Arnett, 2007; Buhse, 2008). Providing informal care for a person with AD is similar to caring for persons diagnosed with other neurological diseases due to the prolonged trajectory of the diseases and the loss of both physical and cognitive abilities. However, the AD caregiving experience is unique because of the care recipient’s gradual memory loss and inability to communicate (Walker et al., 2006; Wilks & Croom, 2008). According to Martinez-Martín et al. (2005) caregiver stress increases in tandem with neuropsychiatric symptoms, physical disability, and dementia.

AD caregivers often suffer alone because they will not ask for help because they experience feelings of guilt and inadequacy (Bookman & Harrington, 2007). Generally, AD caregivers prefer to keep the person at home for as long as possible, until they are eventually moved into a nursing home for the provision of professional care (Alzheimer’s Association, 2010); however, most AD caregivers require outside help at some point (FCA, n.d.). Unfortunately, AD caregivers do not receive the social support needed to mediate the heightened stresses involved in caring for an AD patient (Wilks & Croom, 2008).

In addition to physical and emotional strain, AD caregivers encounter substantial financial strain. Because the amount of time needed to provide adequate care for someone with AD is substantial and increases with the progression of the disease, caregivers must often make changes to their career plans by reducing hours, quitting their jobs altogether, and commonly
postponing the fulfillment of retirement dreams (Austorm & Lu, 2009). An astounding two-thirds of working caregivers reported either reducing their work hours or taking unpaid leave in order to garner time to provide adequate care (FCA, n.d.); consequently the workforce faces decreased productivity and lost wages in paid leave, while AD caregivers encounter decreased financial stability.

Overall, informal caregivers receive little, if any, government assistance to finance the necessities to provide adequate care (Taylor et al., 2001). In the United States, AD has been estimated as the third most expensive disease to treat. The average cost for a person diagnosed with AD, is $174,000 (Alzheimer’s Association, 2010). Caregivers must often foot the bill for prescription drugs, assistive equipment, medical copayments, clothing, and home modifications (Anonymous, 2008; Taylor et al., 2001). In 2011, AD caregivers provided 17 billion hours of unpaid care, a contribution worth nearly $202 billion to the US government due to a significant savings in governmental assistance programs (i.e., Medicare, Medicaid) and a decrease in spending on formal home health care and nursing home care, which is currently unable to meet the needs of the aging population (Alzheimer’s Association, 2011). Family caregivers employ various strategies to compensate for the expense of caregiving; some of the strategies include postponing expenditures seen as less immediate such as major purchases, home improvements, future plans, career advancement, leisure activities, and spending on the caregiver’s health and dental care (Anonymous, 2008).

One of the most important hardships faced by AD caregivers is the increased strain on family members’ relationships. AD is often referred to as a family disease, because watching a loved one decline results in chronic stress that affects everyone (FCA, n.d.). The way a family functions either serves to intensify or reduce caregiver stress (Wall & Spira, 2004). Mitrani et al.
(2006) identified various factors regarding family dynamics that effect caregiver emotional stress which include spousal communication patterns, marital satisfaction, conflict styles, family adaptability, and unclear boundaries (Mitrani et al., 2006). AD caregiver emotional stress is affected not only by family interactions specifically related to caregiving, caregivers are also affected by family functioning in general (Mitrani et al., 2006). As the family member suffering from AD continues to withdraw, caregivers experience heightened levels of stress and anxiety and require increased support from family members.

When multiple family members assume the role of caregiver, conflict often emerges because of different perceptions and lack of communication concerning what constitutes quality of life for the care recipient (Gardner & Kramer, 2009). Deficient communication between informal (often family) caregivers contributes to conflict and increased difficulty in decision-making and advanced care planning, which sadly results in poor end-of-life care for the care recipient (Gardner & Kramer, 2009). Caregivers of AD patients eventually must become the spokesperson for the AD patient, as the individual declines and can no longer communicate his or her preferences. As such families often encounter ethical dilemmas concerning the care recipient’s self-determination and autonomy (Wall & Spira, 2004).

Middle-aged siblings must often make the difficult decision to care for an aging parent; the ways in which siblings approach major tasks related to their parent’s care affects the status of their relationships in later life. When siblings have a positive and close relationship, division of caregiving tasks tends to be divided more equally; however, if the individuals are not close the stress of caregiving causes siblings to distance themselves from one another (Hare, 1995). Conflict that emerges between siblings regarding a parent’s care often occurs because of an
unequal division of caregiving responsibilities or divergent perceptions regarding the parent’s health care needs (Hare, 1995).

Because of the substantial and escalating tasks involved in caring for someone with AD, the high financial costs, and the lengthy trajectory of the disease, individuals with AD often have more than one unpaid caregiver (Alzheimer’s Association, 2010). This situation often occurs when the patient lives with an on-site caregiver but receives additional assistance from a long-distance caregiver. However, the relationship and communication between the caregivers may also affect the division of caregiving responsibilities, their relationship with each other, and the quality of care provided for the patient.

Living in an era that is more global and mobile than previous generations has created unique challenges for individuals who must provide care for family members living at a distance (Collins et al., 2003). Historically, several generations lived in the same home (Collins et al., 2003; Czaja & Rubert, 2002); however, transportation and advanced technology have enabled people to move further away and still maintain contact. As a result, siblings move away from their hometown to various parts of the country to begin their own careers and families, impacting the frequency of visits, quality and quantity of interactions and assistance with chores, and other supportive familial duties (Collins et al., 2003; Czaja & Rubert, 2002). Similarly, when people begin to age and retire, many choose to move to a more comfortable climate (Czaja & Rubert, 2002). The ability to move and maintain contact more easily, combined with increasing numbers of elderly in need of assistance, has influenced the emergence of a phenomenon known as long-distance caregiving.

The average long-distance caregiver is located 450 miles and 7.23 hours of one-way travel away from the recipient (NAC, 2004; Robb, 2007). As a result of the distance between
long-distance caregivers and care recipients, financial costs increase substantially. The mean financial cost of providing long-distance care averages $647 to $751 per month (NAC, 2004; Robb, 2007). Travel also requires long-distance caregivers to miss work to provide care for their loved ones (NAC, 2004). Yet, despite substantial costs, an astounding third of long-distance caregivers report visiting at least once a month and half report visiting a few times each month (NAC, 2004). Between 34 and 52 million caregivers provide informal care for elderly individuals in the US (Collins et al., 2003; Robb, 2007); five to seven million of those caregivers manage care from long-distances (Collins et al., 2003; Miles to go, 2004; Robb, 2007).

Currently, no definitive distance constitutes long-distance caregiving. However, in previous literature, researchers (Roff, Jennings, & Parker, 2004) have identified long-distance caregiving as more than 60 miles or one hour away from the care recipient (NAC, 2004). For the purpose of this study, long-distance caregivers will be defined as those who live an hour or more away from the recipient. The time it takes to get to the care recipient should be considered in conjunction with traffic and other barriers that emerge, which is more important in times of crisis than distance as measured in miles (NAC, 2004).

In order to provide adequate long-distance care, individuals must endure the difficulties of becoming knowledgeable about the specifics of the disease and the available resources from a distance, thus information-seeking behaviors and strategies make a profound difference in care provision (Collins et al., 2003). Distance is regarded as a key factor in determining caregiver responsibilities (NAC, 2004). In order to provide care from a distance, individuals must maintain frequent contact with care providers, mostly by phone, make arrangements with local relatives or neighbors, and keep informed of health developments, changes in care, and emergencies (Collins et al., 2003). Unfortunately, caregiving from a distance is at best partial
because such caregivers are not able to attend to daily circumstances like on-site caregivers. As a result, long-distance caregivers experience increased uncertainty due to the emergence of various unanswered questions (Collins et al., 2003).

Theoretical Framework

Given that the cause, resources for prevention, and cure for AD are unknown, and because the variability in symptoms and behaviors that AD sufferers exhibit makes it difficult to document the course of the disease, uncertainty is a ubiquitous characteristic for all parties involved (Polk, 2005). Uncertainty management theory provides a lens for investigating AD caregiving hardships in the face of uncertainty. Although uncertainty management theory is relatively new (Brashers, 2007), researchers have utilized it as a framework to address uncertainties associated with caregiving (Sanders-Dewey, Mullins, & Chaney, 2001), as well as uncertainty management in other health care contexts including intervention research (Hines, 2001), doctor-patient relationships (Brashers, Hsieh, Neidig, & Reynolds, 2006), and illness (Babrow, Kasch, & Ford, 1998; Brashers, Neidig, & Goldsmith, 2004).

Individuals experience uncertainty when situational details are equivocal, uncertain, complex, or divergent, when information is contradictory or unavailable, and when one feels insecure in his or her own knowledge (i.e., situational and in general) (Brashers, 2001). AD caregivers consistently experience uncertain situations; their uncertainty only increases as the disease progresses and their loved ones gradually lose the ability to make new memories, communicate, and physically function. The AD caregiver may feel insecure when administering medication, assessing the patient’s level of comfort, or determining what the care recipient does or does not understand. Additionally, uncertainty occurs when an individual attempts to assess
the probability that an event will occur; in order to gain a sense of control individuals must decide whether an event either will or will not occur (Brashers, 2001). An Alzheimer’s caregiver may attempt to gain a sense of control and regain stability in his/her life by assessing the caregiving situation and that of the loved one and making plans for the future; however planning for the future is extremely difficult because AD is characterized by instability and uncertainty (Polk, 2005).

Communication is central to the experience of uncertainty as a means of constructing uncertainty, managing uncertainty, and finding resolutions to uncertainty (Babrow, Kasch, & Ford, 1998). “Only when uncertainties are seen, understood, and appreciated can communication be used to foster (re)appraisal of both the uncertainty and alternative coping strategies” (Babrow & Kline, 2000, p. 1814). Communication in AD caregiving is central to understanding the illness, developing expectations for the future, and (re)learning to cope throughout the lengthy disease trajectory. However, AD caregivers often receive little input from medical providers, which complicates illness comprehension, and makes decision-making and adapting more difficult and burdensome (Polk, 2005). While this circumstance is especially problematic for the on-site caregiver who attends to the daily needs of the care recipient, managing the uncertainty of care may be equally or more distressing for a long-distance caregiver.

Alzheimer’s Caregiver Types

On-site and long-distance caregivers for individuals suffering from AD both experience caregiving hardships related to physical and time stressors, stress, fatigue, emotional and psychological burden, and uncertainty; however, the difference between the types of
responsibilities generates different stressors for these different types of caregivers. On-site AD caregivers experience stress and burden differently because of the physical tasks of lifting the patient, shopping, cooking, bathing, dressing, and transporting the patient to and from doctors visits (Alzheimer’s Association, 2010; FCA, n.d.). Additionally, the considerable responsibilities on-site caregivers must execute in order care for their loved ones involve a substantial time commitment; caregivers often forgo pleasurable activities and social outings (Austrum & Lu, 2009; Czaja & Rupert, 2002). The physical burdens do not decrease but continue to increase throughout the disease progression, which may precipitate a decline in the caregiver’s health and an increase in AD caregiver mortality rates (Austorm & Lu, 2009; Wilks & Croom, 2008). Although long-distance caregivers do not assist in the physical aspects of caregiving, in order to provide adequate care from a distance, they must also commit a considerable amount of time to coordinate health services, regularly speak with health care providers, attend to care recipients’ finances and legal documentation, and make frequent visits to the homes of patients and on-site caregivers (Collins et al., 2003; NAC, 2004). 

On-site and long-distance caregivers encounter various levels of emotional and psychological burden, yet the difficulties experienced by both are of notable concern. On-site AD caregivers suffer emotional and psychological burden from watching their loved ones decline mentally and physically (FCA, n.d.; Sanders & Adams, 2005). As care recipients gradually lose memory of people, places, and events, on-site caregivers begin to lose intimacy with care recipients and thus begin to grieve the loss of their loved ones (Sanders & Adams, 2005) often creating a sense of social isolation (Tarrier et al., 2002). Similarly, long-distance caregivers have reported agonizing over their (in)ability to reach the care recipient in adequate time when the life of their loved one becomes endangered (NAC, 2004). Furthermore, long-
distance caregivers endure vast amounts of guilt because of their inability to be present to provide more assistance to patients (NAC, 2004).

Overall, both caregiver types face varying levels of uncertainty because the nature of information needed differs significantly. On-site caregivers experience uncertainty because of low levels of knowledge regarding the particularities of AD and what the future holds for the caregiver and the care recipient (Werner, 2001). On the other hand, one of the main duties undertaken by long-distance caregivers is information gathering (Collins et al., 2003); however, these caregivers must often rely heavily on printed material and informal information because of the absence of local formal resources. Long-distance caregivers also encounter difficulties in locating accessible resources such as educational and support groups, AD associations, formal respite care services, and organizational instructions on how to manage the daily struggles associated with caregiving (Collins et al., 2003). Therefore, these caregivers often feel helpless when trying to manage care from a distance because they experience heightened insecurity when they do not receive pertinent information (NAC, 2004). Long-distance caregivers report feeling left out of decisions made between health care professionals and on-site caregivers because of their inability to have conversations face-to-face (NAC, 2004).

Purpose/Rationale

The ways AD caregivers cope with their loved ones’ diagnoses and seek information are extremely important in understanding how AD caregivers reduce and manage uncertainty. Insight gained into the experience of AD caregiver uncertainty management strategies will inform the development of interventions that seek to improve AD caregiver quality of life. However, little empirical evidence exists regarding the ways in which clinicians and other health
care providers can assist AD caregivers in coping with uncertainties concerning diagnosis, making preparations for the future, and managing long-term stress and uncertainty (Austrom & Lu, 2009). Research is needed to determine how best to assist AD caregivers in learning various coping strategies in order to develop interventions for improving caregiver and recipient quality of life (Austrom & Lu, 2009). This study answers the call for an investigation of uncertainty experienced by AD caregivers and the uncertainty management strategies they employ (Sanders-Dewey, Mullins, & Chaney, 2001). Researchers have yet to consider the variations in uncertainty experienced by on-site and long-distance caregivers as well as differences in uncertainty management strategies.

Given that little is known about how AD caregivers manage their uncertainty and whether differences exist between caregiver types (Polk, 2005), I explore the ways in which caregivers appraise uncertainty, the nature of uncertainty and management strategies they employ, and determine whether differences exist between on-site and long-distance caregiver uncertainty and management strategies. The next chapter provides background information regarding functional decline associated with the different stages of AD, burden and difficulties endured by caregivers of individuals with AD, the relational strain experienced by families who provide AD care, and an overview of uncertainty management theory.
CHAPTER II
LITERATURE REVIEW

Family members who choose to make the substantial sacrifice to provide primary care for individuals diagnosed with Alzheimer’s disease (AD) experience various hardships and burdens that negatively affect their quality of life (Austrum & Lu, 2009; Czaja & Rupert, 2002; Wilks & Croom, 2008). The difficulties experienced by AD caregivers are monumental when compared to other caregivers of the elderly, because of the enduring trajectory of AD (Alzheimer’s Association, 2010; Cooper et al., 2008; Family Caregiver Alliance [FCA], n.d.; Wilks & Croom, 2008); thus AD caregivers encounter diverse forms of uncertainty regarding the disease, the care recipient, as well as their own futures (Polk, 2005). AD caregiver uncertainty differs according to the type of caregiver (on-site, long-distance) and, therefore, these caregivers may utilize different strategies to manage their uncertainty. First, I examine the specific stages of AD, followed by a thorough review of literature regarding the impact of AD caregiving on quality of life, as well as the burdens and challenges AD caregivers routinely face. Next, I review the literature on uncertainty management theory to illuminate the importance of examining AD caregiver uncertainty management strategies. Finally, I explore the growing long-distance caregiving phenomenon to highlight differences of uncertainty management between on-site and long-distance AD caregivers.

Stages of Alzheimer’s Disease

In order to account for the occurrence of various symptoms encountered in the AD illness trajectory, AD has been divided into three stages: early, middle, and late. During the early stage, individuals with AD experience symptoms of depression, apathy, social withdrawal, poor
judgment, loss of ability to cook, shop, and manage finances, and the gradual inability to make new memories and remember recent conversations. In the middle stage onerous behaviors begin to emerge, such as paranoia, anger, irrational/violent behavior, wandering, hallucinating, difficulty eating, incontinence, and repeating questions or statements (Alzheimer’s Association, 2010; FCA, n.d.). Individuals in the middle stage become more reliant on others for activities of daily living (ADL); for example, they need assistance getting dressed, bathing, brushing their teeth, toileting, taking medication, etc. Patients in this stage also experience increased difficulty communicating and comprehending new information, loss of the ability to read, write, and do arithmetic, and experience loss of coordination and spatial orientation. During the middle stage, individuals with AD begin to require around-the-clock supervision and care (Alzheimer’s Association, 2010; FCA, n.d.). In the final stages of AD, individuals lose the ability to recognize loved ones, places, and objects, can no longer communicate, and become bed-ridden and reliant upon 24/7 care until death (AA, 2010, FCA, n.d.). This stage may also result in a loss of basic functions such as swallowing, smiling, walking, and participating in personal care activities.

Caregiving in Alzheimer’s Disease

As individuals with AD transition between stages, AD caregivers face various strains that significantly affect their quality of life, which include strained finances, dysfunctional family dynamics, uncontrollable behavior of the care recipient, and an enormous amount of time required to assist with ADL (FCA, n.d.; Vellone et al., 2008). Georges et al. (2008) surveyed more than 1,000 caregivers and found that as the disease progresses and symptoms become more severe, 50% of informal caregivers of persons with AD spend more than 10 hours/day providing care. They also determined that the most problematic characteristics of disease progression was
coping with daily assistance (68%) and behavioral problems (50%), such as changes in the care recipient’s personality, aggressiveness, and increased levels of dependency. Vellone et al. (2008) assessed the meanings associated with quality of life for AD caregivers and discovered that good quality of life was related to psychological and general well-being, freedom, tranquility, serenity, and acceptable financial status. Factors that were found to improve quality of life for AD caregivers were good health of care recipient, time away from home and independence from the patient, and increased assistance with caregiving. Factors that diminished caregiver quality of life included uncertainty and worries about the future, illness progression, and increased levels of stress. The stress associated with caring for a person with AD is so substantial that once the patient passed, 72% of caregivers reported feeling relieved; consequently, the caregiver often experienced self-reproach and a substantial amount of guilt (Alzheimer’s Association, 2010).

In addition to low quality of life, AD caregivers also lacked knowledge. Werner (2001) assessed family caregiver knowledge regarding AD and its correlates, and found that caregivers had low knowledge levels regarding the prevalence, causes, and symptoms of Alzheimer’s disease. Additionally, Werner found that lower levels of education correlated with low knowledge levels, while duration of care provision did not affect caregiver knowledge. Finally, although Werner did not identify a significant relationship between caregiver burden and knowledge, the author suggested that increased knowledge is not always beneficial. Furthermore, Georges et al. (2008) examined AD caregivers’ perceptions of information availability and discovered that caregivers felt the availability of information regarding all facets of AD was insufficient and crucial services such as home support were not readily available. Despite an abundance of literature focusing on the development of strategies to improve AD
caregiver quality of life, researchers have not explored the meaning of quality of life for caregivers specifically (Vellone et al., 2008).

When individuals assume the role of caregiver for a person with AD, they must engage in continuous physical labor, which commonly results in significant health decline. AD caregivers take on responsibilities that include shopping, cooking, transporting, delivering medications, managing legal and financial affairs, bathing, dressing, feeding, managing incontinence, supervising, and tracking behavioral symptoms (Alzheimer’s Association, 2010). Caregivers of persons with AD are more likely than caregivers of the elderly to assist with activities of daily living (Alzheimer’s Association, 2010). Similar to other burdens and challenges experienced by AD caregivers, increased physical strain becomes more pronounced as the recipient’s disease gradually progresses and memory and motor functions continue to diminish (Austrom & Lu, 2009). Significantly, spouses often care for their loved ones during AD progression, which is immensely alarming given 14% of AD caregivers are over age 65 (Wilks & Croom, 2008) and, therefore, have their own health problems and difficulties to attend to while providing care (Austrom & Lu, 2009).

Providing care for a person with AD causes various forms of social isolation as the caregiver experiences relational strain with the care recipient, lack of time for social engagement, and seclusion due to geographical distance from family and friends (Czaja & Rupert, 2002). Early in the disease, AD caregivers report having difficulty differentiating between their loved ones and the disease as care recipients begin to exhibit behavioral problems and personality changes due to a continuous decline in mental capacity. (Tarrier et al., 2002). Wuest, Ericson, and Norerager (1994) documented the experience of AD caregivers and their deteriorating relationship with care recipients; they found that the original emotional commitment to the
individual increasingly becomes detached as the loved one continues to change and digress into a seemingly different person. AD caregivers interact with the patient on a continuum that ranges from high intimacy in the early stages of disease to low intimacy as alienation increases over the course of the disease (Wuest, Ericson, & Norerager, 1994).

Caring for a person suffering from AD is unique because the continuous progression of the illness gradually affects relationships between caregivers and care recipients as well as caregivers’ relationships with members of their various social networks. For instance, AD caregivers tend to isolate themselves because they worry about their own limitations and become embarrassed by the behavior of care recipients; therefore caregivers tend limit their social outings and forgo pleasurable activities, thereby sustaining a form of self-imposed exile (Austrom & Lu, 2009). Even caregivers who wish to escape and socialize often cannot because of the round-the-clock supervision required to care for an AD patient, which makes it difficult to leave the house (Czaja & Rupert, 2002). In addition to giving up pleasurable activities, AD caregivers often report being isolated from family and friends because of the scarcity of time for interactions and because of geographical distances that separate many caregivers from their loved ones and sources of support (Czaja & Rubert, 2002).

Support services exist for caregivers to provide support for those suffering from social isolation; however, many caregivers do not use such services due to cost, logistical problems (i.e., scheduling conflicts), remote meeting facilities, or difficulties arranging outside assistance (Czaja & Rupert, 2002). Furthermore, AD caregivers often forgo help because to admit the need for outside help often induces feelings of inadequacy and guilt.

Researchers have consistently found that caregivers of individuals with AD have increased levels of anxiety, depression, and grief (Alzheimer’s Association, 2010; Austrom &
Caregivers, especially spouses, who provide care for persons with AD are at high risk for depression due to a loss in relational intimacy, loss of communication, the end of future planning, and a loss of both social and recreational interactions (Austrom & Lu, 2009). While some significant percentage of caregivers (10 to 35%) experience high anxiety and depression (Cooper et al., 2007), much of what gets diagnosed as depression in AD caregivers is actually grief. Moreover, when caregivers experiencing grief are medicated for depression, the treatments are ineffective (Sanders & Adams, 2005).

AD caregivers frequently suffer from grief as the care recipient begins to decline cognitively and functionally and as these losses becomes more evident (FCA, n.d.). Grief is the process of reacting to loss, which involves behavioral and psychosocial elements that might lead to negative emotional reactions (Waldrop, 2007). Sanders and Adams (2005) described grief experienced within the process of caregiving as a state of heightened responsiveness that is proportional to what is lost during a limited amount of time; grieving caregivers reported depression, nervousness, anxiety, tenseness, and problems with concentration (FCA, n.d.). Thus, the ongoing anticipation of ambiguous loss when providing care for a person with AD induces grief-related reactions that increase caregiver uncertainty and the potential for developing depression (Sanders & Adams, 2005).

In addition to depression, anxiety, and grief, caregivers often encounter psychological burdens when they have concerns regarding illness progression and health decline, identifying and managing discomfort, and living in a constant state of uncertainty (Gardner & Kramer, 2010). Gardner and Kramer (2010) found that most family caregivers ranked as their highest concern the ability to meet the patient’s needs, by providing adequate care that meets both
physical and spiritual needs. Caregivers experience psychological burden and difficulty when administering medication to care recipients with AD; psychological burden occurs when caregivers have increased uncertainty about patients’ symptoms and pain as disease progresses and communication becomes more difficult (Austrom & Lu, 2009; Gardner & Kramer, 2010). Because AD caregivers have no formal medical training, these individuals usually worry they are overmedicating; however, the medication administered is often inadequate (Alzheimer’s Association, 2010; FCA, n.d.)

Furthermore, AD caregivers experience psychological burden, a term coined to identify the additional duties and consequential emotional distress associated with AD caregiving, such as taking on the burdensome and difficult responsibility of speaking for patients when they can no longer speak for themselves. In advanced stages of illness, like AD, when an individual can no longer communicate for himself or herself, the caregiver assumes responsibility for advocating for the care recipient first by identifying their physical and emotional concerns and then by informing health care professionals (Gardner & Kramer, 2010). In addition to becoming a voice for the patient regarding pain and emotional concerns, these caregivers must also make decisions regarding end-of-life care preferences (Caron, Griffith, & Arcand, 2005; Gardner & Kramer, 2010). Difficult decisions such as these often cause a great deal of psychological burden as emotions surface when caregivers are unclear about specifics of their loved ones’ preferences. Additionally, most AD caregivers report their role as decision maker is unclear and uncertainty exists regarding what health care professionals expect of them (Caron et al., 2005).

Burden on the Family

In addition to low quality of life due to physical, social, and psychological burden, AD
caregivers also experience considerable burdens that interfere with family members’ interactions, which can cause increased encumbrance on the family unit. The additional stressors of distance and uncertainty regarding the care recipient’s condition affect family functioning, the frequency and channels of communication utilized, and the development and implementation of care plans (Collins et al., 2003). Roff, Jennings, and Parker (2004) discovered that the long-distance caregiver’s perceptions of their siblings’ caregiving competency, willingness to care, ability to provide financial assistance, and the type of personal relationship between the caregiver and recipient were all factors that significantly affected the caregiver’s decision-making and division of labor. Mitrani et al. (2005) called for future research regarding the role of family communicative patterns and their effects upon caregiver stress, burden, and anxiety, for the purpose of tailoring affective interventions to alleviate these symptoms. The declining health of an older family member often results in increased tensions and challenges, placing strain on the family members’ relationships (Wall & Spira, 2004). Family plays a large role in magnifying and reducing caregiver stress (Wall & Spira, 2004); various factors related to familial functioning have been correlated with the emotional functioning of caregivers including marital satisfaction, communication styles, boundary ambiguity, conflict, and family adaptability (Mitrani et al., 2005). Both previously recognized and unrecognized issues of familial relational strain are exacerbated and illuminated when one member of the family suffers from health decline through a debilitating disease like AD (Wall & Spira, 2004).

Scholars have suggested guidelines and solutions for assisting families through the dramatic lifestyle change of caring for a family member with AD. For example, Mitrani et al. (2005) suggested that in order to care adequately for a person with AD, family members must often realign family interactions to assist the individual providing primary care; thus the family’s
previous adaptive structures may become obsolete. Families should monitor how they are affected when a member is diagnosed with AD. When families are more aware and able to adapt to uncertainty and the changing circumstances of caring for a person with AD, caregivers experience less stress and emotional burnout; however, when a family does not adapt, the caregiver is exposed to an increased risk of morbidity (Mitrani et al., 2005). Furthermore, caregivers who share caregiving responsibilities with other family members experience increased relational strain, conflict, and stress, especially with the added dynamic of multiple caregivers and one assisting from a distance.

The responsibilities and burdens endured by AD caregivers include balancing the demands of caregiving with the responsibilities of their own immediate family and career, making decisions for care recipients, attending to medical and financial issues that arise, and increased stress and uncertainty that intensifies with the progression of the disease (Collins et al., 2003; National Alliance for Caregiving [NAC], 2004). Although long-distance caregivers do not experience the physical burdens of transporting, dressing, bathing, caring for a family member on a regular basis, the distance presents unique challenges for these caregivers that stem from uncertainty due to distance. Therefore, the experiences of on-site and long-distance caregivers may differ because the stress of caregiving is divergent for individuals who provide care from a distance. Long-distance caregivers experience increased frustration and isolation because they find it more difficult to participate effectively in care provision through communicative channels such as phone, email, and letters (Collins et al., 2003). The communication channels utilized for long-distance care do not provide caregivers with the physical and emotional support associated with face-to-face interaction. Long-distance caregivers experience more limited awareness regarding what is taking place and the specifics of their loved ones’ disease progression, which
causes increased uncertainty and impedes long-distance care provision (Miles to go, 2004). Therefore, in order to provide adequate care from a distance, caregivers must make frequent visits to attend to family matters (Collins et al., 2003).

Scholars have indicated areas in which on-site and long-distance caregivers can improve their circumstances. For example, Collins et al. (2003) suggested that when providing long-distance care, families need to establish goals regarding the care responsibilities of each family member, especially in terms of developing care plans that are manageable for all involved. In order to decrease burdens associated with families that provide on-site and long-distance caregiving, family members must maintain frequent communication by scheduling time for uninterrupted collaboration by phone, regular home visits, and dividing caregiving tasks in a way that is effective and advantageous for everyone involved (Collins et al., 2003). Regularly scheduled home visits are beneficial to long-distance caregivers as they can visually learn of the changes in health status. Such visits also provide opportunities to meet with various health care professionals to receive reports, pose questions, and plan strategies for optimizing care for the recipient (Collins et al., 2003). Therefore, when on-site or long-distance caregivers have greater knowledge and competence with regard to AD, on-site caregivers are less likely to feel trapped and less likely to experience burden and stress (Jones & McKneely, 2004). The more caregivers know or perceives themselves to know about AD and their role as a caregivers, the less the relationship between caregivers, recipients, and everyone else involved will suffer (Jones & McKneely, 2004).

Uncertainty Management Theory

The experience of uncertainty is complex and, in order to lead contented and productive
lives when faced with uncertainty, individuals must learn to develop skills to manage uncertainty that meet multiple and interrelated goals and associated tasks (Brashers, 2007). In order to gain insight into how on-site and long-distance AD caregivers manage uncertainty, Brashers’ uncertainty management theory was utilized. Through theory Brashers (2001) aims to offer insight into the ways in which communication plays a crucial role in constructing, managing, and finding resolutions to uncertainty experienced specifically within the context of illness. On-site and long-distance caregivers experience different hardships and uncertainties, especially with regard to distance and, therefore, may utilize different strategies to manage uncertainty.

Uncertainty management theory is based on four principles. When a situation causes uncertainty, individuals must first appraise the event thus influencing an emotional response. Depending on the emotion, persons will strive to manipulate the uncertainty into a more comfortable state through a behavioral reaction. In order to achieve the desired state and depending on the behavioral reaction individuals will engage in information seeking behaviors or they will employ strategies to avoid information. The following section will provide a detailed summary of uncertainty management theory.

First, individuals respond to their uncertainty through appraisals, which are connected to the assessment of events in which one considers the probability, evaluates, and judges the meaning of the event based upon perceived relevance to one’s life (Brashers, 2001). Appraisals of uncertainty result in emotional reactions that occur within a range of emotional responses: negative, positive, neutral, and combined. A negative emotional response occurs when an individual views a situation as a potential threat or danger, which arouses emotions of anxiety, fear, panic, or torment. A positive emotional response occurs when the individual appraising a situation frames it as favorable, arousing the emotion of hope or optimism. A neutral emotional
response occurs when an individual perceives a situation as inconsequential, which arouses indifference. A combined emotional response occurs in reaction to high-risk activities (i.e. skydiving); in this instance, the individual appraises the situation as simultaneously positive and negative arousing emotional responses such as danger and opportunity affecting an emotional sense of thrill (Brashers, 2001; Brashers, 2007). People are influenced by their appraisals and emotional responses to an event, experience, or issue that then influences their means for managing uncertainty by attempting to make sense of the circumstances through either seeking or avoiding information.

Polk (2005) indicated that the ambiguous, indefinite, and progressive nature of Alzheimer’s disease causes caregivers to doubt their ability to provide care. AD caregivers experience uncertainty when attempting to appraise the causes of care recipients’ behaviors; as a result, they often doubt their ability to assign meaning to those behaviors and to respond appropriately (Polk, 2005). AD caregivers report feeling more certain when attributing positive behaviors to pleasurable experiences; however, they feel uncertain when behaviors signal displeasure, especially when the reaction contradicts the caregiver’s previously held expectations developed from past experiences (Polk, 2005). Unfortunately, the nature of AD causes care recipients to exhibit unexpected and unexplainable behaviors; such changes cause a negative response as caregivers begin to doubt their ability to provide care, or perceive themselves to be responsible for the patient’s agitation. When caregivers begin to lose confidence in their ability to provide care, the health of both the caregiver and care recipient becomes endangered (Polk, 2005). However, communication researchers have not examined the uncertainties that long-distance caregivers experience. Long-distance caregivers may appraise their capacity to provide care negatively due to the distance and inability to be present; such appraisals likely lead to an
emotional response of guilt. On the other hand, these caregivers may appraise the circumstance of caring from a distance as positive, due to the fact that a trusted family member is serving as on-site caregiver.

Second, a person’s behavioral reactions to appraisal and emotional response depend upon the particular circumstances and the resources available; therefore, individuals choose to reduce, maintain, increase, or adapt to uncertainty by either seeking or avoiding information (Brashers, 2007). Individuals who choose to reduce uncertainty do so by seeking information; this behavior occurs when individuals experience stress and distress due to their uncertain state. On the other hand, individuals may choose to maintain their uncertainty by avoiding information; avoidance occurs if they are comfortable with the uncertain circumstances or when they perceive uncertainty as positive. Additionally, individuals will engage in behaviors to increase uncertainty when they are uncomfortable with their uncertain state (i.e., illness diagnosis) and choose to remain uncertain because they fear the information they will acquire; this behavior occurs when individuals seek information that contradicts their beliefs or the information that has already been provided, which often supplies new alternatives for contemplation (Brashers, 2007). Furthermore, individuals who adapt to uncertainty do so because they have experienced a form of chronic uncertainty, which occurs when the uncertain state lasts for an extended period of time (Brashers, 2007). As such, individuals become more comfortable and tolerant of uncertainty by accepting it as a necessary aspect of life. When acceptance occurs individuals gain the ability to attend to multiple alternatives, possibilities, choices and, therefore, reevaluate their lives and begin to appreciate the fragility of existence (Brashers, 2007). Those who learn to adapt to uncertainty will begin to change how they make decisions and plan for future events.
Additionally, individuals who learn to adapt to chronic uncertainty begin to develop new routines that function as a shield from the complications of life.

AD caregivers report the employment of various strategies aimed at reducing, increasing, or maintaining uncertainty. Caregivers seek to reduce uncertainty in ambiguous situations and to increase uncertainty in difficult times by maintaining a belief that the care recipient will overcome the disease; the admission of defeat could ultimately induce an increase in depression, burden, and burnout (Polk, 2005). Caregivers may also strive to reduce uncertainty by seeking information regarding the disease from local resources and care professionals. Alternately, caregivers may avoid information by isolating themselves from outside resources in order to maintain a state of denial regarding their loved ones’ disease. Additionally, in order to protect themselves from uncertainty and ambiguity, caregivers often attempt to adapt by developing routines in order to establish a sense of structure for both the caregiver and the care recipient (Polk, 2005). Furthermore, Polk reported that caregivers perceive routines as an effective means of decreasing patient agitation. However, uncertainty does not always necessarily denote harm for caregivers. For example, Polk (2005) found that caregiver perceptions of certainty and control over the situation could potentially affect negative consequences, because the disease is uncontrollable and hard to interpret.

The strategies employed by long-distance caregivers have not been addressed in the literature thus far. Long-distance caregivers may seek to reduce uncertainty by seeking information from local resources; however, the information they garner may not be sufficient because it did not originate from sources specifically associated with the care recipient. Long-distance caregivers also have a greater advantage in increasing and maintaining uncertainty because the distance allows for easy avoidance; if these caregivers become overwhelmed they
could potentially avoid communication with the on-site caregiver by not responding to emails and telephone calls. On the other hand, when providing care from a distance, individuals may adapt to uncertainty by developing and/or violating routines for communicating regularly with on-site caregivers and physicians, and for visiting schedules.

Third, individuals engage in information seeking to reduce uncertainty if it becomes the cause of stress or distress. Individuals seek information to reduce uncertainty from a variety of sources such as the Internet, television, books, magazines, and by conversing with others. Individuals seek information in one of three ways: actively, passively, or interactively. Individuals who use active strategies to gather information do not go to the source; rather, they gather information indirectly by asking others about the situation or issues that cause their uncertainty (Brashers, 2001, 2007). The passive strategy involves indirectly seeking information by observing the behaviors of others in order to make inferences about what they seek to discover. The interactive strategy involves gathering information directly from the source, which is the most efficient and most effective means of acquiring information (Brashers, 2007). In order to decrease uncertainty, the information an individual gathers does not necessarily need to be correct, it needs to create the perception of coherence in regard to the situation.

On-site AD caregivers employ specific strategies in order to seek information while immersed in the complex role of providing care for individuals with AD. Polk (2005) assessed the role of communication in AD caregiving and found that caregivers utilize active information seeking as a means of obtaining knowledge in ambiguous situations and employ distractions in order to find practical solutions. Distractions, like changing conversation topics, are helpful in allowing time to assess situations, seek new information, find acceptable solutions, and provide a period of brief respite to deal with emotional reactions to the behavior (Polk, 2005).
caregivers may utilize passive strategies by observing the patient’s behavior in order identify the recipient’s state of mind prior to administering medications. On-site AD caregivers utilize interactive strategies by seeking information directly from the patient’s physician or by joining local associations such as the Alzheimer’s Association to which they can directly ask questions and seek advice regarding uncertainties pertaining to their loved ones. Again, scant literature addresses long-distance caregiving (Roff, Jennings, & Parker, 2004), let alone the experience of uncertainty. It is reasonable to expect that, due to the distance, long-distance caregivers must actively seek information by relying heavily on the Internet, television, books and magazines because they do not have direct access to healthcare staff as an additional resource.

Additionally, long-distance caregivers may utilize active strategies because, from a distance, the specifics are accrued through communicating with the on-site caregiver, health providers, etc. about the circumstances surrounding their loved ones’ health status. Furthermore, these caregivers cannot regularly seek information through passive strategies because the distance prevents them from observing both the on-site caregiver and care recipient’s behaviors and circumstances. Moreover, long-distance caregivers may utilize interactive strategies to ease their uncertain state and find answers to questions by contacting the patient’s health care providers, however the distance may prove to be an obstacle due to scheduling conflicts.

Finally, individuals choose to avoid when they suspect the information will either be distressing or overwhelming. Individuals exhibit five types of information avoidance: direct information avoidance, selective attention, selective ignoring, indirect information avoidance, and social withdrawal. Direct information avoidance occurs when individuals avoid gathering information that may complicate uncertainty or make them certain about a specific issue or situation (i.e., avoiding doctors visits because they fear illness). Social withdrawal occurs when
individuals socially withdraw, especially when the people they are avoiding may raise issues that they do not wish to hear about or discuss (Brashers, 2007). Selective attention takes place when an individual chooses to focus on particular information. Individuals also may choose to ignore information they obtain, especially when they see that information as negative. Psychological and cognitive mechanisms can serve as a form of indirect information avoidance in which the individual disregards negative information by discrediting the source, discounting contradictory facts, considering oneself as unique, or by comparing a failed past prediction with a current prediction to disqualify negative suspicions.

Overall, managing uncertainty can be a challenge because that information is often complex, unavailable, ambiguous, and inconsistent across sources. Because individuals must overcome and interpret burdensome and confusing information, uncertainty often increases when the intent was to decrease uncertainty (Brashers, 2007). Uncertainty management can also be difficult because people possess different information seeking and cognitive-processing skills and abilities; however, they may compensate for this deficiency by soliciting help from another person (Brashers, 2007). Individuals seeking to manage their uncertainty may also become overwhelmed because coordinating the various goals of those seeking and providing support can become a challenge; supporters may also provide unsolicited advice and information, which can create conflict between each person’s goals (Brashers, 2007). Caregivers need to have pertinent information and knowledge regarding AD in order to make rational, well-informed decisions, and decrease uncertainty regarding the future. By providing caregivers with information concerning the progression of the disease and informing them of what to expect, caregivers will feel prepared to confront the upcoming challenges and will experience an improved quality of life (Georges et al., 2008; Werner, 2001).
On-site AD caregivers may become overwhelmed by the vast number of resources and the amount of information available to them regarding AD in general and their role as caregiver. Attempting to navigate the health care system, locate credible information, and provide full-time care for a loved one can become overly complex and, in seeking to reduce uncertainty, these caregivers are likely to increase it. Additionally, some caregivers are fortunate to have outside assistance from a long-distance caregiver who likely assists in information gathering and in determining the credibility of the information. However, the additional dynamic of another caregiver who assists in managing and processing the vast amounts of information could increase uncertainty because of the need to keep abreast of the additional caregiver’s actions and means of assistance. Nevertheless, long-distance caregivers also must cope with expansive information while maintaining their life away from the care recipient. Additionally, long-distance caregivers may encounter increased uncertainty because of their inability to be present and retrieve information needed to reduce and manage uncertainty.

Although the percentage of middle-aged adults who provide long-distance care for their parents is on the rise, relatively few researchers have addressed the long-distance caregiver’s experience (Roff, Jennings, & Parker, 2004). There is a need to address the importance of task-centered discussions regarding care provision from a distance, the effects of AD on communication within the family context, and individual meanings AD caregivers attach to their role as informal care providers (Collins et al., 2003). In addition to the need for long-distance caregiver research, to my knowledge prior researchers have yet to consider the ways in which on-site and long-distance AD caregivers manage uncertainty. Therefore, it is vital to consider the ways in which on-site and long-distance AD caregivers experience uncertainty and whether
the uncertainty management strategies differ. Thus, the following research questions were used to guide this study:

RQ 1: How do caregivers appraise the uncertainty of caregiving for a loved one with AD?

RQ 2: How do AD caregivers manage their uncertainty?

RQ 3: What are the differences in uncertainty and management strategies between on-site and long-distance caregivers?

This chapter has provided an overview of AD, the burden experienced by AD caregivers, and distinguished between two types of caregivers. Uncertainty management theory was outlined as a framework for guiding the investigation of the experience of on-site and long-distance caregivers and the potential differences between the caregiving types. The following chapter provides a description of the methodology utilized to conduct this study.
CHAPTER III

METHOD

Caregivers of individuals with Alzheimer’s disease (AD) experience heightened hardships and burden that decrease their quality of life and increase mortality (Alzheimer’s Association, 2010). AD caregivers encounter increased difficulties as compared to other caregivers due to the progressively debilitating nature of the disease. Moreover, AD is characterized by uncertainty and, as such, AD caregivers utilize various forms of uncertainty management regarding care recipients, disease specifics, and their own futures. Because AD caregivers may be on-site or long-distance, uncertainty and uncertainty management may vary by caregiver type (Polk, 2005). For this study, uncertainty management theory provided insight into the different experiences of uncertainty and allowed me to explore the uncertainty management strategies between on-site and long-distance caregivers. This chapter provides an outline of the methodology, participants, and data analysis for this study.

Approach

Researchers of AD caregiver coping strategies should investigate more than general situations through quantitative methods; they should also seek qualitative insight into participants’ lived experiences and individual circumstances (Cooper, et al., 2008). Stress and coping in illness and health related contexts have generally been examined via descriptive approaches because the phenomenon of uncertainty in the context of health care is extremely complex, layered, and interrelated (Babrow et al., 1998). Consequently, qualitative studies are particularly popular for assessing uncertainty management because this method allows for data to emerge from the participants (Babrow, et al., 1998). Furthermore, qualitative methods have been
used to explore the lived experiences of individuals who encounter uncertainty when living with other acute or chronic illnesses; this approach generally consists of semi-structured or unstructured interviews, which are analyzed to provide a glimpse into uncertainty as experienced by specific populations (Montgomery, 2010). The caregiving literature suggests the importance of extending beyond the primary caregiver to include other family members such as long-distance caregivers in order to obtain rich, complex data sets that can yield more dimensional conclusions and ultimately lead to the development of more effective interventions (Pruncho, Burant, & Peters, 1997).

Participants

In order to gain insight into the overall AD caregiver experience and their uncertainty and management strategies, AD caregivers were recruited. In order to participate in this study, on-site caregivers had to meet one of the following criteria: (1) provide local care for an individual with AD or (2) oversee care of a loved one in a long-term care facility. Long-distance caregivers, the other population included in this study, were required to live at least one hour away (in terms of travel time) from the care recipient.

Recruitment

After receiving UNT Institutional Review Board approval, participants were recruited in three ways. First, the program manager at the local division of the Alzheimer’s Association notified caregivers about the study and eligible participants contacted the researcher. Second, the researcher announced the study at an Alzheimer’s support group and those interested in participating in the study signed up by providing their names, contact information, and
availability. Finally, participants were recruited through snowball sampling. The different strategies utilized for recruitment purposes were appropriate for this particular study because caregivers who were affiliated with the Alzheimer’s Association and support groups engaged in information seeking, whereas individuals who were identified through snowball sampling did not necessarily actively seek information. Therefore, these strategies provided a foundation for gaining insight into the experience of uncertainty and management strategies used by the AD caregiver population.

Procedure

Following study consent, interviews were conducted either by phone or face-to-face with each AD caregiver. Participants responded to open-ended questions about their experiences of uncertainty and their strategies for uncertainty management. Interviews were audio-recorded and later transcribed.

In order to gain insight into on-site and long-distance AD caregiver uncertainty, participants answered a total of 11 questions. The interview protocol also included demographic information (see Appendix).

For RQ 1 (How do AD caregivers appraise the uncertainty of caregiving for a loved one with AD?), I asked the following questions: (1) Tell me the story of how you became an AD caregiver. (2) Describe things that make you feel unsure or cause you to have questions about Alzheimer’s disease and caregiving. (3) Fill in the blank, caring for an Alzheimer’s patient is like ______. (4) How would you describe the stress you feel in your role as a caregiver? (5) Of all the things you are worried about, what is the most distressing?
To gather data to answer RQ 2 (How do AD caregivers manage their uncertainty?), I asked the following: (6) Tell me the story of a recent event in which there was a problem with your loved one’s care and how it was resolved? (7) When there are problems with your loved one’s care, what do you do? Who do you turn to? (8) When you experience stress when caring for your loved, how do you cope? What resources do you have? What resources have you used in the past? (9) How do you find/get information about Alzheimer’s disease (i.e., Internet, television, books, magazines, talking to others, other sources)? How do you use it? Describe how actively and regularly you seek out information on AD. (10) What kinds of information do you seek? What types of information do you find most helpful? How do you judge what is believable in terms of information?

Finally, to answer RQ 3 (What are the differences in uncertainty and management strategies between on-site and long-distance caregivers?), I asked the following question (11) Tell me about how things work between you and other family members who may be assisting with care.

Throughout the interview process, follow-up questions were used to probe participants for elaboration and to clarify issues and confirm interpretations.

Data Analysis

In order to gain an understanding of uncertainty and uncertainty management from the perspective of the participants, a thematic analysis was conducted using uncertainty management theory as a coding lens. A theoretical thematic approach is driven by the researchers theoretical interest in the area (Boyatzis, 1998). Thus, the researcher encodes qualitative information using an existing code or an a priori theoretical lens and then organizes and interprets the data in order
to identify prominent themes within the data set (Boyatzis, 1998; Braun & Clarke, 2006). First, each participant’s audio file was transcribed word-by-word and saved as individual documents.

In order to answer to the first research question, I analyzed the responses to the first five questions of the interview protocol, which were related to caregiver appraisals and uncertainty. The emotional response behind the appraisal was identified and categorized as negative, positive, neutral, or combined. Responses were coded as negative if a negative word or expression could be determined by reading the transcript. Similarly, responses were regarded as positive when a positive element or sense of optimism could be detected from the transcript. Caregiver responses were coded as neutral if no positive or negative emotive word was apparent within the utterance. Finally, combined emotional responses were coded when both a positive and negative emotive word could be found within the same utterance.

Once the data was separated by response type, each category was examined for emergent themes. In order to identify themes, each utterance was labeled by identifying the primary emotion(s) demonstrated within each statement. Once the primary emotions were identified, the transcripts were reexamined to determine the most prominent emotions within each appraisal category. After identifying the primary emotions the data was conceptualized and categorized into overarching themes.

The second research question was analyzed in two ways. The first step involved identifying uncertainty management strategies as either information seeking or information avoiding. The responses to questions eight through ten on the interview protocol were examined from each transcript. Each response was coded based upon a specific type of seeking or avoiding behavior as outlined by Brashers (2001). If the participants engaged in information seeking the responses were further identified according to a specific category (i.e., active,
passive, or interactive). Active seeking was coded when the participant actively sought information without going directly to an expert source. Passive information seeking was identified as passively accruing information through email list serves. Finally, interactive information seeking was identified when participants indicated that they sought information directly from an expert source.

If participants engaged in information avoiding the responses were also separated by category (i.e., selective attention, selective ignoring, or indirect information avoidance). Utterances were coded as selective attention when individuals noted that they purposefully avoided information or socially withdrew to avoid gathering information. The responses were coded as selective ignoring when participants identified making conscious choices to avoid specific sources of information. Finally, indirect information avoidance was indicated when caregivers stated they avoided information either by discrediting the source, considering their situation to be unique, or by comparing a failed past prediction with a current prediction to disqualify their negative suspicions. After data was coded into information seeking or avoiding management strategies, a thematic analysis was conducted to determine source type and content sought as well as the rationale for avoiding.

The second step in data analysis for research question two involved analyzing questions six and seven of the interview protocol. Responses were divided into one of the four types of behavioral reaction (reduce, maintain, increase, adapt) outlined by Brashers (2001). Participants’ responses were coded as reducing when they sought information in an attempt to reduce stress. Maintain was coded when participants avoided information because they were comfortable with uncertainty or perceived it as positive. Caregiver behavioral responses were coded as increasing when respondents described searching for information that contradicted their beliefs and
provided new alternatives to consider. The participants’ behavioral responses were coded as adaptive when participants demonstrated they were comfortable with an uncertain state and had reevaluated life and changed the way they made decisions and planned for future events. Each behavioral reaction was analyzed thematically to determine what factors influenced information seeking or avoiding management strategies.

Finally, to answer research question three, which addresses differences between on-site and long-distance caregivers, comparisons were made between the two caregiver types on the analysis conducted in the steps outlined above.
CHAPTER IV

RESULTS

Alzheimer’s disease (AD) is inherently ambiguous due to the unknown cause of the disease and the lack of preventative measures or a cure. Individuals who assume the difficult role of AD caregiver encounter uncertainty on a daily basis (Polk, 2005). On-site and long-distance caregivers were recruited for this study through a local Alzheimer’s Association and responded to open-ended interview questions regarding their caregiving experiences and information seeking behaviors. My goal was to investigate the ways AD caregivers appraise and manage their uncertainty. Interview transcripts were coded utilizing uncertainty management theory as a lens for analysis. This chapter details the findings of the study.

Participants

Participants for the study consisted of 13 caregivers (8 on-site and 5 long-distance), currently providing care for at least one family member with AD. The interviews ranged in duration from 18 to 57 minutes, with an average length of 32 minutes, resulting in 68 total pages of single-spaced transcript. All participants lived in a large southwestern state. Participants ranged in age from 37 to 81 years, with an average age of 58.5 years. On-site caregivers’ ages ranged from 57 to 81 years, with an average age of 64. Long-distance caregivers ranged from 37 to 57 years, with an average age of 54 years. Out of the 13 respondents, 11 were women and two were men. One participant identified as Hispanic and 12 identified as Caucasian. Overall participants were highly educated, as two caregivers had completed some college coursework, 4 had obtained bachelor’s degrees, 6 had obtained graduate degrees; 1 had obtained a high school degree only. Table 1 and Table 2 provide an overview of the demographics for participants.
Table 1

*Participant Demographics*

<table>
<thead>
<tr>
<th>Caregivers (N = 13)</th>
<th>n (% )</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Caregiver type</strong></td>
<td></td>
</tr>
<tr>
<td>On-site</td>
<td>8 (62)</td>
</tr>
<tr>
<td>Long-distance</td>
<td>5 (38)</td>
</tr>
<tr>
<td>30-39</td>
<td>1 (8)</td>
</tr>
<tr>
<td>40-49</td>
<td>1 (8)</td>
</tr>
<tr>
<td>50-59</td>
<td>4 (31)</td>
</tr>
<tr>
<td>60-69</td>
<td>5 (38)</td>
</tr>
<tr>
<td>70 and over</td>
<td>2 (15)</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>30-39</td>
<td>1 (8)</td>
</tr>
<tr>
<td>40-49</td>
<td>1 (8)</td>
</tr>
<tr>
<td>50-59</td>
<td>4 (31)</td>
</tr>
<tr>
<td>60-69</td>
<td>5 (38)</td>
</tr>
<tr>
<td>70 and over</td>
<td>2 (15)</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>1 (8)</td>
</tr>
<tr>
<td>Some college</td>
<td>2 (15)</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>4 (31)</td>
</tr>
<tr>
<td>Graduate degree</td>
<td>6 (46)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>11 (85)</td>
</tr>
<tr>
<td>Male</td>
<td>2 (15)</td>
</tr>
<tr>
<td><strong>Race</strong></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>12 (92)</td>
</tr>
<tr>
<td>Hispanic</td>
<td>1 (8)</td>
</tr>
<tr>
<td><strong>Relationship to the patient</strong></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>3 (23)</td>
</tr>
<tr>
<td>Child</td>
<td>9 (69)</td>
</tr>
<tr>
<td>Sibling</td>
<td>1 (8)</td>
</tr>
<tr>
<td><strong>Length of diagnosis</strong></td>
<td></td>
</tr>
<tr>
<td>Less than 1 year</td>
<td>1 (8)</td>
</tr>
<tr>
<td>1-2 years</td>
<td>2 (15)</td>
</tr>
<tr>
<td>3-5 years</td>
<td>5 (38)</td>
</tr>
<tr>
<td>6-10 years</td>
<td>5 (38)</td>
</tr>
<tr>
<td><strong>Caregiver length</strong></td>
<td></td>
</tr>
<tr>
<td>Less than 1 year</td>
<td>1 (8)</td>
</tr>
<tr>
<td>2-5 years</td>
<td>5 (38)</td>
</tr>
<tr>
<td>6-9 years</td>
<td>6 (46)</td>
</tr>
<tr>
<td>More than 10 years</td>
<td>1 (8)</td>
</tr>
</tbody>
</table>

The familial role of the caregivers in this study consisted of three spouses, nine children, and one sibling. The overall length of AD diagnosis ranged from seven months to 10 years, with an average of five years. The overall length of time providing care ranged from seven months to 12 years, with an average of 5.4 years. In terms of day-to-day care, on-site caregivers provided a range from one hour of care per day to 24-hour care. Long distance caregivers reported an average of one to ten hours per week of contact with the on-site caregiver. The distance travelled
for long-distance caregivers ranged from 50 to 1,485 miles. Two of the long-distance caregivers traveled via car, two traveled via plane, and one chose car or plane depending on the circumstances.

Table 2
On-site and Long-distance Participant Comparison

<table>
<thead>
<tr>
<th>On-site caregiver (n = 8)</th>
<th>n</th>
<th>(%)</th>
<th>Long-distance caregiver (n = 5)</th>
<th>n</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avg. hrs in contact w/caregiver or patient</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-5</td>
<td>1</td>
<td>(12.5)</td>
<td>1 to 5</td>
<td>4</td>
<td>(80)</td>
</tr>
<tr>
<td>6-10</td>
<td>2</td>
<td>(25)</td>
<td>6 to 10</td>
<td>1</td>
<td>(20)</td>
</tr>
<tr>
<td>11-20</td>
<td>1</td>
<td>(12.5)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>above 50</td>
<td>1</td>
<td>(12.5)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24/7</td>
<td>3</td>
<td>(37.5)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>50-59</td>
<td>1</td>
<td>(12.5)</td>
<td>30-39</td>
<td>1</td>
<td>(20)</td>
</tr>
<tr>
<td>60-69</td>
<td>5</td>
<td>(62.5)</td>
<td>40-49</td>
<td>1</td>
<td>(20)</td>
</tr>
<tr>
<td>70 and over</td>
<td>2</td>
<td>(25)</td>
<td>50-59</td>
<td>3</td>
<td>(60)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school</td>
<td>1</td>
<td>(12.5)</td>
<td>Bachelor’s degree</td>
<td>2</td>
<td>(40)</td>
</tr>
<tr>
<td>Some college</td>
<td>2</td>
<td>(25)</td>
<td>Graduate degree</td>
<td>3</td>
<td>(60)</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>2</td>
<td>(25)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Graduate degree</td>
<td>3</td>
<td>(37.5)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>6</td>
<td>(75)</td>
<td>Female</td>
<td>5</td>
<td>(100)</td>
</tr>
<tr>
<td>Male</td>
<td>2</td>
<td>(25)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>1</td>
<td>(12.5)</td>
<td>Caucasian</td>
<td>5</td>
<td>(100)</td>
</tr>
<tr>
<td>Caucasian</td>
<td>7</td>
<td>(87.5)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship to patient</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>3</td>
<td>(37.5)</td>
<td>Child</td>
<td>5</td>
<td>(100)</td>
</tr>
<tr>
<td>Child</td>
<td>4</td>
<td>(50)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sibling</td>
<td>1</td>
<td>(12.5)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Length of diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 years</td>
<td>1</td>
<td>(12.5)</td>
<td>Less than 1 year</td>
<td>1</td>
<td>(20)</td>
</tr>
<tr>
<td>5 years</td>
<td>4</td>
<td>(50)</td>
<td>1-2 years</td>
<td>1</td>
<td>(20)</td>
</tr>
<tr>
<td>7-10 years</td>
<td>3</td>
<td>(37.5)</td>
<td>3-5 years</td>
<td>1</td>
<td>(20)</td>
</tr>
<tr>
<td>Caregiver length</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2-5 years</td>
<td>3</td>
<td>(37.5)</td>
<td>Less than 1 year</td>
<td>1</td>
<td>(20)</td>
</tr>
<tr>
<td>6-9 years</td>
<td>4</td>
<td>(50)</td>
<td>2-3 years</td>
<td>2</td>
<td>(40)</td>
</tr>
<tr>
<td>More than 10 years</td>
<td>1</td>
<td>(12.5)</td>
<td>6-7 years</td>
<td>2</td>
<td>(40)</td>
</tr>
<tr>
<td>Miles from care recipient</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>50</td>
<td>1</td>
<td>(20)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>280</td>
<td>1</td>
<td>(20)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>400</td>
<td>2</td>
<td>(40)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1485</td>
<td>1</td>
<td>(20)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transportation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Car</td>
<td>2</td>
<td>(40)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plane</td>
<td>2</td>
<td>(40)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plane or Car</td>
<td>1</td>
<td>(20)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The following section summarizes the thematic analysis based on uncertainty management appraisal and uncertainty management strategies. First names presented here are pseudonyms used to protect the identity of study participants.

Uncertainty Appraisal

Negative Appraisal

According to Brashers (2001), an appraisal resulting in a negative emotional response triggers emotions of anxiety, fear, panic, or torment. Negative appraisals from AD caregivers revealed that they were overwhelmed by caregiver burden, feelings of guilt, and felt doubtful.

Overwhelmed

Caregivers who provided negative appraisals of AD caregiving described being overwhelmed by the magnitude and burdens associated with the AD caregiving role. AD caregivers discussed being overwhelmed by the necessity of assuming the role of surrogate decision maker as well as the overwhelming burdens associated with the caregiving role.

Negative appraisals resulted from feeling overwhelmed by surrogate decision-making responsibilities. AD caregivers described enormous pressure to take on the role of caregiver. For example, when asked how she became a caregiver Rachel replied:

Well, being the eldest daughter. You know the profile of the eldest daughter is the fixer (laughs) the one that takes care of the rest of the family. You know it’s not necessarily a role that I would like to—I mean I don’t enjoy doing that. I don’t like being responsible for lots of people and when you start taking care of a family member that has Alzheimer’s you start taking care of the mother or the father, and all of their siblings. You suddenly become responsible for everybody so that is an interesting thing that I didn’t realize was going to happen...And my mother actually, and without being real obvious about it, she basically chose me to be the one to take care of them.

In this example, Rachel described taking on the role because it was expected of her as a woman,
the eldest child, and because her mother chose her, not because she desired to be a caregiver. In fact, she went on to say that this role was not one she was eager to take on and she did not enjoy being responsible for others. The responsibilities of surrogate decision-maker were perceived as a burden.

Negative appraisals were also related to feeling overwhelmed at having to take on the role of surrogate decision-maker in addition to other responsibilities. An example of this negative appraisal occurred when Dale described what was distressing to him now that he was providing care for his wife:

I’m not going to say that she ever stresses me out; I don’t really feel stressed with her. I feel stressed because I have my work and I have her both. That’s a little stressful for me, because I have a lot of things going on. I write a blog, I do a podcast, and I really have cut back on both of those…because it’s just gotten to the point where it’s getting a little bit too stressful to do those things and do my work, because my work is 24/7 when I’m on the road…and then when you throw her in on top of that, it makes it pretty stressful.

Dale negatively appraised the situation of working and providing primary care for his wife. The difficulty he described was the result of having different responsibilities now that he had to juggle them in tandem with caring for and worrying about his wife. Similarly, Karen explained, “Sometimes it is very stressful. When I kind of took on more of a caregiver role, it was stressful because…I was taking over a lot of the financial responsibilities… and the decision-making.”

This example is comparable to many of the caregivers’ responses suggesting that taking on the additional responsibilities of a surrogate decision maker as an AD caregiver may cause significant stress and feelings of being overwhelmed.

In addition to feeling overwhelmed because they had to assume the role of surrogate decision maker, caregivers depicted being overwhelmed by the burdens of caregiving. AD caregivers described feeling overwhelmed as a result of three types of caregiver burden; physical, social, and emotional. The first form of caregiver burden was described as physical
burden due to fatigue and providing 24/7 care. According to Brashers (2007) when a situation occurs that causes unease, the individual must first appraise the uncertain situation resulting in an emotional appraisal. Physical burden was identified as an emotional appraisal because the caregivers appraised their circumstances of providing continuous care for an undetermined length of time as an overwhelming burden that stemmed from the uncertainty of their role as caregivers. Jacklyn provided an example of overwhelming physical burden when she admitted to feeling fatigued when caring her mother:

Sometimes I am so tired...that I don't make a real concerted effort to feed her. Sometimes I'll go “Mamma are you hungry?” “No not really” and when I’m peppy, I’ll go “it doesn’t matter Mamma, I’m gonna bring you something to eat and you’re gonna eat it, you’ll see you’ll like it” and she will eat sometimes. And sometimes I’ll say “Mama you hungry?” and I’m kind of so tired that when she says no, I go “Oh thank God” because I feel like, you know its no big deal, just scrambling an egg is simple, so I’ll have to talk myself into it and say “remember it’s really simple, it’s really simple, go ahead and fix it for her.”

In this example, Jacklyn explains the physical burden she experiences resulting in overwhelming fatigue, which she feels affects her ability to provide quality care for her mother. Jacklyn also reported feeling guilty and ashamed for allowing her fatigue to affect her mother’s care. Marcie was also overwhelmed by fatigue:

Oh this is a big stress...you just have to be with that person 24 hours and take care of her 24 hours. And you have ups and downs, you know, like in our family setting everybody is taking care of her, not only me, everybody, because when I’m gone to work, my two sons sometimes have to take care of her, and my husband. It is my whole family; the stress is going all around my house. So I mean it’s been 24/7 for the whole year, 365 days a year, for the last five years.

Marcie demonstrates the enduring overwhelming physical burden experienced by AD caregivers and families; by framing her statement as a stress on the family, she depicts a negative appraisal resulting from the physical burden of fatigue. Marcie described the physical burden and fatigue that had extended to her entire family while caring for her sister. She later expressed that she
wished she was not a caregiver because it was affecting the family’s quality of life, however she had mixed emotions because to wish for that would mean wishing for her sister to pass away.

In addition to overwhelming physical burden, caregivers also experienced social burden, the second form of burden that contributed to caregivers feeling overwhelmed. One example of the social burdens of caregiving occurred in Dale’s discussion of caring for his wife:

I have found that most people just—and we find that sometimes among some of our children, we’ve got six—and we find that some of them just stay away, and she's hard to understand that. Of course, I would like to explain to her, you know, they don’t know how to deal with Alzheimer’s, so they stay away from it. I mean I won’t tell her but I’m sure that’s what it is.

Dale confided that his six children do not know how to cope with their mother’s disease and as a result they stay away. Unfortunately, when Dale’s children avoid confronting the fact of AD, they are also isolating their father, who later described a desire for more support from his family. Similarly, when asked how she copes with the burden of caring for her mother Gwynn replied, “I will sometimes talk to my friends about it, but you know, but not often…they don’t know exactly what to say or how to deal, they’re just—they're not in my shoes.” In this quote, Gwynn identified another burden from the social aspect of caregiving, the desire to maintain friendships and share experiences with friends who do not understand the circumstances of the caregiver.

The overwhelming social aspects of caregiving were demonstrated numerous times in caregivers’ discussions of social isolation from family and friends. Although caregivers described many instances of needing support from friends and family, a few reported a lack of support regarding their social needs.

Caregivers also felt overwhelmed from the emotional burden of caregiving. In this study emotional burden encompassed anxiety, depression, and sadness. An example of an emotional burden due to anxiety occurred when Rachel shared, “I’m seeing a psychologist and I’m taking
anti-anxiety medication. I have a pretty good sense of humor about it, I’m not suicidal or ready
to throw myself off of a cliff literally, but it is a very stressful thing.” Like Rachel, many
caregivers referred to anti-anxiety medication when asked how they cope with the stress
associated with providing care for a person with AD. By depicting anxiety medication as a
source of relief from the overwhelming emotional distress that accompanies care provision,
caregivers in this study demonstrated a negative appraisal of the burden associated with
caregiving. Lara also expressed emotional burden:

Her behaviors are as if she were a child; she can have a temper tantrum "you don’t love
me, how come you’re mean to me?" she hasn’t done that for a while because she has
deteriorated. But it’s very much like being a child except for with a child there's hope
that they're gonna learn and you know that things are gonna get better. With Alzheimer's
you know there’s NOT hope, you know they’re not gonna get better, and they are gonna
digress and get even worse. So it's a sadness that increases the stress.
Lara’s poignant description of having to watch her mother deteriorate, loss of hope, and the
knowledge that her mother would digress even further, induced emotional burden that increased
with the sadness as the disease progressed.

Guilt. AD caregivers frequently described feelings of guilt. Three forms of guilt were
apparent in the caregivers’ negative appraisals: preparative, reactive, and scarce companionship.
The first form of guilt focused on the caregivers’ need to make decisions in order to ensure the
safety of the AD patient, and the realization that these decisions might not make their loved ones
happy. As AD progresses patients begins to lose cognitive, functional, and communicative
abilities. As a result, AD caregivers must take action to ensure patients’ safety (hire an aid, take
away car keys, take credit cards, etc.), which simultaneously reduce the recipients’ sense of
independence. When preparing to take action that would decrease the patients’ sense of
autonomy to ensure safety, caregivers expressed feelings of guilt for taking away aspects of their
loved ones’ independent living. For example, Rachel moved her parents to an independent living
retirement community a mile away so she could care for her dad who had advanced AD and her mom who had early onset AD. She described feeling guilty for having to make these decisions:

She keeps saying that her memory is getting worse, and that is of great concern to me…I’m gonna have to be the bad guy at some point in the near future and just say 'Mother I don’t care what you want' (laughs)...I am just gonna have to be the bad guy at some point and insist because the stress of her worrying about not being able to take care of herself.

Rachel knew her mother did not like to be dependent upon others; however, she also acknowledged that for her parents’ safety, she would soon need to make decisions that would take away her mother’s independence. Thus, Rachel felt guilty for planning to take action knowing her mother would not be happy. Likewise, Karen also worried about making decisions that did not harmonize with her father’s desires:

[I worry about] making a decision that will make my Dad unhappy. It’s kind of…its stressful having all of that power, you know, to determine where someone’s life is gonna go, and right now we’re talking about where we’re gonna move him and I just dread doing something that’s gonna make him depressed or really unhappy.

Karen’s feelings of guilt arose from having that authority to make decisions, and her awareness that her decisions would likely cause her father to become depressed.

Regretting care choices emerged as the second form of guilt experienced by caregivers. For example, Rose explained that her husband liked routine and food was something that would maintain his focus. For instance, he would forget they finished a meal, and five minutes later he would repeatedly question when and what they were going to eat. Each time he asked, Rose would answer but he would soon forget and the cycle would repeat, over, and over. Rose, when describing her response to her husband’s repetitive behaviors, explained:

There are times that I feel guilty and I may speak harshly to him or raise my voice at him, and then...when he sits down and he's so sweet and smiles, then I'm "Oh why did I do that? Lord help me to keep my patience."

Rose’s guilt not only stemmed from her reaction but also from recognition that she should be
more patient.

The third form of guilt emerged when caregivers’ perceived they were spending what they felt was inadequate time with the care recipient. For example, Mary, who is the primary caregiver for her mother who is now in a nursing home, explained:

I guess the only misgiving I have is what most caregivers have, that I’m not giving her as much time as I should. I think you always have that guilt in the back of your mind that I need to get over there and make sure she’s okay.

In this example, the caregiver moved her mother into a nursing facility and as a consequence, felt guilty that she was not spending enough time with her. Still, caregivers who lived with care recipients also expressed guilt because they felt the amount and quality of time spent was insufficient.

Doubt

Doubt, which encompasses feelings of confusion, unease, and disbelief, was also an emotional response characteristic of negative appraisals. Brashers (2007) portrayed fearfulness and unease as two examples of negative emotional responses that emerge from negative appraisals of uncertainty. For caregivers, negative appraisals stemmed from three types of doubt: doubting the nature of the disease, doubting the quality of care, and fear of the future. The theme of doubt encompassed the largest number of codes among all appraisal themes.

First, caregivers demonstrated feelings of doubt when they discussed the ambiguous nature of AD. Caregivers’ inability to understand how the disease affected their loved ones’ functional and cognitive abilities created doubt in care choices. Rose’s description of what distresses her most about caring for a person with AD illustrates her doubt: “It's hard to understand when a person can do this right now and can not do this right now, what makes the
difference? It's the dementia. And that's hard for me to realize, and it causes stress.” Interestingly, when asked the same question, Rose’s daughter Debbie, the long-distance caregiver replied, “the uncertainty of knowing what the patient knows or doesn’t know. Trying to understand how to reach him.” Rose and Debbie both negatively appraised their inability to assess the experience and the abilities of their loved one. Similarly, Edwin explained, “I guess the thing you always wonder is what do they understand, what's going on in that precious mind of hers. You know, is she hurting?” Similar to Rose, Debbie, and Edwin, many caregivers described the unknown nature of AD as a significant source of doubt and therefore attributed a negative appraisal.

Second, caregivers were doubtful of their ability to provide quality care. An example of this doubt occurred when Pam explained, “I guess you’re never really sure what you're doing is the right thing. You want to make sure they’re comfortable, but because they can’t tell you, you don’t know if they are or not. You don’t know whether they're happy.” In this example, Pam described the doubt she had in her caregiving abilities, especially in light of the inability to assess the situation due to loss of care recipient function. Similarly, when Dale described his distress in caring for his wife, he explained:

I will get stressed when she goes catastrophic on me. That’s extremely stressful. And I really have a hard time not knowing how to deal with it because you really can’t do anything. You can’t confine her, you definitely can’t strike her, and you really can’t do anything, you can’t explain it. One of the things I’ve had to learn the hard way is that you can’t explain something to a confused person…I could try to explain it to her and she won’t get it, and so the best thing to do sometimes is just not try to do it. And that can become a little bit frustrating…

Because Dale could not talk to his wife rationally, he described a feeling of helplessness and doubted his ability to provide quality care because of the difficulty he experienced when
attempting to calm her down. Many caregivers in this study reported feeling doubt that emanated from their inability to provide quality care.

Caregivers also doubted whether their loved ones were receiving quality care, especially when the patients were unable to communicate. An illustration of this type of doubt occurred when Jacklyn stated:

What concerns me is that she can’t really tell me what it is that hurts…I can tell she is hurting when she stretches out her knee…She’ll ask me, “why do you keep asking me?” and well “because you have a frown on your face. Do you feel sad or frustrated, or what is it?” and through all the emotions. And sometimes she can give me an answer and sometimes no. She’ll look so sad and I’ll go, “Mamma are you feeling sad for some reason?” and she’ll go “no,” looking sad. So she’ll sadly say no.

Doubt often occurred when the symptoms of AD prevented caregivers from assessing the care recipients’ well-being; communicative inabilities, in particular, caused increased doubt regarding the quality of care they provided to their loved ones.

Finally, caregivers expressed a sense of doubt regarding fear of the future. These fears included fearing the next crisis, fearing the patients’ disease progression, and fearing their own future. Rachel provided the following analogy:

It’s like going down a real steep hill and not knowing if your next step is going to send you off the cliff…There's a lot of uncertainty, you feel like you are standing on shifting ground and you never know when the next crisis is going to occur.

Rachel explained that her fear of the future manifested in the form of dread regarding the next crisis. In a similar way Gwynn stated, “I am concerned that he’s going to totally lose reality. At this point, he is not wandering and he does have some moments that he is lucid, but eventually I know he’s probably going to be gone totally, and that’s scary.” Gwynn’s fear lay in the progression of her father’s disease and his inability to maintain his current level of functioning. Likewise Gail revealed, “the most distressing is probably what the future holds. Thinking about when is she gonna forget me? When is she gonna forget my dad? You know, its distressing to
think that, you know, that’s gonna happen.” Gail’s mother was diagnosed with AD seven months before the interview; therefore, her fears of the future reside in the earlier stages of the disease. However, Edwin, whose wife who had been diagnosed with AD for ten years, shared his fearfulness of the end stages of his wife’s illness when he stated:

   I regret what I hear will probably happen in the last stages of her Alzheimer’s. That being they forget how to swallow and will probably have to be fed intravenously or however they do that. I understand that it's quite normal that they forget how to eat or forget how to chew and swallow, and I dread the day if that is the case with her, I dread the day that will begin to happen. In fact I thought I would see that decline way before now.

Edwin explained that he dreaded what he knew what would likely happen at the end of his wife’s life, in fact he was surprised that she was still healthy and eating well. Similarly, when asked what is most distressing to her Marcie remarked, “that she's not going to be around soon. So that is what I’m thinking.... That for me is very stressful.” Each of the caregivers interviewed expressed fears regarding their loved ones’ uncertain futures.

   In addition to fearing the future in regard to loved ones, caregivers also negatively appraised their uncertainty by describing fears of their own future due to the possibility that Alzheimer’s may be hereditary. A prime example occurred when Lara described comprehending her mother had Alzheimer’s disease, she declared:

   So finally, of course it hits you in the face and you can’t deny it, but I think that’s what's the hardest thing for me is realizing 'yes' this is real and that she has it. Of course, what that does is it opens you up to "does that mean I’m gonna get it?" Scary.

Lara’s new understanding opened questions regarding her own future and the uncertainty regarding the source of AD. Additionally, a few caregivers shared that their memory is not as good as it once was and some were fearful they were already showing signs of AD.
Positive Appraisal

A positive emotional response to an appraisal can be detected when an individual frames their uncertainty as favorable, which affects an emotion of hope or optimism (Brashers, 2001). Feelings of optimism characterized positive appraisals of AD caregiving. Optimistic appraisals were demonstrated when caregivers compared their loved ones’ health status to other individuals with AD. An example of an optimistic appraisal made through a comparative statement occurred when Rose depicted taking care of a person with AD as similar to taking care of a baby, however she continued:

But yet a baby in some respects is more demanding than my Roy is right at the moment. But even though he is diagnosed as severe Alzheimer’s, I cannot see that he is severe compared to others that I know that I would consider severe. Severe would mean feeding them, taking care of their personal needs, but as far as the mind it probably is how they are diagnosing him.

In this example, Rose demonstrated optimism when she compared her husband’s severe diagnosis with others who have progressed more severely. By focusing on her husband’s current status in a positive light rather than discussing the negative future, Rose clearly demonstrated an optimistic and, therefore, positive appraisal of her husband’s current status and stage of AD.

Positive appraisals were also depicted by optimistic thoughts and feelings that focused on the positive rather than the negative aspects of the disease or the circumstances. For example, Jacklyn said:

I didn’t have any children, so I love holding her as if she were my child, and I love it when it’s easy. When it’s easy, like when she’s comfortable and you know when we’re talking and we’re saying all kinds of jokes or when she’s witty, she picks up a lot of my jokes and she's witty and so we have fun.

In this statement, Jacklyn emphasized positive moments rather than the difficulty she experiences in her role as caregiver; in so doing, she highlighted her appreciation for the caregiving experience by comparing it to taking care of a child. Furthermore, Jacklyn framed
her experience in a positive light by focusing on what is easy rather than stressing the difficult aspects of providing care and, therefore, demonstrated a positive appraisal through optimistic affect. Finally, Dale demonstrated optimism when he stated, “things are getting better; and I say things are getting better because I'm better. I’m learning more, and the more I learn the better it gets.” In this example, Dale shared his belief that his circumstances improve as he learns more by acquiring new information. Overall, few positive appraisals were identified among study data.

Neutral Appraisal

According to Brashers (2001) when a person judges the meaning of their uncertainty and finds it to be inconsequential, an emotion of indifference is expressed. The majority of neutral statements from AD caregivers included accounts of how and why the caregivers took on the role of care provider. These stories were coded as neutral because no words in the utterance depicted positive or negative emotions. For example, when Lara was asked how she became an AD caregiver she replied, “how I fell into that role is the luck of the draw, I'm the oldest (laughs).” Likewise, Dale responded, “Well, she's my wife (laughs). Who else is gonna watch her? You know, I mean that’s part of marriage and love, I mean for better or worse, right?” Debbie responded, “[I am the] only surviving child of a parent with this disease.” Because the respondents use no words that suggest a positive or negative appraisal, these responses portraying the assumption of the caregiver role were identified as neutral. Some caregivers provided more extensive stories of the way they became caregivers. The following is Karen’s story, which is representative of other neutral caregiver stories:

My dad was diagnosed with Alzheimer's while my parents were separated and so he has been living alone for, I guess about three and a half years, so about a year before he was
diagnosed. And since he’s living alone he needs some extra help and so my parents have since divorced and my brothers and I have all become caregivers, along with, along with my mom, she helps out a lot too.

Brashers (2007) explained that when uncertainty is perceived as neutral individuals appraise their circumstances with an emotional response of indifference. However, within the context of AD caregiving, neutral appraisals occurred as an emotion that stemmed from inevitability.

Combined Appraisal

According to Brashers (2001; 2007) a combined emotional response occurs when an individual appraises the source of uncertainty as simultaneously positive and negative that arouses an emotional response of thrill. However, thrill is not an emotion experienced by AD caregivers; therefore for the purpose of this study a combined emotional response was identified as encompassing simultaneous polar emotions and the volatile emotions that occur over long periods of time. An example of a simultaneous volatile emotional response is evident in Lara’s statement:

Caring for an Alzheimer's patient is like being on a teeter-totter. You never know. Well, for example like now my mother is in a hospice unit, yesterday I called the family together and tomorrow we are gonna have a meeting with the doctor because I thought her death was imminent. Today, I go there and she's alert and talking to me…but yesterday I couldn't wake her when I talked to her or touched her. So one day you can think it's the end and then the next day you think oh no we're not near there. Up and down.

Lara’s analogy and description of her experience as an AD caregiver is volatile, one day she feels one emotion and the next day another depending on her mother’s status. Jacklyn also described the unpredictable nature of AD and the variable emotions caregivers experience when caring for a person with AD:
I can’t really explain how it feels, but sometimes your emotions are like a rollercoaster, my emotions are like a rollercoaster, because I want to be here for her. I want to make sure that I am here, I want to make sure that she’s taken care of and treat her like a queen. But there are times when my husband and I go out to breakfast, and I go “gosh lets go do something else.” It’s like I don’t want to lose her, but yet it’s the same thing over and over everyday.

The above utterances illustrate the simultaneous experience of contradictory emotions.

However, many caregivers expressed combined emotional affect when describing the inconsistent emotional experience that occurs over longer periods of time when caring for a person with AD. For example Karen shared:

Now that I’ve kind of gotten settled and I've gotten in the routine as far as paying his bills, it’s a little less stressful right now, but…there’s lots of peaks and valleys. When I start to talk to my brothers about when are we gonna move dad into some type of retirement community that has some assistance, that’s stressful. When I found out that he got stopped by a policeman and we need to talk about taking away his keys, that’s very stressful. So it’s just kind of up and down. Day-to-day, it’s not too bad right now. As the changes are coming, you know, every time there’s like a big change, there's a lot of stress. But it is very stressful.

As the three examples above demonstrate, AD caregivers in this study illustrated the combined appraisals as a volatile emotional response within the context of AD caregiving. Sometimes the negative and positive emotions occur simultaneously; at other times they occur successively and only periodically.

According to Brashers (2007) a combined appraisal of uncertainty generates simultaneous feelings of excitement and fear resulting in an emotional response of thrill. Similar to Brasher’s depiction, AD caregivers conveyed a combined appraisal by describing AD caregiving as an emotional rollercoaster due to simultaneous feelings of comfort and angst. However, caregivers also portrayed unpredictable oscillating polar emotions that fluctuate over time in line with the care recipients’ status. The unpredictable and gradually progressive qualities of AD prevent caregivers from formulating solid plans for an unforeseeable future,
which causes caregivers to appraise negatively and to doubt their circumstances rather than feeling a sense of thrill.

Uncertainty Management Strategies

As previously stated, Brashers (2007) determined that when an individual experiences uncertainty he or she must first appraise the uncertainty as negative, positive, neutral, or combined, which results in an emotional response. The emotional response then influences the behavioral reaction of the individual as he or she seeks to reduce, maintain, increase, or adapt to the uncertainty. The aim of research question two was to explore how AD caregivers manage uncertainty.

Reducing Uncertainty

According to Brashers (2007), when uncertainty causes feelings of stress and torment, individuals attempt to reduce uncertainty by seeking information. Information seeking serves to assist individuals in gaining confidence to predict what the future may hold. Individuals engage in information seeking via active, passive, or interactive strategies. AD caregivers utilized active strategies by accessing traditional resources and from “someone who’s walked in those shoes”; passive strategies allowed caregivers to wait for information to emerge; and interactive strategies emerged when caregivers sought expert advice from the Alzheimer’s Association or from a physician.

Active Strategies

Brashers (2001) described active information seeking as an uncertainty management
strategy in which the individual does not go directly to the source but gathers information indirectly and by asking others. Active strategies employed by AD caregivers involved seeking traditional resources and gathering information from someone who had similar experiences. Caregivers described finding useful information in books about caregiving for a person with AD and dementia and deemed books a significant source for information. For example, when asked how she finds information about AD, Rose stated:

There is a book called *The 36-Hour Day* and it has a world of information. It’s not a book that I can sit down and—I was told you cannot read it from cover to cover; you use it as you need it. And it has been a great help to me. Another book that I had, a resource, was the one by the coach over in Arkansas, his wife had Alzheimer's and he wrote a book after she passed, about how he handled his wife and that was the most interesting book.

For Rose both of these books were sources of information that helped her decide how to handle situations with her husband as they arose. Interestingly, the book Rose mentioned, *The 36-Hour Day*, was described as a useful resource by many caregivers in this study, including Dale who remarked, “I had to do a lot of study on my own, and read the book 36-Hours…so I’ve just learned a lot myself over the past couple of years on how to deal with her.” Additionally, Marcie shared, “I think you get a lot of information from books. You can go buy books, go to the library, or go and look for books about dementia.” Many caregivers described books as an important resource for seeking information.

Active information seekers also described the Internet as a useful and convenient source for information regarding how one should care for a person with AD and about AD in general. Karen shared, “Well I haven’t done a lot of, as far as talking to the Alzheimer's Association. But I have used the Alzheimer's website quite a bit to try to find some answers on things.” Similarly, Gwynn explained, “Mostly I find information online and then through the alz.org website.” Not
surprisingly, many caregivers described the Internet as a convenient and helpful resource in the search for information regarding AD.

Caregivers also described actively seeking information and support from members of their social networks. Social networks included family, friends, and church members. Many caregivers described their spouses as a primary source of assistance and support, as well as someone to whom they could vent. Gwynn shared, “I talk to my husband a lot about it, he listens very well; I mean he’s in this as much as I am so we talk about things together.” Gail, a long-distance caregiver, described the relationship with her mother and sister in this way:

Oh I talk to my mom, I mean in fact sometimes you have to laugh because that helps you get through it. But I think talking about it is the best thing. And so that’s one reason that my sister and I call every day is just to let her release, and then we feel like we are in touch too, and we know what’s going on. So I think talking about it helps.

Interestingly, Gail, who provides long-distance care, sought information from her mother who provided on-site care for her father. She described that maintaining contact with her mother helped reduce her uncertainty and kept her informed, while simultaneously serving as support for her mother by providing her an outlet for venting.

Other caregivers received support from friends, as Debbie explained, “I cope through support, friends support, they keep me strong so I can be—and prayer support from friends. They keep me strong so I can be strong for my mom, the primary caregiver.” Debbie described managing her uncertainty by support from her friends who kept her grounded so she could be the rock for her mother who provided on-site care. Church was another resource that most of the caregivers mentioned as most helpful in managing uncertainty. For example, Edwin remarked, “I don't know what a person would do without a strong church backup for strength. We have many, many friends at church. They have been very helpful, and they visit occasionally.” Like
Edwin, the caregivers in this study described church as a crucial resource for support and assistance.

Another active strategy was seeking information from “someone who’s walked in those shoes.” Overwhelmingly, AD caregivers depicted the most helpful and most frequently sought source of information came from people with similar experiences. Caregivers sought information from others who either were or had been an AD caregiver at some point; these sources included coworkers who provided care or had a family member with AD as well as caregivers in support groups, among others. For example, when asked where she looks for information on AD and caregiving that is most believable, Debbie replied, “It’s more just through others that maybe have walked in those shoes, than picking up literature and reading it.” Debbie suggested that she would prefer to hear the story of another caregiver than read informational literature regarding her sources of uncertainty. Moreover, she later described that information from “someone who’s walked in those shoes” as more believable because they lived it, like she has been doing for the past seven years. Similarly, when asked what information she found most believable, Gwynn replied:

I have a supervisor and he’s also a good family friend of ours, his mother recently had Alzheimer's and passed away in May, so I ask him questions...because he is somebody who had been there done that...I guess usually when it comes through somebody’s perspective and their story; you know, you have to take information from organizations and facilities and you know medical doctors, sometimes you have to take things with a grain of salt because there’s always a study somewhere else that contradicts that. But when it’s somebody telling their story and I can relate to it, or it sounds familiar, then I usually take that as believable.

Gwynn described stories of other caregivers as being most relevant and believable when actively seeking information to reduce uncertainty. Other caregivers also described engaging in activities and attending support groups in order to meet people who have experienced AD caregiving. An example of this occurred when Rachel remarked:
I started doing volunteer work at the [Alzheimer’s] Association. When you go in and stick labels on envelopes, you’re in a room full of people who all have had responsibilities of taking care of somebody with Alzheimer’s. And just in casual conversation I’ve gotten more out of just showing up and sticking labels on a mailer...it’s a more informal situation and you end up getting...they end up telling you their story and you get a little something out of that.

Rachel’s means of information-seeking brought her to the Alzheimer’s Association where she volunteered, gained perspective from other’s in similar circumstances, and was given the chance to tell her story. When caregivers heard the stories of other AD caregivers and recognized that their experiences were similar to their own, they began to feel normal, which helped reduce uncertainty. Similarly, Edwin commented, “I think its important to get with a group of caregivers, and if nothing else just hearin’ ideas.”

Brashers (2007) described active information seeking as gathering information indirectly by asking others about the source of uncertainty. Within the context of AD caregiving, participants illustrated active strategies to manage and reduce uncertainty through traditional resources, like books and the Internet, as well as from “someone who’s walked in those shoes,” which they characterized as the most beneficial resources. This finding supports Brashers (2007) contention about active seeking. Caregivers did not go directly to an expert source to ease uncertainty, rather they described books, Internet, social support, and the perspectives of other caregivers as the most influential resources.

Passive Strategies

Brashers (2007) explained that individuals sometimes attempt to reduce uncertainty by engaging in passive information seeking. Passive information seeking occurs when individuals indirectly seek information by observing others’ behaviors and make inferences regarding what they hope to realize. AD caregivers in this study exhibited a tendency to seek information
indirectly by waiting for information to emerge through email list serves, Facebook, by saving indirectly collected information for future reference, and through media outlets. Passive uncertainty management often occurred as a result of a negative uncertainty appraisal, however the caregivers were selective about which information they found pertinent.

For example when asked how he found information about AD and caregiving, Dale responded, “I have a number of different people from the Alzheimer's Association that send me stuff and the emails, so I’m constantly reading that stuff.” Dale went on to explain that he did not actively seek information and, therefore, he was strategically passive in terms of information gathering. Furthermore, when asked what information she sought and found most helpful, Debbie replied, “Sometimes I read it and sometimes it’s kinda like it’s just out there. I think it hasn’t been that helpful to us, really.” Debbie demonstrated that she was not actively looking for information on AD or caregiving; she also indicated that the information she stumbled upon was not beneficial for her particular situation. Furthermore, when asked what types of information she sought, Gwynn remarked:

I’m keeping all of the emails that are sent to me on the alz.org website, they send me newsletters…email updates, and I’m Facebook friends with them. So if its something that perks my interest ill read it, if not ill put it in a folder for future reference, you know when I’ve got time to sit down and just go through it all.

Additionally, caregivers like Jacklyn described passively seeking information through media resources:

When I go to the doctor’s office and…I see magazines, if they say caregiver this or caregiver that, I read the thing to see if there is something that will help me either de-stress or just something that will help me take better care of her. And sometimes there’s people like Doctor Oz that maybe I trust them a little bit more, you know or mainstream information like Dianne Sawyer and those kind of people that I hope have really done their research.
In this example, Jacklyn demonstrated passive information seeking by waiting until she happened upon a media source she felt was pertinent to her situation. She went on to say that she perceived television shows and media reports as the most reliable sources of information.

Brashers (2007) described passive information seeking as watching the behaviors of others in order to infer what one hopes to find. However, within the context of AD caregiving, caregivers could not easily watch the behaviors of care recipients to infer answers to their questions. Therefore, caregivers engaged in passive information seeking by attending to information that emerged through email list serves, Facebook, and by collecting data for future reference. However, passive information seekers also actively sought information through other sources (support groups, books, Internet), however they only attended to information they perceived as pertinent to their particular stage in caregiving.

Interactive Strategies

Brashers (2007) explained that interactive information seeking occurs when individuals gather information directly from the source. Because it results from direct information gathering, interactive seeking is regarded as the fastest and most effective means of reducing uncertainty. Caregivers in this study engaged in interactive information seeking by contacting the Alzheimer’s Association directly, attending Alzheimer Association functions, and seeing a physician.

AD caregivers frequently identified seeking information by directly contacting the Alzheimer’s Association as a principal interactive strategy. For example, when asked what she does when she experienced problems with her husband’s care, Rose explained:

My first call is always to the [local] Alzheimer's Association, and there was some lady by the name of [June], she'd hear my voice and say "What's going on" (in a concerned voice)
and though she has been most helpful I have not had to call in several months now, but that would be my first call. For information I have...a number that is a direct line to an Alzheimer's person and [they] listen to whatever my needs are...they're most helpful with all the information you ask for, and they send it to me immediately.

Rather than waiting for information to come to her, Rose actively sought information from an expert source and, therefore, sought information interactively. Similarly, Mary explained:

I’m always skeptical when I hear things like you get Alzheimer’s from cooking with aluminum pans. That sort of information sounds less than scientific to me, so I usually go to the people at Alzheimer's and say what's this about and something that we are actually researching.

In addition to contacting the Alzheimer’s Association, many caregivers attended Alzheimer’s Informational Symposums that are held each year. For example, Edwin stated, “I have been to all of those for about the last five years…I recommend those to anyone that I know who has an Alzheimer’s person in their family.” Similarly, Debbie stated, “I’ve been to Alzheimer's seminars flash awareness a couple of times.” The Alzheimer’s Symposums are conference-like gatherings with panels to address different topics of interest to caregivers and family members of persons with AD. The symposiums are interactive because they provide expert informational sources and provide a place for caregivers to share with one another, gain new information, and ask questions of the physicians and Alzheimer’s Association personnel.

Additionally, when caregivers responded to a question about what they would do if they encountered a problem with their loved ones’ care, a few stated that they would take the care recipient to see a physician if the problem was medical. An example of this type of response occurred when Jane stated:

You know if it were a pathology like a disease or an infection...obviously I would be taking him to his primary care doctor. If the situation were that he had moved into another layer of debilitation where something new has happened when he can no longer do one certain thing that he used to be able to do, then probably the person that I’m going to rely on...well I rely on all the people that deal with Alzheimer’s. So I call Susan
Interestingly, Jane described the primary care physician as a source she would consult if her father’s health were in decline. However, she went on to say that if the problem was specific to his AD diagnosis, she would contact the Alzheimer’s Association. By directly seeking information from one of two expert sources, Jane demonstrated interactive information seeking. Similarly, when asked the same question Marcie replied, “you can discuss it with the doctor, with the neurologist. I work in the hospital and I work in the neurology department so I ask a lot of doctors in my department what is wrong with her.” Marcie also described interactive information seeking because she would go directly to an expert source. However, the expert source in Marcie’s case is more readily available to her than to most AD caregivers.

Maintaining Uncertainty

Brashers (2007) explained that individuals who are comfortable with their uncertain state or perceive their uncertainty as positive may wish to maintain their uncertainty by avoiding information. Although Brashers (2007) identified three avoidance strategies, the AD caregivers interviewed for this study engaged in two: selective ignoring and indirect information avoidance.

Selective Ignoring

Selective ignoring occurs when a person selectively chooses which information to attend to or ignore, particularly when the information is seen as negative (Brashers, 2007). AD caregivers utilized selective ignoring when describing what types of information they would not consider as a resource for managing uncertainty. When asked if she had contacted the Alzheimer’s Association or visited a support group, Marcie responded, “No we don’t use any of that, but we know its out there for us, we know that.” Although she knows about the resources
available to her, Marcie has chosen not to use them. According to Brashers (2007), Marcie is maintaining her uncertainty by selectively choosing the information she seeks. In addition to avoiding available sources of helpful information and support, caregivers also described avoiding certain media exposure in order to maintain their constant and comfortable state of uncertainty. In this example, Mary demonstrated selective ignoring:

I will watch programs on TV if I don’t think they are gonna be too emotional. There is a movie for example, called “The Notebook” and I never have been able to make myself watch because its just too poignant from what I’ve heard.

Additionally, Gail shared that she is “very leery really of going online, because sometimes not only is there too much information but…it can be alarming, and its not always correct.” By avoiding the Internet, Gail aims to protect herself from becoming inundated with information that may or may not be correct, thus Gail is attempting to maintain her uncertainty.

*Indirect Information Avoidance*

Indirect information avoidance, according to Brashers (2007), occurs as a result of psychological and cognitive mechanisms that attempt to avoid negative information by discrediting the source, considering oneself as unique and special, discounting contradictory facts, or by comparing a failed prediction from the past to a current prediction to eliminate negative suspicions. By indirectly ignoring information, individuals attempt to maintain their uncertainty in order to disqualify negative information that may be perceived as threatening. AD caregivers engaged in indirect information avoidance as a means to maintain uncertainty by discrediting the source, and by considering their situation as unique.

Jacklyn demonstrated indirect information avoidance by discrediting the source of her mother’s diagnosis, in this case the doctor:
I tend to second guess what the doctors say because she’s still so lucid, I can still teach her some things and she can kind of memorize them. Some things she forgets things like the death of my uncle; three days in a row I told her he had died and still the next day she couldn’t remember, so from then on I just talk to her as if he is alive, still living. But there’s other things that she does forget those things that just happened, five minutes ago she will forget or yesterday, needless to say. But I can teach her a short prayer and I repeat it enough she remembers some of it the next day.

In this example, Jacklyn described second-guessing her mother’s diagnosis in the same sentence that she discussed the problems her mother has with memory. Jacklyn explained that her mother could still learn short prayers after multiple repetitions, which serves to support her hypothesis that the doctors diagnosed her mother incorrectly. Similarly, Debbie described her attempts to maintain uncertainty by discrediting a source at the Alzheimer’s symposiums:

The seminars, the couple that I have been to, and the speakers that are just—they bring in an outstanding speaker. It’s someone who is living personally as an Alzheimer's patient, and that person has nothing in common with my dad, so why sit there and listen while they mainstream when he's not mainstream so I don’t see them as any benefit.

In this example, Debbie demonstrated indirect information avoidance by discrediting the speaker as a credible source, and by considering her father’s experience with AD as unique. By discrediting the source and considering her father as unique, Debbie attempted to avoid the information by discounting its importance.

Increasing Uncertainty

Individuals who feel uncomfortable in their state of certainty (e.g., terminal illness) attempt to increase uncertainty by seeking information that contradicts their established beliefs (Brashers, 2007). For a few AD caregivers, this occurred as attempts to search for clinical trials and revolutionary medications to find a cure or to curtail the disease’s progression. For example, Lara who is an Alzheimer’s education specialist revealed, “I’m always looking for medication. Is there that miracle something? Not that I think she is going to be cured, but something that's
going to help.” Interestingly, Lara’s knowledge of AD she acquired over many years of providing AD caregiver education and support did not change the fact that she wished to increase her uncertainty by continuously searching for novel medications. Similarly, Marcie shared her desire to increase her uncertainty:

Oh every week, every week, every week I am on the computer looking for research, maybe something new is coming that can help, or maybe some kind of drug is coming that is new on the market, but basically I don’t find anything. I do find a couple research groups but she is not qualified because she is mute, she cannot speak.

Adapting to Uncertainty

Finally, Brashers (2007) suggested that individuals who live in a state of chronic uncertainty (e.g., long-term illness) may begin to accept uncertainty as a necessary fact of life and as a result they learn to attend to multiple alternatives and choices as they begin to re-evaluate life and value the delicacy of existence. In order to achieve the ability to adapt to uncertainty, individuals eventually learn to avoid information. As a result of changed perspectives, these individuals begin to develop new routines, which serve as a shield from everyday life complications (Brashers, 2007). AD caregivers demonstrated the ability to live with and adapt to uncertainty by expressing acceptance of their uncertain state and the willingness to take it one day at a time.

In the beginning stages of AD caregiving, participants reported actively seeking information to reduce and increase uncertainty, but after years of being in a chronic state of uncertainty many caregivers reported coming to terms with their loved ones’ disease. An example of this process occurred when Pam described her experience of uncertainty while caring for her mother:
I looked for a lot of types of drugs that my mom was on; to see what the side effects were, see what pills that were out there that might be a little bit better. When she was first diagnosed, just the signs were, what the symptoms were, what to expect, how to care for her. And like I say she is now at the point where it is just a matter of making sure that she’s comfortable.

Pam described different stages of uncertainty management in which she attempted increase uncertainty by looking for alternative treatments, reduce uncertainty by searching for answers to her caregiving inquiries, and finally accepting her mother would pass; as a result, she arrived at her current goal: to ensure her mother is comfortable. Similarly, Rose explained her road to adapting to the chronic uncertainty of caring for her husband who is diagnosed with AD:

In the beginning, honey, I was going to two different support groups. I was reading everything that I could get my hands on, and it was overpowering. You can just get so involved in it, that it just literally demands your whole life and runs your whole life. And we were missing some neat times together, and so I decided to that I wanted to live it rather than just crawling in it, moment by moment.

In this example, Rose described her attempts to reduce uncertainty as taking precious time she could have been spending with her husband and she finally decided to live the experience rather than continuously attempt to predict the future. When asked how actively and regularly she seeks information on AD and caregiving Rachel shared her experience:

Well there’s a while I was very actively seeking it out. At this point, I kind of wait for a change and once the circumstances change then I may feel like I need to go out and ask some questions and get some more information. But I think that I had to go through a little flurry, you know a real steep curve there for a while, and now it’s leveled out, where I feel like I’m as competent as I’m gonna be, doing this. And when the next crisis occurs, at that point I will do what I need to do. And if it involves getting some more information then I will.

Similar to other AD caregivers, Rachel demonstrated acceptance of her uncertainty when describing confidence in her AD and caregiving knowledge. Rachel explained the process of learning to adapt to the chronic uncertainty associated with AD caregiving by changing the way
she plans for the future. Gail also shared her information seeking habits and experience as an AD caregiver:

As far as actively looking at this point, you know, I don’t feel the need. With my mom we are kind of taking it one day at a time, and you know, looking now at a year ago he’s so much worse. But one day at a time, it took a long time to get to this point, you know, it took a year to get to this point. But if you look at it from the context of February-to-February it is drastic, but in the context of the year it wasn’t as much, it was just really gradual.

As with many other caregivers, Gail has chosen to accept the uncertainty of her father’s illness and to take what the disease brings one day at a time by focusing on the present rather than thinking of the past or future.

The above sections outlined the findings regarding how AD caregivers appraised and managed uncertainty. However, it remains important to seek insight into the ways on-site and long-distance caregivers appraise and manage uncertainty differently. The next section provides findings from the comparative analysis of on-site and long-distance caregiver uncertainty appraisal and management strategies, the focus of Research Question 3.

Differences between On-Site and Long-Distance Caregivers

Appraisal Differences

Overall, on-site caregivers appraised uncertainty as negative. Negative appraisals primarily stemmed from the overwhelming responsibilities of being the surrogate decision maker. Due to the duty of providing primary care, on-site caregivers assumed the role of surrogate decision maker and often felt burdened by the magnitude of responsibility that is necessary to ensure the well-being of the care recipient. Also tied to the primary care provider role, on-site caregivers shared feelings of doubt when attempting to understand what their loved one knew or was experiencing. Doubting the quality of care they were delivering produced
negative appraisals, more so than the burden of care itself. On-site caregivers likely expressed
doubt more than burden because on-site caregivers focus primarily on the well-being of the care
recipient before their own. However, a minority did appraise uncertainty as positive through
optimistic statements that revealed a sense of comfort and confidence when providing care for
their loved one, however positive appraisals occurred primarily from caregivers who had been
providing care for extended periods of time.

While long-distance caregivers also appraised uncertainty as negative they did so for
different reasons. Long-distance caregivers expressed guilt as a result of the distance and
inadequate time spent providing assistance to the on-site caregiver. Furthermore, long-distance
caregivers experienced heightened feelings of guilt due to concerns regarding the effects of long-
term care provision on the on-site caregivers’ health and well-being. Intriguingly, long-distance
caregivers made no references to indicate positive uncertainty appraisals, perhaps due to the
substantial guilt they felt because of their distance from the loved one and their inability to
provide greater assistance to the on-site caregiver.

Management Differences

Given their role as primary care providers, on-site caregivers reported heavy dependence
on active information seeking in order to deliver care. For on-site caregivers, active information
seeking consisted of the traditional resources such as books and the Internet; however, they also
described actively seeking support from members of their social networks. The on-site
caregivers’ heavy reliance on active information seeking is not surprising given their role as
primary care provider, which requires more knowledge and skill to provide hands-on care. On-
site caregivers specifically described searching for practical, how-to information directly related to the needs of the care recipient at particular times in the disease’s progression.

Long-distance caregivers also reported a substantial dependence on active information seeking, however unlike on-site caregivers, long-distance caregivers did not seek information from books. Because books contain information on providing primary care for a person with AD, they are typically written for the perspective of a primary AD caregiver. Consequently, long-distance caregivers primarily engaged in active information seeking through a reliance on the Internet; in fact, they reported searching the Internet more often than on-site caregivers. For long-distance caregivers, the Internet was a convenient resource they could use to familiarize themselves with the symptoms of AD and disease progression in order to gain confidence and comfort by learning what to expect.

Likewise, long-distance caregivers actively sought information and support from social networks, particularly family, more often than on-site caregivers. Long-distance caregivers reported frequent contact with the primary caregiver in order to provide support by giving them a chance to vent frustrations while simultaneously reducing their own uncertainty by learning about the well-being of the caregiver and care recipient. Long-distance caregivers also sought support and information by maintaining frequent contact with other siblings who assisted in providing long-distance care. Furthermore, long-distance caregivers actively sought spousal support and support from children.

This chapter detailed the findings associated with the three research questions concerning AD caregiver uncertainty appraisal, AD caregiver uncertainty management strategies, and the differences between on-site and long-distance uncertainty appraisal and management strategies. The following chapter interprets the findings in relation to previous research, discusses the
implications of this study, outlines the limitations of the study, and provides suggestions for future research.
CHAPTER V
DISCUSSION

Uncertainty management theory is a useful framework for gaining insight into the perspectives of individuals who experience uncertainty, particularly within the context of health care (Brashers, 2001). When one encounters an uncertain situation they first appraise the source of uncertainty and, depending on the emotional appraisal, they seek to reduce, maintain, increase, or adapt to uncertainty (Brashers, 2007; p. 237). As family members assume the caregiving role for loved ones diagnosed with Alzheimer’s disease (AD), the caregiver also inherits the experience of chronic uncertainty because the cause, means for prevention, moderation, and a cure are unknown (Alzheimer’s Association, 2011). Findings from this study illustrate how AD caregivers manage the uncertainty of the disease and primary care, as well as how uncertainty differs between on-site and long-distance caregivers.

Heightened feelings of responsibility and anxiety created overwhelming burden for caregivers, especially on-site caregivers who served as long-term surrogate decision-makers for loved ones. Taking on the role of surrogate decision maker required caregivers to speak for the patient in identifying pain and emotional difficulties (Caron et al., 2005; Gardner & Kramer, 2010). Consistent with prior research, this study found that psychological burden surfaces when caregivers are uncertain about their role as surrogate decision-makers, particularly when they are uncertain of their loved one’s wishes (Caron et al., 2005). This study suggests that overwhelming pressure to take on the responsibility of surrogate decision-maker impacts other familial and work related roles. The overwhelming responsibility to make decisions for their loved one’s well-being resulted in AD caregiver feelings of heightened stress and burden as they attempted to negotiate their new role in tandem with other responsibilities. When taking on the
role of surrogate decision-maker, the AD caregiver must manage the uncertainty of the effects of the new tasks on his or her life, as well as the uncertainty of what the new obligations entail. These findings suggest that AD caregivers require more guidance and support when taking on the role of surrogate decision-maker in order to alleviate the overwhelming stress and burden associated with newly acquired responsibilities.

When individuals become overwhelmed with new information they may attempt to reduce uncertainty by gaining knowledge or retreat by avoiding information (Brashers, Neidig, Haas, Dobbs, Cardillo, & Russell, 2000). Health care professionals should provide complete information about the disease, assist caregivers in addressing the guilt that accompanies the newly acquired role, and remain available for assistance and support (Charon et al., 2005). However, AD caregivers do not seek support or information about AD or caregiving from health care professionals. AD caregivers sought support first and then information, which is why they looked to the Alzheimer’s Association rather than physicians. Future research should seek to understand the reluctance of caregivers to seek information from health care providers.

Health care practitioners are in an advantageous position to assist AD caregivers in managing uncertainty during the transition to the role of surrogate decision-maker. However, many health care providers lack familiarity with geriatric knowledge and the best medical practices tailored for the older population which negatively affects care quality for elderly patients and family members and creates increased frustration for physicians when delivering care to the elderly population (Thomas, Johnson, Dunn, Sullivan, Brett, Matzko, & Levine, 2006). The increasing aging population has resulted in substantial demand for professional health care workers who are skilled in gerontological issues (Cohen, 2009). Unfortunately, physicians and nurses have continually expressed dissatisfaction with the healthcare
infrastructure regarding elderly care, which has further increased the shortage of geriatricians. Because physicians do not focus on geriatric care and chronic illnesses associated with the elderly population, their lack of knowledge may affect their communication with AD patients and caregivers. Moreover, future research should examine the ways in which physicians break the diagnosis of AD to patients and family members.

In order to solve the shortage of medically trained professional providers, the health care system must implement increased training in geriatrics and gerontology in order to facilitate interest and support greater competency in terms of skills and knowledge when understanding and communicating with the elderly population (Cohen, 2009). Consequentially, physicians will benefit from education and training regarding the elderly population and the nature of ailments and chronic diseases experienced by this population.

Feeling guilty also contributed to caregiver uncertainty. Given that uncertainty stems from the uncertainty of the disease (Brashers, Neidig, Haas, Dobbs, Cardillo, & Russell, 2000), AD caregivers experience difficulty when assessing the abilities and needs of the patient. For example, AD caregivers felt the need to choose between the patient’s wishes and safety needs, which is an emotionally arduous task, especially when caregivers felt unsure of their loved ones’ needs. Furthermore, this finding provides insight into the emotional turmoil experienced by AD caregivers who must advocate for the well-being of loved ones while facing uncertainty when making decisions. This form of heightened uncertainty and emotional turmoil has the potential to delay definitive decisions and action (Brashers, 2001; Boss, 1993), putting the patient and others at risk. Because of the unpredictable progression of the disease, AD caregivers must often take action with little planning, after which many reported feeling tremendous guilt and regret.
Length of time in the caregiving role also contributed to a range of psychological and behavioral responses to uncertainty. In this study, the on-site caregivers who demonstrated healthy psychological states did so by making optimistic statements, revealing a sense of confidence and comfort. Interestingly, only on-site caregivers who provided care for an extended duration of time exhibited positive appraisals of the caregiver role and the uncertainty of AD. However, on-site caregivers did portray a sense of extreme unease when describing the early stages and discussing past attempts to acquire information to gain confidence. Eventually, the caregivers portrayed acceptance of the circumstances and emphasized the need to take it one day at a time. The finding suggests that AD caregivers arrive at positive appraisals only after many years of caregiving, indicating that over time AD caregivers eventually surrender, accept, and adapt to chronic feelings of uncertainty (Brashers et al., 2000). Although a small number of caregivers appraised uncertainty positively, it is important to consider the implications of who made the positive appraisals. Brashers et al. (2000) described the extended trajectory of chronic illness as one in which individuals may learn to accept the uncertainty and learn optimism. The findings of this study support Brashers’ claim.

In contrast, distance and inability to assist with primary care resulted in uncertainty for long-distance caregivers. This finding is congruent with results from previous studies, which suggest that long-distance caregivers feel extreme guilt because of their inability to be present and to provide more assistance to the patient (NAC, 2004). This study, however, highlights a different source of guilt and concern for long-distance caregivers, one that stems from the ill effects of caregiving on the primary caregivers’ health. These findings suggest that future research is needed to learn more about caregiver guilt and how it impacts on-site care decision-
making; however, in the case of long-distance caregivers, guilt may impact their ability to provide support to the on-site caregiver.

AD caregivers sought traditional resources, such as books and Internet searches, along with social support networks to reduce uncertainty. Both on-site and long-distance caregivers reported the most viable and credible source was someone who had AD caregiving experience. This finding aligns with Brashers, Neidig, and Goldsmith (2004), who claimed that others have a profound effect on the ways individuals manage uncertainty. However, unlike on-site caregivers, long-distance caregivers were unlikely to attend support groups in order to gain this particular type of information. This finding suggests that long-distance caregivers may perceive themselves as different than other AD caregivers and, therefore, they do not naturally seek out support from others. However, it may also mean that long-distance caregivers avoid support groups as a means of information because they do not want to know the hardships with which the on-site caregiver is faced (Brashers, 2007). Future research should address long-distance caregiver strategies for uncertainty management.

Another notable finding revealed that long-distance caregivers sought information and support from family members more often than on-site caregivers sought support from family members. By maintaining contact with the on-site caregiver, long-distance caregivers were able to both provide and receive support. Moreover, by maintaining frequent contact and communication with the primary caregiver, long-distance caregivers managed to provide a form of social support through indirect assistance, which researchers defined as a form of emotional support (Brashers, Neidig, & Goldsmith, 2004). Furthermore, long-distance caregivers reported providing direct assistance to primary caregivers by helping with financial obligations, looking for end of life facilities, and sharing information obtained with the on-site caregivers. Direct
assistance occurs when individuals help others facilitate uncertainty management by acting as a source of information, assisting in information gathering, and helping evaluate information (Brashers, Neidig, & Goldsmith, 2004). The dynamic that exists between on-site and long-distance caregivers appears to be a unique context in which uncertainty management theory and the effects of different relational dynamics should be further investigated.

Overall, AD caregivers managed uncertainty by interactively seeking information when they became fearful for the well-being of their loved ones. Wackerbarth (2002), who developed a typology for AD caregiver decision-making, determined that AD caregivers who seek to reduce uncertainty by collecting information from professionals, are proactive caregivers who obtain information in order to plan ahead. Through information seeking these caregivers are able to achieve confidence in their ability to act in the event of a crisis.

Interestingly, AD caregivers only sought information from a physician or health care professional when they discovered a problem regarding the care recipients’ health and well-being. This finding was supported by Polk (2005), who claimed that AD caregivers often receive little input from medical providers, which further complicates illness comprehension, and makes decision-making and adapting more difficult and burdensome. According to Wackerbarth (2002), AD caregivers who wait for a crisis or a trigger event before seeking information from health care professionals are more likely to be reactive caregivers who make decisions in reaction to a crisis. This finding is significant regarding uncertainty and management strategies, as it provides insight into the experience of uncertainty from the perspective of AD caregivers and how they act on different forms of uncertainty. However, it opens the door for future researchers to examine why caregivers do not readily seek information from health care providers. This finding has remarkable implications for understanding the communicative
behaviors of all participants engaged in cases of chronic uncertainty (Brashers, 2000), which in this case includes physicians, AD caregivers, and patients.

To manage uncertainty about the disease and its progression, caregivers engaged in source discrediting. Both on-site and long-distance caregivers discredited sources of information as incredible by questioning the validity of the diagnosis, discrediting support groups, and by discounting speakers for the Alzheimer’s Association. Brashers (2007) identified this strategy as indirect information avoidance. Similarly, Wackerbarth (2002) postulated that inactive AD caregivers avoid information so as to eschew making decisions. By maintaining the belief that their loved ones were unlike other persons with the disease, AD caregivers attempted to maintain uncertainty, which they appraised as more positive than the alternative, continuous degradation and eventual death.

Over time AD caregivers learned to adapt and live with uncertainty by developing new goals, routines, and methods of approaching life as caregivers. When describing the AD caregiver journey, those who eventually adapted to the chronic uncertainty, portrayed past attempts to reduce, increase, and maintain uncertainty. However, the AD caregivers were able to adapt as they began to accept the unpredictable circumstances as a necessary part of life (Brashers, 2007). These findings indicate that caregivers may develop the skills to adapt to uncertainty over time as the disease continually progresses. Adapting occurs when individuals accept and learn to manage chronic unease as they change the way they plan for the future (Brashers, 2007). Over time, AD caregivers may adapt to the uncertain state through the progression of the disease as their loved one deteriorates. Therefore, attempts to intervene and assist caregivers in adapting to uncertainty should be made earlier in the process of AD caregiving. This finding is supported by Kuhn (2003), who explained that the early stages of AD
may endure for an extended length of time, however disease progression varies from person to person. Because the future is uncertain for AD caregivers, to prepare for contingency would be unrealistic, unpractical, and emotionally draining. Therefore AD caregivers may find it helpful to learn about the future through interventions that assist in adapting to chronic uncertainty. However, researchers who design interventions should be mindful of the overwhelming nature of information particularly when detailing the final stages of AD. AD caregivers often become stressed and overwhelmed by excessive information (Kuhn, 2003). Future researchers should remain cognizant of the abundant available information regarding AD when designing interventions aimed at assisting AD caregivers in developing the skills to adapt to chronic uncertainty.

An abundance of information and resources exist for AD caregivers upon diagnosis including Internet sources, books, support groups, media, and contact with the Alzheimer’s Association. In this study, on-site caregivers found reading books and searching the Internet particularly helpful in the beginning stages of the diagnosis, which helped to reduce fears of the future through learning disease specifics. Likewise, in order to gain a sense of comfort, long-distance caregivers searched the Internet for information regarding symptoms and disease progression yet they never gained confidence in their knowledge of the disease. The findings of this study demonstrate that support groups and the Internet are useful sources for obtaining information regarding the nature of AD, the disease progression, and primary care. However, these sources did not account for the needs of long-distance caregivers or the psychosocial needs of on-site caregivers, particularly in the beginning stages of the disease.

This study revealed a few shortcomings of uncertainty management theory within the context of AD caregiving. First, uncertainty management theory should be expanded to
encompass additional sources for information-seeking and support. For example, the caregivers in this study repeatedly described prayer as a predominant source of support and guidance, however prayer did not fit within the theoretical approach. Additionally, neutral and combined emotional appraisals, as described by Brashers (2001; 2007), did not adequately represent the appraisals of and responses to uncertainty for on-site and long-distance AD caregivers. For example, caregivers who expressed a neutral emotional response did not display indifference; rather a neutral response occurred when caregivers recounted the events of becoming an AD caregiver without expressing positive or negative emotions. Furthermore, the participants in this study did not reveal a combined emotional response of thrill (Brashers, 2001; 2007); within the context of AD caregiving, a combined emotional response manifested through volatile emotions that occurred simultaneously and over time. Finally, the theoretical approach did not adequately fit the uncertainty management strategies of long-distance caregivers. Long-distance caregivers sought information and support from the on-site caregiver. Using uncertainty management theory, it remains unclear whether information-seeking between on-site and long-distance caregivers represent active or interactive strategies.

In order to resolve the shortcomings of uncertainty management theory illumined by this study, future researchers should utilize grounded theory to gain comprehensive insight into uncertainty and management strategies of on-site and long-distance AD caregivers. A theoretical approach grounded in the experience of AD caregivers will provide a foundation for the development of a new model of uncertainty management that represents the experience and tactics utilized specifically by on-site and long-distance caregivers for seeking coherence and understanding within a largely unpredictable situation.
Limitations

Several limitations of this study should be noted. First, the sample for this study was almost universally Caucasian, which cannot represent the experiences of numerous caregivers from other cultural backgrounds. Second, the participants were disproportionately female, however this circumstance, while not representative, is not uncommon since 60% of persons who provide informal care for individuals with AD are female (Alzheimer’s Association, 2010). Third, the imbalance between on-site and long-distance caregiver participants may have skewed the data. Finally, the strategies used to recruit AD caregivers (Alzheimer’s Association, support groups) may have produced a biased sample because the caregivers affiliated with these organizations likely sought support and information more actively, and therefore may manage uncertainty better than other AD caregivers. However, the snowball sample recruitment strategy may have reached caregivers who do not readily seek information from organizational support networks. Overall, this study provided a foundation for future studies on AD caregiving and uncertainty management.

Future Research

Findings from this study suggest that long-distance caregivers influence on-site caregiver burden and strain by providing social support and a chance to vent frustrations. In order to gain a balanced perspective for on-site and long-distance AD caregiving, researchers should investigate the differing perceptions between on-site and long-distance caregiving dyads. Future researchers should go beyond uncertainty management and examine the ways in which AD caregivers’ uncertainty management strategies are influential in caregiver decision making. Additionally, researchers should conduct studies regarding the resources caregivers perceive as
most helpful, beneficial, and convenient, throughout the different stages of AD for both on-site and long-distance caregivers. By gaining this understanding, researchers can develop information for interventions aimed at relieving the burden of AD caregivers.

Conclusion

AD is a chronic disease that spans two to 12 years, while the average person lives for eight years after diagnosis (Alzheimer’s Association, 2010). For those living with AD, family caregiving support is necessary to ensure adequate care and quality of life (Boss, 2003). This study investigated the experience of AD caregivers by examining their emotional responses to uncertainty and the subsequent strategies employed to manage their uncertain state. Findings from this study suggest that the experience of uncertainty and management strategies differ between on-site and long-distance caregivers. Moreover, this study suggests that the sources available to AD caregivers are not beneficial to the needs of the long-distance caregiver or the psychosocial needs of on-site caregivers. More work is necessary to ensure that AD caregiver support needs are met as they tackle the difficult task of encountering and overcoming the burden associated with the uncertainty of AD caregiving.
APPENDIX

INTERVIEW PROTOCOL FOR ON-SITE AND LONG-DISTANCE CAREGIVERS
Surveys will be audio-taped

Demographics:

Age __________ Sex: Male     Female

Education: less than high school   high school   some college

Bachelor's degree   graduate degree

Race: Caucasian     African American     Hispanic     Asian     Other

Circle one: On-site Caregiver     Long-distance Caregiver

If long distance, how many miles away from care recipient? ______________

If long distance, how do you usually travel to see care recipient? ______________

(car, plane, etc.)

Relationship to Care Recipient:

Spouse      Sibling     Child     Grandchild     In-law     Neighbor

Relative_______     Other_______

Number of Living Grandparents ______________

On-site caregiver—Average Hours/Week Providing Care:
1-5    5-10    10-20    20-30    30-40    40-50    above 50    24/7

Long-distance caregiver—Average Hours/Week in contact with caregiver/care recipient:
1-5    5-10    10-15    15-20    20-25    above 25

How long has it been since your loved one was diagnosed with AD? __________

How long have you been a caregiver? __________

AD Caregiver Uncertainty Experience

1.)    Tell me the story of how you became an AD caregiver.
2.) Describe things that make you feel unsure or cause you to have questions about Alzheimer’s disease and care giving.

3.) Fill in the blank; caring for an Alzheimer’s patient is like _____.

4.) How would you describe the stress you feel in your role as a caregiver?

5.) Of all the things you are worried about, what is the most distressing?

**AD Caregiver Uncertainty and Management**

6.) Behavioral reaction component of UMT: Tell me the story of a recent event in which there was a problem with your loved one’s care and how it was resolved? (Probe: How did you feel about this?)

7.) Behavioral reaction component of UMT: When there are problems with your loved one’s care, what do you do? Who do you turn to?

8.) Information-seeking component of UMT: When you experience stress when caring for your loved, how do you cope? What resources do you have? What resources have you used in the past?

9.) Information-seeking component of UMT: How do you find/get information about Alzheimer’s disease (i.e., Internet, television, books, magazines, talking to others, other sources)? How do you use it? Describe how actively and regularly you seek out information on AD.

10.) Information-seeking component of UMT: What kinds of information do you seek? What types of information do you find most helpful? How do you judge what is believable in terms of information?

11.) Tell me about how things work between you and other family members who may be assisting with care.
REFERENCES


