

CAREGIVER PERCEPTIONS OF WANDERING BEHAVIOR IN THE ADRD
(ALZHEIMER'S DISEASE AND RELATED DEMENTIAS) PATIENT

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The dissertation examined family caregivers' perceptions of wandering behavior after their loved one has been diagnosed with ADRD (Alzheimer's disease and related dementias). Semi-structured in-depth face-to-face interviews of a convenience sample of 22 caregivers in the Dallas metropolitan area were conducted. Responses were analyzed using a grounded theory approach. The use of qualitative methods facilitated the study of how caregivers of a loved one with ADRD understood and explained in their own voice the wandering behavior associated with the disease and how their views of the behavior informed the caregiving process. In particular, this research examined why some caregivers tend to recognize wandering behavior as significant early on while the ADRD patient is still living in the home (and community) and modifications can be made to keep him or her there despite the behavior, and why some caregivers do not.

Findings indicated that caregivers were concerned about the general safety of their loved one. Precautions were taken within the home for conditions related to frailty, but were much less likely to be taken to address wandering behavior and its negative consequences. Three groups of caregivers emerged: (a) those who primarily reacted to their loved one's problem behaviors including wandering, and intervened minimally; (b) those who were proactive, making modifications in their routines and environment to protect their loved one after a trigger event; and (c) those who had a mixed response, who

did the best that they could with what they had. This last group of caregivers took on additional roles, modified their homes for safety, but environmental stressors and inadequate supports limited their interventions. Implications of the findings for aging in place and community, further research, policy-making, and practitioners are discussed.

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CHAPTER 1

INTRODUCTION

Worldwide, Alzheimer's disease and related dementias (ARD) have affected nearly 36 million persons (Alzheimer's Disease International, 2010). Presently, 5.4 million Americans are living with ARD; this is expected to grow to 16 million by 2050 (Alzheimer's Association, 2011). Defined as loss or decline in memory and other cognitive abilities, ARD is caused by various diseases and conditions that result in damaged brain cells. For a diagnosis of ARD, there must include a decline in at least one of the following areas: (a) ability to generate coherent speech, (b) ability to recognize and identify objects, (c) ability to execute motor activities, or (d) ability to think abstractly and make sound judgments (Alzheimer's Association, 2012). The prognosis for people with the ARD is death. However the disease's progression is slow, between 2 and 20 years (Alzheimer's Association, 2012). The disease progresses through a series of stages, with increasingly negative impacts on the patient cognitively, affectively, and behaviorally.

A hallmark of ARD is behavior change. While there are many behavior changes that can impact negatively on the ARD patient's safety, a significant behavioral issue is wandering. Defined as "forays into the community without the supervision of a caregiver" (Rowe & Glover, 2001, p. 344), wandering is estimated to occur in the majority of ARD cases (Alzheimer's Association, 2010b). According to the Alzheimer's Association (2010b), about 60% of those diagnosed will have at least

one incident of wandering). Wandering can be very dangerous; when a cognitively impaired person gets lost, they often do not know how to get back home or remain safe. Indeed, if a wanderer is not found within 24 hours, the probability increases that they will be found seriously hurt or dead (Alzheimer's Association, 2010b).

Over 80% of ADRD patients continue to live at home, with family acting as primary caregiver (Alzheimer's Association, 2011). Moreover, because the disease progresses so slowly, over 32% of caregivers provide help for more than five years (Alzheimer's Association, 2011). As the spouse is usually identified as the caregiver of choice, he or she is at particular risk of developing health problems, mental health issues and increased financial burden due to the stress of caregiving for a protracted period of time (Family Caregiver Alliance, 2004).

Spouses and other family caregivers are reluctant to force role change on their loved one (Robinson et al., 2007). The diagnosis of ADRD is devastating for patient and caregiver and often the caregiver denies the lifestyle changes that are required to keep the patient safe (Ablitt, Jones, & Muers, 2009). In addition, caregivers often delay accessing services to assist in caring for their loved one with ADRD (Adams, 2006). While caregivers tend to make some adjustments to their homes to accommodate the changes brought on by the diagnosis of ADRD, they often hesitate to take action to prevent a wandering incident. Kelly (2009) suggests in many cases it is only after 6 to 8 wandering incidents that the family recognizes wandering as an issue. Family members tend to misinterpret and minimize wandering events until the event is repeated numerous times or involves serious injury (Kelly, 2009; Robinson et al., 2007). While there are

interventions available to keep an ADRD patient who wanders safe in the home, the interventions often are not used until after an incident or even several incidents of wandering have occurred (Rasquin, Willems, de Vlieger, Geers & Soede, 2007; Rowe & Glover, 2001). By the time wandering is recognized as an issue, it is often considered so overwhelming that placement outside the home occurs (Aditya, Sharma, Allen, & Vassallo, 2003).

Both the emotional impact and the financial impact of placement of any senior, but especially the ADRD patient, outside the home can be severe. Gerontologists remind us that older adults should be permitted to “age wherever they want to live”; that is, they should not be forced to relocate (Alkema, Wilber & Enguidanos, 2007, p. 459). Studies have shown that seniors tend to prefer to age in place (Bookman, 2008). In addition, aging in place (and community) is often less disruptive and provides more satisfaction to both the ADRD patient and their caregiver (Bookman, 2008; Tornatore & Grante, 2002). Studies have found that when caregivers are educated about the diagnosis and feel that they have appropriate support, they are more likely to care for the ADRD patient in the home and community for a longer period of time (Mittelman, Roth, Haley, & Zarit, 2004).

The cost of placement outside the home is high and many cannot afford it. In 2008, the median income for a single person aged 65 and older was \$18,208 and the median income for households was \$31,157 (Alzheimer’s Association, 2010a). Assisted living care costs an average of \$37,572 per year, making it unaffordable for many seniors (Alzheimer’s Association, 2010a). Skilled nursing care costs were even higher at

between \$72,000 and \$80, 000 per year (Alzheimer’s Association, 2010a). The costs to Medicaid for nursing home care for ADRD was \$21 billion in 2005, was expected to increase to \$37 billion by 2011, and accounts for almost half of the \$200 billion spent annually for long-term care in the U.S. (Alzheimer’s Association, 2011). This trend is significant because when private funds run out, families look to Medicaid to continue the placement.

While placement under Medicaid has increased dramatically, given the present legislative agenda and mood, it is doubtful that Medicaid will meet the demand posed by a rapidly aging population. Presently 12% of the population is over 65; by 2050, this group will account for over 20% of the population (Olshansky, Goldman, Zheng, & Rowe, 2009). By the middle of the century, a substantial number of these seniors are expected to be living with ADRD (Alzheimer’s Association, 2011).

Changes in the structure of the family further complicate the picture. Families are often disenfranchised due to distance and time constraints. The “sandwich generation” is a term that is applied to females who attempt to provide care for the elderly parents while also taking care of children and work (Steinhardt, 2012). Little time is left to provide adequate support of a parent with ADRD.

However, placement outside the home is not the only option for overly stressed family caregivers, especially those who may be particularly vulnerable after dealing with disruptive behaviors. Research indicates that knowledge and understanding of the behavior of wandering and appropriate interventions to deal with the behavior reduce caregivers’ stress and increases confidence in their ability to provide appropriate care

(Drentea, Clay, Roth, & Mittelman, 2006). Caregivers who receive appropriate education, support, and respite are able to remain successful as primary caregivers for longer periods of time.

Purpose of and Rationale for the Study

Minimal research has addressed the issue of wandering among ADRD patients, and even less has explored caregivers' perceptions of this behavior. It is significant to consider this issue, since projections indicate that the number of elderly is growing. Future projections suggest that with the increasing number of those over 65, there will be a dramatic increase in those diagnosed with ADRD (Alzheimer's Association, 2011). The increase of those impacted by the disease coupled by a decrease in funds available both privately and in the public sector for placement suggests more effective interventions must be utilized to assist the caregiver in both the recognition of and response to the wandering behavior associated with ADRD.

Hence, the principal purpose of this dissertation was to examine family caregivers' perceptions of this behavior after their loved one has been diagnosed with ADRD. Semi-structured in-depth face-to-face interviews of a convenience sample of 22 caregivers in the Dallas Fort-Worth metropolitan area were conducted. Responses were analyzed using a grounded theory approach (Charmaz, 2006). The use of qualitative methods facilitated the study of how caregivers of a loved one with ADRD understood and explained in their own voice the wandering behavior associated with the disease and how their views of the behavior informed the caregiving process. In particular, this

research examined why some caregivers tend to recognize wandering behavior as significant early on while the ADRD patient is still living in the home and modifications can be made to keep him or her there despite the behavior, and why some caregivers do not.

Results of the study have implications for the development of appropriate interventions by the professional community to assist family caregivers with their loved one's aging in place (and community). To increase the population of ADRD patients aging in place (and community) successfully, intervening with caregivers by providing appropriate support will benefit the community from both quality of life and fiscal perspectives.

Structure of the Dissertation

Chapter 2 begins with a review of findings from the research literature and concepts from various theoretical perspectives that provided some insight and guidance for the study's examination of family caregivers' perceptions of their loved one with ADRD and the wandering behavior associated with the disease. Chapter 3 discusses the methods that were used in the study. Chapter 4 presents the results of the study. Chapter 5 discusses the issue of role change, the significant finding of this qualitative research. Chapter 6 presents case studies to exemplify the issue of role change. Chapter 7 provides both a summary of the research and suggestions for the future. Appendices A and B present the schedule of semi-structured, open-ended questions that guided the in-person interviews of family caregivers and the brief closed-ended home modification

questionnaire asking caregivers about the likelihood of making various modifications to their home to address the wandering behavior associated with the ADRD diagnosis.

Consent forms and related documents are provided in Appendix C.

CHAPTER 2

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

Literature and aging theory aid the researcher in understanding the perspectives that have guided gerontology research, as well as give hints of gaps in research that further research can then fill. This chapter begins with a literature review on topics related to the ADRD patient and the family caregiver. Gaps in this literature are identified and discussed. The second half of the chapter discusses a variety of theoretical perspectives related to the aging process, illness, family relationships and other significant factors. Concepts from these perspectives are used to inform our understanding of the family caregiver's perception of a difficult behavior such as wandering and how it affects the caregiving process.

Literature Review

A literature search was conducted to review available information on ADRD, wandering, caregiver perceptions of wandering, and the results of wandering behavior. While there was some literature on wandering from a *search and rescue* perspective, and abundant literature on caregiver stress, there was limited literature on how caregivers perceive wandering behavior in the ADRD patient.

Prevalence and Consequences of Wandering

While wandering was acknowledged as a significant behavior among ADRD

patients, the statistics regarding its prevalence varied among authors from 6% to 100% (Carr et al., 2009; Hope, Tilling, Gedling, Keene, Cooper, and Fairburn, 1994; Kiely, Morris, & Algase, 2000). An Alzheimer's Association program in one community that evaluated wandering risks in those diagnosed with ADRD found that 615 incidents of wandering had occurred over 13-month period (Rowe & Glover, 2001). Of this group, "four deaths occurred and 30 sustained significant injury" (Rowe & Glover, 2001, p. 347). In a separate, retrospective study of 29 search and rescue cases related to Alzheimer's disease, researchers found that the mortality rate was 46% when the wanderer was not found within 24 hours after becoming lost (Koester & Stooksbury, 1992, p. 24). In addition to death and serious injury, consequences of wandering also include placement outside the home. Indeed, in one study "77% of those who wandered and got lost were subsequently placed out of the home" (McShane et al., 1998, p.556).

Caregiver Perception of the Problem of Wandering

Several authors highlight the role of grief. Following the ADRD diagnosis, both the ADRD patient and their caregiver have been observed to experience a grief reaction, often complicated by the stigma associated with the disease. "Grief is often disenfranchised because of the shame, secrecy and stigma associated with Alzheimer's disease" (Silverberg, 2006, p. 220). Interestingly, the impact of the diagnosis is felt by not only the ADRD patient and their family caregiver but the physician as well. Physicians described counseling patients and families regarding their diagnosis and subsequent need for behavior change such as giving up driving as one of the most

difficult aspects of providing care (Aminzadeh, Byszewski, Molnar, & Eisner, 2007). Nevertheless, understandably, denial appears to be more evident among family caregivers, who often differed from professional caregivers in their perception of risk of wandering, with a tendency to value independence of the ADRD patient over potential risk involved (Robinson et al., 2007).

The historical relationship between caregiver and care recipient and their established patterns of exchange was also noted in the literature. The term *ambivalent normalization* was used to describe a coping process used by caregivers for their loved one with ADRD (Kuo & Shyu, 2010). Slight changes in behavior and personality were noted, but caregivers attributed the changes to normal aging rather than the disease process, *optimistic appraisal* (Kuo & Shyu, 2010). “Ambivalent anticipation often developed in caregivers, that is, they felt burdened and worried about the uncertain future of the ADRD diagnosis” (Kuo & Shyu, 2010, p. 3479). An extreme case was described as caregivers who deny problems with their loved one with ADRD and thus do not think they need to obtain assistance with their care; denying the diagnosis, thus denying the need for the caregiving role (Silverberg, 2007). Family dynamics further complicate the caregiver’s acceptance of the behavior. For example, when historically there has been a significant power imbalance in the marital relationship, “the controlling spouse with the disease is insistent of still being the decision maker and the controlled spouse is fearful” (Silverberg, 2007, p. 227).

The issue of caregiver stress and burden was also discussed in the literature (Ankri, Andrieu, Beaufiles, Grand, & Henrard, 2005). When compared to the role of the

caregiver of other conditions common in aging, the ADRD caregiver's role is different in two distinct ways. First, the ADRD caregiver is responsible for physical as well as the mental well being of their loved one, which becomes increasingly difficult as the disease progresses. Second, the caregiver often remains in this role for a much longer period of time, as the trajectory of ADRD is longer than many other diseases common in aging (Sales, 2003). Moreover, "the quality of life of the caregiver is inversely related to the severity of behavior symptoms and duration of their loved one's disease" (Ferrara et al., 2008, p. 93). Thus, it is not too surprising to find that the impact of a behavior as difficult to deal with as wandering has been shown to provide a catalyst for high levels of burden and "collapse of care giving at the home" (Gort et al., 2007, p. 961).

A number of studies have examined the impact of lifestyle changes on the relationship between the family caregiver and their loved one with ADRD when the time spent on the tasks of caregiving infringes on the caregiver's personal time and socialization (Ferrara et al., 2008; Montgomery & Williams, 2001). The demands of caregiving have been found to lead the family caregiver to increased perceptions of burden and stress (Montgomery & Williams, 2001; Sales, 2003). Primary stressors include cognitive changes and problem behaviors in the care recipient. These changes lead to secondary stressors for the caregiver. These secondary stressors include "role change that is forced on the caregiver and a loss of self-esteem" (Montgomery & Williams, 2001, p. S24). "If the perceived level of burden is high, the caregiver often shows higher levels of anger-resentment toward their loved one with ADRD" (Croog, Burleson, Sudilovsky, & Baume, 2006, p. 87).

Many authors have discussed the concept of objective and subjective burden (Ankri et al., 2005; Roth et al., 2003; Sales, 2003). Objective burden is the time spent by the caregiver providing assistance with activities of daily living, supervising, and controlling behavioral issues of their loved one with ADRD. “The increased time and role pressure placed on the caregiver tends to lead to a decrease in time available to continue with life roles deemed important” (Sales, 2003, p. 36). “With the progression of the disease, the ADRD patient needs more support, further impacting the caregiver’s social life, leaving them emotionally drained” (Roth et al., 2003, p. 906). Other dimensions of burden include psychological burden and feelings of guilt (Ankri et al., 2005).

Perception of burden has been studied using the Zarit Burden Inventory. Three main areas were identified: social consequences, psychological burden, and feelings of guilt (Ankri et al., 2005, p. 257). Perceptions tended to differ by the family caregiver’s relationship to the patient. Spouses often scored higher in the area of social consequences because of the forced change in their personal and social life and the negative impact on their own health. Children scored higher in feelings of guilt, which increased as the disease progressed.

Higher levels of caregiver burden were correlated with disruptive behaviors such as wandering (Corcoran et al., 2002). Lack of knowledge about both the behavior and appropriate interventions to deal with wandering incidents led to higher levels of caregiver frustration and stress and was found to be dangerous for the ADRD patient (Cooper, Katona, Orrell, & Livingston, 2006).

In a study conducted by Dodds (1994), caregivers whose loved one with ADRD attended an adult day facility were interviewed. The author asked about wandering incidents and the strategies that were used to deal with the behavior (Dodds, 1994). The caregivers described using several inappropriate coping strategies, including “physical restraints, night sedation, alcohol, verbal and physical aggression, and lying, to prevent an incident of wandering” (Dodds, 1994, p. 752). An interesting aspect of the study was the caregivers’ reluctance to utilize authority figures. “While caregivers were willing to contact neighbors when their loved one became lost, they were reluctant to call the police” (Dodds, 1994, p. 754). Another study linked inappropriate coping strategies to higher levels of caregiver anxiety (Cooper et al., 2006, p. 19).

Ethnicity and gender also played a significant role in both prevalence and perception of wandering behaviors. “While both the black and Latino populations tend to have higher percentages of ADRD than the white population” (Sink, Covinsky, Newcome, & Yaffe, 2004, p. 1280), white caregivers reported relatively more problems with behavior than non-white caregivers (Roth et al., 2003).

Gender impacted the perception of difficulty in dealing with behavior. “Female caregivers reported more problems with behavior than did male caregivers” (Roth et al., 2003, p. 915). Researchers utilizing the Zarit Burden Interview found that wives often showed higher scores in “anger-resentment” category, while husbands scored higher in “need to do more” (Croog et al., 2006, p. 92). “Both women and men were similar in their use of social support and emotion-focused coping strategies” (Hooker, O’Dell, Monahan, Frazier, & Shifren, 2000, p. 572).

As indicated earlier, the tension between the right to autonomy of the ADRD patient and the need to protect from harm is a strong issue for family caregivers. “Family caregivers exhibited a higher tolerance to risk than professional caregivers who favored patient safety over autonomy” (Robinson et al., 2007, p. 400). The issue of surveillance and its impact on individual rights was discussed as well. Caregivers were reluctant to monitor the behavior of their loved one because they felt it was obtrusive and worried that it would cause problems in their relationship (Askham, Briggs, Norman, & Redfern, 2007). Monitoring also took time away from doing other things that the caregiver enjoyed doing. Caregivers utilized monitoring for specific reasons. These included harm prevention, to reduce anxiety in their loved one, or to prevent “socially unacceptable behavior” (Askham et al., 2006, p. 14).

Skills Training for Successful Caregivers

A number of authors looked at skills training for the ADRD caregiver. Studies examined such aspects as personality, coping skills, and support. One study, for example, determined that three personality components were needed for caregiver skills training: openness, connectedness, and involvement (Chee, Dennis, & Gitlin, 2005). If the caregiver was not ready to accept additional roles, they were not ready for skills training. The degree of behavioral issues that had developed in their loved one with ADRD had a significant impact. “Caregivers were more willing to engage in skill-building when their level of stress was higher because of difficult behaviors: (Chee et al., 2005, p. 56).

Teaching “active” coping strategies instead of emotion-focused strategies tended to lower levels of stress in the ADRD caregiver (McConaghy & Caltabiano, 2005, p. 89). The NYU Caregiver Intervention study utilized a *multi-modal* approach providing both behavioral and environmental interventions on a four-year basis. Researchers found that even when difficult behaviors increased, the caregiver’s reaction indicated less distress than the control group, who did not receive the intervention (Mittelman, Roth, Haley et al., 2004).

The REACH II (Resources for Enhancing Alzheimer’s Caregiver Health) intervention was discussed by authors as being successful in diverse environments and with varying ethnic groups (Elliott, Burgio, & Decoster, 2010). Self-care behaviors were taught to caregivers based on their scores on an initial assessment. The behaviors included stress reduction, *reframing* or redefining the reason for the behavior, utilizing support systems, and health promotion activities. Caregivers reported improvements in self-reports regarding health, sleep quality, and emotional health. The authors found improvement across all of the ethnic groups included in the study (Elliott et al., 2010, p. 36).

In another study, authors developed an intervention that dealt specifically with wandering. “The Environmental Skills Building Program” utilized a three-pronged approach: caregiver education, home adaptation, and caregiver skills training (Corcoran et al., 2002, p. 84). An occupational therapist worked with the family caregiver, and targeted a protocol in all three areas for each problem behavior. Such interventions as placement of visual cues and installation of alarms to keep track of movement were used.

This approach empowered the caregiver to identify and resolve behavioral issues (Corcoran et al., 2002, p. 83).

Many authors have discussed social support and its relationship to personality style of the caregiver (Dal Santo, Schlarch, Nielsen, & Fox, 2007; Hayslip, Han, & Anderson, 2008; Wilks & Croom, 2008). Personality style and outlook on aging are important considerations in the development of coping strategies. While social support was very important for some caregivers, other personality styles benefit from a more problem-focused approach. “Understanding which approach works best for a specific personality allows the caregiver to learn appropriate techniques and support prior to active care giving, which impacts the caregiver’s perception of burden” (Hayslip et al., 2008, p. 963).

In another study, authors found that social support contributed to higher levels of resiliency in caregivers when moderate levels of stress were present (Wilks & Croom, 2008). Family support had an even greater impact than friendships. “Assisting caregivers to identify and utilize available support networks is an important role for health-care professionals” (Wilks & Croom, 2008, p. 364).

The combination of social support with secondary services such as respite and counseling was found important in physically demanding care situations (Dal Santo et al., 2007). Counseling services were provided as a complement to respite support. “Counseling helped the caregiver focus on what event gave rise to their stress, the meaning of the situation, and effective ways to deal with the symptoms of stress” (Dal

Santo et al., p. 31). The development of these coping skills for the spousal caregiver led to delay in institutionalization for the care recipient (Dal Santo et al., 2007, p. 44).

Summary

While there is plentiful literature on the issues of caregiving, as well as literature that addresses caregiving when a diagnosis of ADRD is present, the specific dilemma of the family caregiver dealing with wandering behavior of their loved one at home is minimally addressed. Wandering is considered a common behavior with potentially severe consequences, yet there is little research that has examined how family caregivers perceived their role regarding this particularly troublesome behavior with respect to their loved one with ADRD in the home. This dissertation addresses this gap in the literature.

Theoretical Framework

The dissertation utilized a grounded theory approach (Charmaz, 2006). When utilizing a grounded theory approach, the researcher “starts with a series of hunches and explores the way they relate to the research problem” (LeCompte & Schensul, 1999, p. 10)). Concepts from a variety of different theoretical perspectives provided insight and direction for the research. Included among these perspectives were life course theory, disengagement theory, caregiver identity theory, grief theory, and competence-environmental press theory.

Life Course Theory

Life course theory is a sociological perspective that conceptualizes how lives are structured by individual choices and the structure of society at a particular moment. The life course is defined as “embedded in and shaped by the historical times and places that were experienced over a lifetime” (Elder, 2001, p. 183). The life course perspective brings attention to the role transitions in later life and the influence that life experience, gender, race/ethnicity, and social class has on these transitions (Street, 2007). The adaptation of the family caregiver’s behavior through his or her own aging process as well as coping with the disease process of their loved one often is embedded in experiences from the past. The life course perspective postulates that the first half of life is centered on the development of autonomy, and later years to the passing on of wisdom and understanding, and old age is a period when the gains of independence and autonomy change to “the creative use of dependence” (Baltes, Staudinger, & Lindenberger, 1999, p. 478). Increased vulnerability leads to efforts to compensate for age-associated deficits (Baltes et al., 1999, p. 479). Caregivers attempt to maximize gains and minimize losses through compensation designed to maintain desired levels of functioning. Thus, one of the questions the life course perspective raises is, with a devastating diagnosis like ADRD, do caregivers underestimate the severity of the behavior in an effort to minimize perceived losses?

Disengagement Theory

Disengagement theory explains the interplay of the aging process and the process

of cognitive decline. Normal aging involves inevitable disengagement from the social world (Street, 2007). The stigma associated with the diagnosis of ADRD and the inevitable functional and cognitive declines mean that decisions tend to be made to expedite the process of disengagement. Each stage of the disease involves greater cognitive, functional, and behavioral decline, thus the process of disengagement begins immediately due to a loss of the skills necessary to interact appropriately and social systems which do not accept or accommodate the changing level of cognition. If optimal aging from a disengagement perspective involves disengaging in ways that are least disruptive to the social system, placement outside the home becomes the functional outcome for the social system (Street, 2007 p. 148).

Caregiver Identity Theory

Gerontologists have increasingly considered the caregiving role and its impact on role relationships for both caregiver and care recipient (Montgomery, Rowe, & Kosloski; 2007). With each additional functional and/or cognitive decline in the ADRD patient, the caregiver is forced to take on more responsibility for household functioning and personal care, resulting in role conflict both for the caregiver and the ADRD patient, who is reluctant to give up both power and control. “An incongruence between the care giving tasks and personal identity standards cause caregiver distress” (Montgomery et al., 2007, p. 442). When maladaptive behaviors such as wandering develop, the caregiver is expected to deal with behaviors that were often not anticipated. This is further complicated because the caregiver often does not possess the knowledge or experience to

cope with the difficult behaviors (Corcoran et al., 2002). Available outside resources, such as police, are frequently not utilized, as caregivers are embarrassed and ashamed that they cannot handle their loved one's behavior (Adams, 2006). The intensity of the wandering behavior, coupled with the overwhelming sense of helplessness that it tends to bring for the family caregiver, often triggers placement of their loved one outside the home (Aditya et al., 2003). Because of the caregiver's negative emotional response, lack of support, and lack of education regarding appropriate home-based interventions for wandering, the caregiver enters the last phase and places their loved one in an institutional environment, thus giving up responsibility for their loved one's care (Corcoran et al., 2002).

Grief Theory

When faced with a major life loss, one tends to cycle through a series of coping mechanisms, articulated by Kubler-Ross (1969). The first stage is described as denial; *not me, it can't be true*. For example, by denying the impact of the diagnosis of ADRD, lifestyle changes are not deemed necessary until a crisis occurs. The crisis response is often drastic due to the over-whelming emotional impact; thus the most drastic response may be undertaken, that of placement of the ADRD patient in an institution (Silverberg, 2006). There are four other stages of grief identified by Kubler-Ross (1969): anger, bargaining, depression, and acceptance. However, it is the denial stage that seems most useful in explaining the caregiver's reaction to behavior change that is brought on by ADRD (Silverberg, 2006, p. 227).

Competence-Environmental Press Theory

The competence-environmental press (or fit) theory is useful in explaining why a caregiver has not adjusted to the increased responsibilities brought on by the diagnosis of ADRD. That is, a poor fit exists between the abilities of the caregiver and the demands of the new environment created as a result of ADRD diagnosis. The person with ADRD misinterprets information in the environment, and the caregiver is expected to modify the environment when dangerous behaviors develop (Corcoran et al., 2002, p. 83). Often, the caregiver denies wandering and the potential severity of the behavior. After a number of wandering events, the caregiver feels incompetent to deal with the issue, and looks to other solutions, such as placement outside the home, to resolve the issue.

The concept of burden, already discussed in some detail earlier in the literature review, is also useful in understanding how the caregiver perceives the additional roles that they must assume. Objective burden is the direct care tasks that must be assumed as cognitive level declines. Subjective burden is the emotional reaction to caregiving; the level of distress experienced by the caregiver (Sales, 2003). “Conflict arises when caregivers are forced to give up desired roles that have been central to their life because they are now caregiving for their loved one, which leads to their perception of burden” (Sales, 2003, p. 36).

Summary

These theoretical perspectives are useful in gaining insight into how the family caregiver develops perceptions. In sum, life course theory explains the dilemma felt by

the caregiver who is suddenly being forced to take on a difficult, unwanted, and socially stigmatized role that negatively impacts previous lifestyle and preferred roles.

Disengagement theory highlights the societal expectation that the ADRD patient should disappear from society in the least disruptive way. Denial is related to grief and loss;

when caregivers deny the severity of negative behavior, there is no impact on lifestyle until the severity of the consequences of the behavior forces a more realistic assessment.

Competence-environmental fit theory further explains how incompetent and

overwhelmed the caregiver feels in their new role. Caregiver identity theory explains that role conflict causes strain on both the caregiver and their loved one with ADRD. The

caregiver feels shame at their inability to attain mastery due to lack of knowledge and experience in the caregiving role. The care recipient is angry that he or she is forced to

relinquish cherished roles. The concept of burden is utilized to understand that role

change has both physical and emotional components. In short, the changes brought on by ADRD are all encompassing. When denial is no longer possible, the caregiver feels

incompetent to deal with the much more challenging role of caring for the ADRD patient, and, consequently, often turns to outside resources such as placement outside the home

for support.

Conclusion

ADRD is a complex behavior with many facets. It involves changes in cognition as well as changes in behavior. There have been studies on many aspects of the disease, including the complicated and dangerous behavior of wandering. The literature review

found research regarding the wandering event, the reasons for the behavior, and the dangerous consequences, including death. Literature was plentiful on the role of the caregiver, in general. The concept of burden has been applied to the role of the caregiver, highlighting the increased responsibility combined with anger, sadness, and denial of the changes that come with the disease. Caregivers respond to ADRD with varying levels of acceptance, understanding, and support.

The literature is relatively sparse on how these factors influence the family caregiver's perception of and response to a dangerous behavior like wandering in a loved one. Why do some caregivers acknowledge and make modifications to avoid the potentially severe consequences of wandering for their loved one who remains in the home? And, why do other caregivers seem to be in denial about the behavior and its consequences and take no action? Using a qualitative approach, the dissertation examined these issues. The research questions that guided the study included: What were the changes in the home since the diagnosis? What was the level of concern that the caregiver has about wandering? Did the caregiver worry about their loved one becoming lost? Had their loved one gotten lost? What factors impacted the caregiver's perception of wandering? How had a wandering event acted as a catalyst for change by the caregiver? Had placement outside the home been considered? Was wandering a primary reason for placement? Was the caregiver likely to use home-based interventions? The next chapter describes the methods of the qualitative approach used to answer these questions.

CHAPTER 3

METHODS

This study looked at variations in caregiver attitudes regarding the behavior of wandering. Wandering is regarded as one of the most dangerous behaviors that develop with a diagnosis of ADRD, and often leads to placement outside the home. I wanted to understand how family caregivers of a loved one with ADRD view wandering, and what safeguards they have undertaken to protect him or her. I used a qualitative research procedure to gather data on caregivers of Alzheimer's patients. I conducted 22 semi-structured, face-to-face, in-depth interviews with caregivers of ADRD patients. Most of the interviewees were recruited from support groups sponsored by the Alzheimer's Association Greater Dallas Chapter.

I chose a grounded theory approach to analyze the interviewees' responses. This approach provided me with a systematic, yet flexible guideline for collecting the data and analyzing the data based on the idea that theory was *grounded* in the data itself (Charmaz, 2006). Utilizing a grounded theory approach meant that I was able use observations and interactions from the interviews in order to pursue my hunches. These hunches were developed into analytic ideas (Charmaz, 2006). Themes were developed that explained caregivers' perceptions of wandering by looking at series of related issues. These issues developed during the interview and data analysis process (Strauss & Corbin, 2008). Details of the methods used in the study are provided below.

Recruitment of Sample

I used a type of non-probability sampling known as *snowball sampling* to recruit study participants. The respondents self-identified and expressed their willingness to participate. I developed a flyer describing the study and requested that family caregivers of ADRD patients contact me if they would be interested in participating. I began the process of passing out flyers in November of 2011. I physically dropped off flyers at approximately 10 locations, and emailed many others to professionals within the community.

I utilized the Alzheimer's Association, Greater Dallas Chapter, as initial point for recruiting volunteers. I used them for several reasons. First, it is the largest non-profit provider of education and support regarding ADRD in the Dallas metropolitan area, as well as the nation. I enlisted the support of the local chapter office to assist me in soliciting volunteers for my study. I also felt that using support groups as the venue for disseminating information about my study would be beneficial because it would connect me to a broader population seeking support with ADRD as well as many professionals who work with those suffering from ADRD. In addition, I was familiar with the Alzheimer's Association as a former employee and current volunteer.

Flyers inviting participation in the study were distributed to ADRD support groups from UT Southwestern Alzheimer's disease center, to many local churches as well as Alzheimer's day programs, and Alzheimer's assisted living communities from Duncanville, Texas to Denton, Texas. While the Alzheimer's Association Greater Dallas Chapter was helpful in distributing my flyers, I also physically attended two types of

support groups, the general caregiver support group and the Trailblazers group, to distribute flyers.

The Trailblazers group program was developed and established by Sydney Farrier, L.C.S.W., an Alzheimer's Association former employee. The program is a series of 8 weekly sessions providing education and support for those recently diagnosed with ADRD or with a diagnosis of early stage dementia. The group facilitator is a volunteer with expertise regarding ADRD. Most of the volunteers are professionals who work in the aging community in the Dallas metropolitan area. The program is designed so that both the person with ADRD and their "Care Partner" both attend the education component. The second half of the meeting involves a support group that separates the persons with ADRD into one group and the Care Partners into another. This allows those with ADRD to meet and discuss their issues with others suffering from ADRD, something that is both unique and powerful; it is nice to not be alone with such a stigmatizing diagnosis. After the eight-week series, the program continues on a monthly basis in order to provide continuing support for both the person with the diagnosis and their loved one, and it also provides a social outing.

I became familiar with the Trailblazer's groups and how beneficial they were for those suffering from ADRD as a former employee of the Alzheimer's Association. As an employee, I facilitated one of the eight education sessions and then continued in this role as a volunteer. The other reason I felt the Trailblazers groups would be an appropriate venue to seek volunteers because in addition to providing access to caregivers, they would also allow me access to the professional community that worked with ADRD

patients in the Dallas metropolitan area as they often volunteer as facilitators for Trailblazers groups. It would allow me to present my flyer to not only participants of the support groups, but key professionals would be aware of my study and might inform others who were not directly attending an activity affiliated with the Alzheimer's Association.

I also attended two general support group meetings. The Alzheimer's Association Greater Dallas Chapter sponsors over 50 support groups in the Dallas metropolitan area. The groups are held in various locations such as local churches, centers where seniors gather, residential care communities, and Alzheimer's adult day programs. The support groups' facilitators are either volunteers or staff members of the facility hosting the group who also act as volunteer facilitators for the Alzheimer's Association. I attended general support groups at an Alzheimer's adult day program as well as at an Alzheimer's assisted living community.

By disseminating the flyer to diverse locations, I hoped the information would be shared with a diverse group of caregivers and that my sample would reflect the diversity of population within the Dallas metropolitan area. I attended all but two of the group meetings for only the first 10 minutes of the meeting. (The two exceptions are explained in the participant observer section below.) I was there in order to introduce myself and pass my flyers out, and then I left the meetings. Participation in the study was described as completely anonymous and voluntary. Because participation was completely voluntary, I was never aware of where the volunteers learned of my study. They

contacted me by telephone or by e-mail based on the information that was provided on the flyer.

I received 24 contacts, which resulted in 22 interviews. One of the interviews ended abruptly, and while I attempted to reschedule, no response was received, so the partial information has been used. The interview length varied from between 30 minutes and 90 minutes long with the average interview length of 60 minutes. While all 22 interviews were conducted with family caregivers, not all were the primary caregivers due to placement or relationship with the person with ADRD. In one case, the interviewee was the elderly mother who provided part-time care to her daughter. In 17 of the cases, the person with ADRD remained in the home. In four cases, the person with ADRD had been placed in a skilled nursing facility and one was living temporarily out of state. Since caregivers essentially self-selected for the study, I was unaware of these issues until the interview process was officially begun.

Participant Observation of Two Support Groups

In order to better understand the role of the caregiver of an ADRD patient and the importance of relationship between caregivers, as part of this dissertation study, I attended two support groups as a participant observer. As a participant observer, the investigator becomes a part of the setting or process being examined (Sofaer, 1999). I obtained written consent from the administrator of each facility before attending the groups. Since I recorded the group meeting, the group facilitator asked for the group's verbal permission of my recording of their meeting. The participants were assured that

the recording would be used for purposes of this research project only and would contain no identifying information. Their participation would remain confidential. In both cases, permission was granted. My role of observer was to better understand the caregiver's role with ADRD, their perception of their role, and the impact that the support group setting provided for them. Since my topic involved issues related to wandering, I was specifically interested in discussion among caregivers regarding wandering incidents. Support groups serve an important role in the community because these groups provide education, information, and support (Javadpour, Ahmadzadeh, & Bahredar, 2008).

The support groups that I attended were in two different venues; the first one was affiliated with an adult day program, and most of the caregivers were still caring for their loved one at home. There were many topics that were discussed during the meeting of this group. Coping with behavior change was a significant topic of discussion; caregivers verbalized that their *normal* responses to their loved one were often ineffective in achieving the behavioral goal in ADRD. Adjusting their responses to deal with cognitive impairment was both new and difficult for them, which led to stress. One caregiver described to the rest of the group an incident involving his wife. He said that he dozed off after lunch one day, and when he woke up, he found his wife on the floor, unable to get up. He and others in the group attempted to find humor in this difficult and dangerous situation. He stated "I knew I was going to be accused . . . I did not hit her," and laughed along with the group. This incident exemplifies the life of the ADRD caregiver; behavior of their loved one with ADRD is often unexpected and dangerous and can change in a moment. Caregivers voiced enormous guilt, shame, and anger about

their loved one's behavior as well as at themselves for not providing appropriate protection. There was a lengthy discussion among caregivers about getting help in their home with their caregiving tasks. Caregivers were not sure about how much help they should get. They also seemed to have little knowledge of the kinds of help resources available and indicated they did not know how to find *good* ones.

The second support group took place at an Alzheimer's assisted living facility. The caregivers in this group had recently placed their loved one in the facility. All expressed sadness and guilt that their loved one's behavior change had made it impossible for them to keep him or her at home. Interestingly, while one of the caregivers in attendance described numerous wandering incidents by her spouse with ADRD, she maintained that she placed him in the facility primarily because of his extreme incontinence. It appeared that while wandering was an issue, it was the enormity and complexity of the other behaviors that had also developed that became overwhelming to her and eventually led to placement of her spouse outside the home.

The issue of wandering was discussed minimally by participants in both support groups. While wandering is a significant event, these caregivers did not seem to construe it as particularly dangerous for them at the time. There were many other behavioral issues that they described that were of much more consequence to them.

While the goal of my attendance at the support group meetings was to explore how often wandering is discussed among caregivers in these settings, I came away learning about the complex and painful nature of caregiving for a loved one with ADRD and that emotions related to this role present as differently as the caregiver themselves.

Attendance also reinforced the need for volunteer facilitators who were knowledgeable about the disease and its associated problem behaviors that could provide guidance as well as empathy.

The facilitators of the two support groups that I observed skillfully provided education; they discussed resources to help the caregiver, including all forms of home support. They eased spouses into the holiday season, a difficult time for those with ADRD and their loved ones. They allowed the caregiver to express their pain but then also provided them with hope.

The support groups provided me an additional opportunity to introduce myself and pass out my flyers, and as with the previous groups, I utilized 10 minutes at the beginning of the meeting and then quietly observed the process of the next hour and a half. As an observer, I entered a social setting for caregivers which I had not previously known (i.e., the general social support group instead of a Trailblazers meeting), and was given an opportunity to observe their interactions with each other that I otherwise would have been unaware of (Corbin & Straus, 2008).

The Interview Process

While my role was that of observer during the support groups, the same observational skills were utilized in a more active manner during the 22 interviews that were conducted. The difference was that the interview process allowed me to explore more deeply the topics that were discussed (Schensul, Schensul, & LeCompe, 1999).

While I recognized that my primary role was that of researcher, I found this role was both

complemented and complicated by my secondary role as a clinician. As a clinician, I tend to approach human interaction with a diagnostician's perspective; thus each interview went beyond a discussion of ADRD and potential safety concerns in their home or with their loved one, and became an opportunity to see how painful the process of caregiving was. The person they knew and loved had become someone different; their behavior and emotions were changed by ADRD. I listened to the caregivers and I probed their answers for further clarification. I sought to understand their answers within the context of their relationship and lifestyle. I listened as these caregivers expressed worry and fear of what was yet to come and grieved what had been lost in their relationship.

The interview process began with a phone call or email from the potential interviewee. We would agree on a meeting location, date, and time. Interviews occurred at churches, in coffee shops, restaurants, a library contained within an adult day program building, or in the caregiver's home. I reminded the caregivers that I would be recording the interview. I arrived a few minutes early, but since I did not know whom I would be interviewing, I often stood at the door of the venue waiting for someone to approach me; *the lady with the briefcase*. Once seated, I would produce the consent form and ask the potential interviewee to read and sign it. After he or she had read and signed the form, I would then give them a copy of the consent and ask for permission to record the interview. Once I received verbal permission to record, I would utilize two recording devices, a primary recorder and a secondary recorder, which was used as a back-up.

The interview process consisted of a combination of qualitative and quantitative data collection approaches. The qualitative approach allowed me to use the research

questions to guide the interview process. This research utilized a grounded theory approach; in other words, as a researcher, I studied what was happening and made a conceptual rendering of the actions (Charmaz, 2006). When utilizing a grounded theory approach, a few broad, open-ended questions are used to elicit a detailed discussion of the topic (Charmaz, 2006). The research questions provided a series of hunches, which were then tested through data collection. The research questions looked at the areas of home safety, the caregiver's perception of wandering, and whether wandering had occurred. The data that I collected was then used to develop analytical ideas that I could use to help me see the full picture contained within the data (Charmaz, 2006).

The semi-structured interview allowed me to guide the interview, but when topics developed that I felt warranted further discussion in order to better understand the relationship dynamics, I could do so (LeCompte & Schensul, 1999). It allowed me to see the complexities of each caregiver's unique relationship with their loved one with ADRD. Since decisions made by the caregiver were reflective of their values, past relationships, and present concerns, the flexibility of the semi-structured interview process allowed me to develop these themes. This same flexibility was available to some extent to the caregiver as well; the semi-structured interview process allowed for versatility within the interview to explore the issues that the caregiver wanted to talk about (LeCompte & Schensul, 1999). The aim of the semi-structured interview process was to find stable patterns of communication as well as new information that led to other patterns that help to explain how the caregiver perceives wandering in their loved one with ADRD (LeCompte & Schensul, 1999).

The schedule of questions that guided the interview process is provided in Appendix A. Initial questions were socio-demographic in nature. The first substantive area of questioning concerned the relationship between the caregiver and their loved one with ADRD and general home safety. Another area of questioning related to actual wandering incidents, the outcome of the incidents, and what changes had taken place related to the incidents. A final area of questioning related to what the caregiver perceived as his or her supports, both related to family relationships and various third party services such as respite services and adult day programs.

At the end of the qualitative data collection approach used, that is, the semi-structured interview, interviewees were asked to provide quantitative data by completing a self-administered questionnaire, the “home modification questionnaire” (Appendix B). Eight home safety modification strategies related to wandering were contained within the questionnaire with a scale that ranged from 1 (*not likely to enact*) to 10 (*in place*). Thus, the questionnaire was designed to determine the likelihood of the caregiver implementing each of the strategies. The questionnaire included such simple modifications as the utilization of a fence or locked gate to wandering-specific interventions such as camouflaging doors or purchasing a tracking device.

Sample Characteristics

Demographic information, such as caregiver age, ethnicity, relationship, and date of diagnosis, was also collected. When the specific diagnosis was not Alzheimer’s disease, but some other form of dementia, the caregiver pointed this out to me as well.

Age Range of Caregivers

Ages of the 22 interviewees ranged from 50 to 82. Over 70% were over the age of 60. Thus, at an average age of 66 (SD 8.4), the majority of caregivers were senior citizens. This is significant because it means these caregivers are at greater risk for physical and medical conditions related to aging themselves.

Ethnic Mix of Caregivers

The ethnic mix of the population included 18 respondents identified as Caucasian. The sample was under-representative of other ethnic groups; 3 identified as African American and 1 identified as Hispanic.

The majority of the interviews occurred in the communities of North Dallas and Plano, which partially explains for the predominance of one ethnic group, as it is the predominant ethnic group in those areas. Outreach occurred in many other areas including South Dallas and Duncanville, however, a very limited response occurred in those areas. There were a limited number of Hispanic respondents as well, which could partially be explained by language issues, the investigator speaks English, thus the flyer was English only.

Caregiver Relationship

The 2009 Behavioral Risk Factor Surveillance System (BRFSS) survey found that ADRD caregivers were more likely to be older, female, married, and white as compared to caregivers of those with other medical conditions (Alzheimer's Association, 2010).

The BRFSS survey found that in most cases, children were caregiving for parents.

Spouses acted as caregiver about 15% of the time. However, in my research, the majority of caregivers were spouses.

Figure 1 shows the caregiver's relationship with their loved one with ADRD. Of the 22 interviewees, the majority (64%) of caregivers were spouses. Spouses ranged in age from 55 to 82, with an average age of 68.7 years (SD 5.5). Thus, the caregiving spouses were senior citizens themselves.

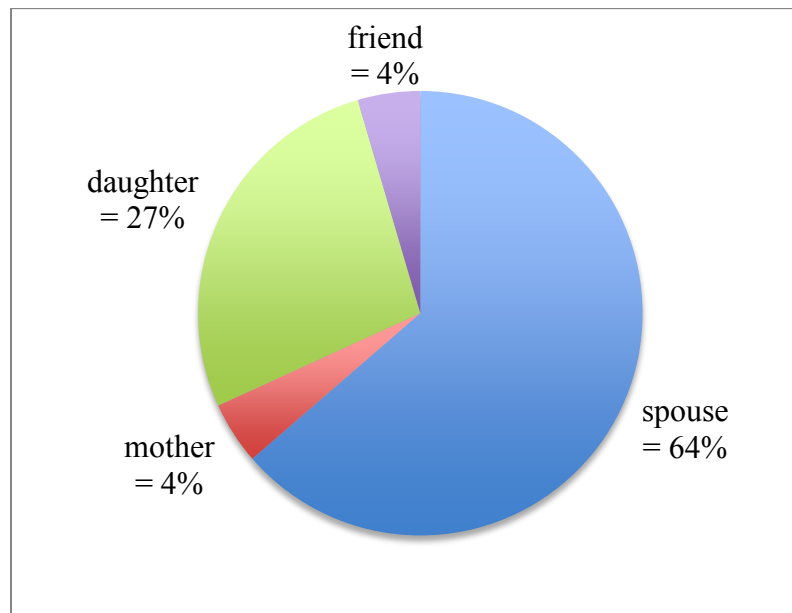


Figure 1. Caregiver relationship to loved one with ADRD (N = 22).

Seniors are often at high risk for illness or frailty due to the numerous chronic conditions that develop (Ferrini & Ferrini, 2008). Providing care to a senior with ADRD was described as physically and emotionally exhausting. Spouses described their numerous roles as caregiver, including monitoring medication compliance, helping with dressing and bathing, and helping with incontinence. They described their responsibility for tasks

that had previously belonged to their spouse, such as bill paying and home repair. They also described the tedious tasks that are required to monitor and protect their loved one from a wandering incident. A number of spouse caregivers described long marriages, with one reporting they had been married for 56 years. The majority of the spouses did not identify as wage earners. Many identified a traditional marriage role.

Over one-fourth (27%) of interviewees were daughters. One daughter indicated she was presently living with her mother on a full-time basis and acting as full time caregiver. A second caregiver stated she was living with her father part-time and sharing caregiver responsibilities with her sisters. Other daughters had different arrangements. For example, two daughters interviewed indicated that they were working outside the home, and one shared caregiving responsibility with her siblings and acted as caregiver on the weekends only. The other working daughter indicated that her mother's condition had deteriorated to the point that she did not feel she could keep her with her at home, and was planning to move her mother to a care facility. These cases are consistent with the research on children as caregivers, and the multiple responsibilities of working, caring for their own families as well as caring for a parent, leading to stress and burden (Street, 2007).

It is interesting to note that daughters represented the primary caregivers in three of the four cases where placement outside the home had occurred. This is consistent with caregiver identity theory which states that the conflict between the prior role relationship (e.g., role of child) and what is now being asked of the caregiver often leads to placement. This is particularly true in the case of a child, who is not ready to assume the enormous responsibility of caregiving for an ADRD patient (Street, 2007).

Two interviewees had unique relationships with the ADRD patient. One caregiver was an elderly mother who boasted that she had just turned 80 years old. She was assisting her son-in-law in caregiving for her 50-year-old daughter who has a diagnosis of early onset dementia. Another caregiver described herself as the best friend and roommate of the ADRD patient; a long-time friendship that became a caregiver relationship when the diagnosis of ADRD was made. She works on a full-time basis and acts as primary caregiver.

Diagnosis

ADRD represents a cluster of symptoms such as memory loss, change in ability to recognize objects, change in ability to execute motor activities, change in ability to think abstractly, and symptoms severe enough to interfere with daily life (Alzheimer's Association, 2011). The Alzheimer's Association provides descriptions of over 10 common types of dementia, noting that the cluster of symptoms often is essentially the same. It is interesting to note the different types of dementia that occurred within the study. Fronto-temporal dementia, early onset Alzheimer's disease, vascular-related dementia, and dementia related to brain injury were present within the population being cared for. While the basic symptoms of these diagnostic categories are included under the umbrella phrase of dementia, each of these categories contains unique behavioral traits as well. Early onset Alzheimer's disease is diagnosed prior to age 65. One care recipient in this study fell into this category; a mother was acting as caregiver for her daughter, who received the diagnosis around age 50. Fronto-temporal dementia

symptoms include personality and behavior change, as well as difficulty with language. It is the exaggeration of the behavioral issues that are described within the interview that concerns the caregiver. Vascular-related dementia occurs due to decreased blood flow to the brain as a result of mini-strokes. It is considered the second most common type of dementia. Moderate head injury is defined as a loss of consciousness or post-traumatic amnesia lasting more than 30 minutes. Moderate head injury is associated with twice the risk of developing Alzheimer's disease, and severe head injuries associated with 4.5 times the risk (Alzheimer's Association, 2012,). Behavioral symptoms such as wandering are exacerbated in fronto-temporal dementia and dementia related to head injury. The increased *acting out* behavior of care recipients with these dementias was found to often have a negative impact on caregiving.

Stage of ADRD

Caregivers were asked to describe their loved one's stage of the disease process. They described mild, moderate, and severe stages; at times stating they had no information in order to provide a stage. The categories were purely descriptive; there was no scale provided to the caregivers to rate the severity of the symptoms. Thus, stage represented the subjective experience of the caregivers. As such, the stage reported may be considered a reflection of burden being experienced by the caregiver. It is interesting to note that the National Institute on Aging and the Alzheimer's Association are recommending a change from a previous 7-step criteria to a 3-step criteria; mild, moderate, and severe. The criterion is based on the physician's judgment, the results of

cognitive testing, general neurological assessment, and a biomarker test. Many caregivers reported that their physician had not indicated a stage; rather, they determined it on their own.

Date of Diagnosis

The diagnosis dates often indicated a point when symptoms became severe enough to warrant some form of medical attention, and ultimately resulted in the diagnosis of ADRD. In many cases, it also signified a time when caregivers became responsible for additional roles and duties. Ten caregivers reported that their loved one had been diagnosed between 2007 and 2012, or within the past five years. Eleven caregivers reported that their loved one was diagnosed between 2001 and 2007, or within the past 10 years. One caregiver indicated that the diagnosis was received prior to 2000. It is significant that over 50% of the sample had been in the caregiving role for five years or longer. National reports indicate that over 32% of ADRD caregivers provide help for more than five years, and the ADRD caregiver tends to provide care twice as long as other caregivers (Alzheimer's Association, 2012).

Data Preparation and Analysis

Transcribing the Data

Transcription of each of the audio taped interviews was a detailed process that involved listening, playing back, and then listening again to make certain of speech intonations. In the final analysis, I listened to the recording again in order to finalize the

text and add appropriate transcription notations such as pauses, interruptions, etc. In all examples presented in the dissertation, “I” represents the Interviewer and C represents the caregiver. An example of a transcription follows:

I: What kinds of things does he do by himself?

C9: He is very rarely by himself, when he is, like right now, he’s sleeping. That’s where I left him, I left him notes . . . if he’ll look. But if he’s by himself, its best to . . . he does like to play solitaire on the computer, or he likes to watch TV. I guess that’s what he does by himself.

I: OK. Has your home changed since the diagnosis?

C9: I guess you would say so . . . conversation is not as spontaneous as it once was, so I guess you would say that it is as far as his taking part in what we’re going to do, or planning what we’re going to do, it’s pretty minimal.

Coding the Data

I began the process of microanalysis of the data while interviewing. This was done by transcribing the data as close to the point of interview as possible; usually transcription occurred within a day of the interview in order to focus on pieces of the data that seemed relevant in order to generate ideas (Strauss & Corbin, 2008). This allowed me to check out the interpretations that were being developed against the incoming data. I would continually ask questions about what the data was showing me, and then make comparisons in order to look at concepts that developed from interview to interview within the data.

I utilized the Atlas TI coding software package to begin the process of coding; that is extracting concepts from the raw data of the interview and developing those in terms of properties and dimensions (Strauss & Corbin, 2008, p. 159). The use of

conditional coding allowed me to look at the data broadly to see what themes were emerging. As I coded, I constantly looked for any potential bias from me; as a clinician with years in the field of aging, I had to be careful not to allow my own beliefs to enter into the analysis.

As themes began to emerge, I utilized the Atlas TI coding software package to develop broad categories of themes within the codes. The coding continued from broad themes such as “wandering incidents” and “safety concerns” into a process of integrating categories around specific core issues such as “relationship style.” I used a strategy for analyzing the data based on the process or flow of interactions and emotions by looking across all 22 interview transcripts and developing predominant themes.

All the time that data collection and coding were occurring, I was writing notes about themes that had emerged, ideas for new codes, similar themes across the interviews, and where the interviews diverged. As themes began emerging from the codes, I went back to the interview transcripts and pulled specific information out of each related to the emerging themes. In particular, I looked for information about what was emerging as the central core category: role change. I deemed it the central core category because it could be related to all other major categories that had developed in the data, it appeared frequently in the data, and it grew in explanatory power as the relationships around this theme developed such as relationship change and situational stressors (Corbin & Strauss, 2008).

Development of Grounded Theory

The coding process resulted in an integrated theory that involved linking these categories around the central theme of role change. I felt that sufficient sampling had occurred because the major theme of role change was developed in a way I thought not only showed a relationship to other categories, but also provided a significant understanding of the concept.

Summary

This research utilized a primarily qualitative approach to examine how caregivers of AD/HD patients viewed wandering behavior in their loved ones. The research aimed to better understand the safety issues of importance for the caregiver, the caregiver's view of the risk of wandering, and the factors that influence this view. The study sample represented a somewhat diverse population of caregivers, with the majority being elderly themselves. In general, however, the caregivers in this study were mostly Caucasian and female and had been providing care for over five years. Through the process of coding the data, looking for themes and then studying specific elements with the themes, one central category emerged. The importance of role change emerged as the conceptual basis of the study. Using the data collected, Chapters 4, 5, and 6 examine various aspects of the impact of role change and its relationship to the caregiver's perception of level of risk of wandering. The concept of role change, and its relationship to past history and present circumstance, is key to understanding the caregiver's perspective on the issue of wandering.

CHAPTER 4

FACTORS INFLUENCING THE CAREGIVER'S PERCEPTION OF WANDERING

While the statistics related to other chronic diseases, such as heart disease and cancer, in the United States show a decline in numbers, those impacted by Alzheimer's disease and related dementias continue to increase. ADRD is the fifth leading cause of death for those over 65 years old in the United States (Alzheimer's Association, 2012). A diagnosis of dementia must include a decline in at least one of the following areas: (a) ability to generate coherent speech, (b) ability to recognize and identify objects, (c) ability to execute motor activities, or (d) ability to think abstractly and make sound judgments (Alzheimer's Association, 2012).

ADRD differs from many other chronic diseases in that the symptoms are cognitive and behavioral. The disease process impacts not only the persons suffering from the disease but their loved ones as well. ADRD means the loss of cognitive function. The ability to carry out normal daily functions and roles changes for the person with ADRD and caregivers are expected to take these roles on.

The Significance of Wandering in ADRD

ADRD brings with it significant behavioral problems. Wandering is considered one of the most dangerous behaviors that can develop. Wandering is a particularly high-risk behavior due the cognitive changes that occur in dementia such as memory loss and judgment impairment (Alzheimer's Association Facts and Figures, 2012). Wandering is

defined as “forays in the community without the supervision of the caregiver” (Rowe & Glover, 2001, p. 344) and can take many forms. The Alzheimer’s Association estimated that 60% of those with a diagnosis of ADRD have had a wandering incident (Alzheimer’s Association, 2010b). Even just one wandering incident can be dangerous. All 22 caregivers interviewed in this study described at least one incident of wandering. Some of the most common that were described in this study were driving, walking around the neighborhood, getting lost at the mall, or leaving home and being unable to get back safely.

There are many behaviors that develop during ADRD that are troublesome, but wandering is particularly dangerous. When an ADRD patient wanders away, they may not remember how to return home. They may not realize that they are in an unsafe situation. Search and rescue data indicate that if a wanderer is not found within 24 hours, there is a high probability that he or she will be found dead (Koester & Stooksbury, 1992).

Caregiving for ADRD

Over 80% of ADRD patients continue to live at home with family acting as caregiver (Alzheimer’s Association, 2012). Caregivers are often reluctant to take action to prevent a wandering incident. Anecdotal evidence suggests that 6 to 8 cases of wandering may occur before the family recognizes that wandering is a serious behavioral issue (Gaines, 2009). Wandering is a primary reason given for placement. Placement is very expensive, averaging \$41,724 per year for assisted living care and \$79,110 to

\$87,235 per year for nursing home care (Alzheimer's Association, 2012). Placement with ADRD is complicated by the need for security to protect from a wandering event. This issue means specialized units that are even more expensive. When private money runs out, Medicaid is expected to cover the cost. Medicaid is expected to spend \$35.5 billion on those with ADRD during 2012 (Alzheimer's Association, 2012). The amount of money spent on care will continue to rise as the numbers diagnosed with ADRD are expected to triple by 2050.

Appropriate intervention in the home can reduce wandering events and keep a loved one with ADRD there. How do caregivers perceive and respond to wandering behavior? This chapter explores these perceptions and responses, as well as the factors that influence those perceptions and responses.

Research Questions

The following research questions guided the analysis. How have things at home changed since the loved one's diagnosis? What was the caregiver's level of concern about the safety of their loved one? Did he or she worry about their loved one getting lost? Had their loved one gotten lost? How many times? Where? What happened? How did wandering affect the caregiver? What were the factors that impact the caregiver's perception of wandering? How had a wandering event acted as a catalyst for change by the caregiver? Had placement of their loved one outside the home been considered? Was wandering behavior considered a primary reason for placement outside the home? How likely was the caregiver to use various home-based interventions, such

as child-proof door-knob covers, a personal tracking device, etc., to protect a loved one from the negative consequences of a wandering event? Why or why not?

What were the issues and concerns that shaped their perception of Alzheimer's disease, and the negative behaviors associated with it such as wandering? What was the relationship between caregiver and ADRD patient? What were the stressors that impacted the caregiver's role with their loved one? The instruments (i.e., interview schedule and self-reported home modification questionnaire) used to collect the data to answer these questions are provided in Appendices A and B. The consent form and related documentation is found in Appendix C.

Theoretical Bases

Concepts from several theories contributed to an understanding of how family caregivers of a loved one with ADRD perceived their caregiving role and how it was impacted by wandering, a particularly troublesome behavioral symptom associated with the disease. The concepts were drawn from both macro-level and micro-level sociological theories. For example, life course theory provided a macro-level sociological perspective to help us understand how lives are structured given the constraints of society combined with individual history (Street, 2007). Micro-level theories are often similar to psychological theory in their focus on the individual experience (Street, 2007). Micro-level theory helped explain how the caregiver views behavior change through their unique approach to aging, and their perception of healthy

aging. In common with life course theory, some micro-level theories view aging as a continuation of previous roles and lifestyle.

For example, continuity theory provided a social psychological perspective that described aging viewed through the personality traits that developed in middle age that are expected to continue into old age (Street, 2007). Skills, activities, roles, and relationships developed in middle age are also expected to continue as the elderly person adapted successfully and extended those skills, activities, roles, and relationships into old age. Earlier life experiences are expected to create coping strategies that can lead to adaptation of changing circumstances (Street, 2007). The caregiver is expected to cope with the disruption brought on by ADRD in their loved one using strategies that were developed and successfully utilized in the past.

Disengagement theory highlighted the disruption that the ADRD diagnosis brings. One tends to become disengaged from usual roles and activities with the occurrence of a crisis, disruption, or *pathological change*. ADRD is such a disruption, because it impacts skills, activities, and roles, because of the cognitive decline that occurs. Disengagement is viewed as dysfunctional.

Caregiver identity theory provided an understanding of caregiving as a process involving change in relationship and increasing responsibility for care activities, which results in a change in the caregiver's identity (Montgomery et al., 2007). Caregivers tend to experience tension when they are forced into caregiving activities that are "inconsistent with their views of self" (Montgomery et al. 2007, p. 441). The role of caregiver has its initiation in the existing role relationship, the role that has developed over the years, and

involves such roles as wife, husband, mother, daughter, and friend. The initial relationship is forced to give way as the needs of the care recipient increase. Care tasks are often out of alignment with the previous and familiar role, causing tension and frustration. With ADRD, the shift is often severe because of the enormity of behavior change and level of dependency. The role of caregiver emerges and transforms the relationship, often with negative consequences.

Caregiver identity theory describes five phases that typically accompany the family caregiving role (Montgomery et al., 2007). During the first phase of role onset, the caregiver is not aware that role change is occurring. During the second phase, caregivers are doing things that go beyond their normal familial role. In the third phase, the caregiver assumes the predominant role in the relationship, and significant role change occurs. In the fourth phase, caregivers often consider placing their loved one in a nursing home as they question the enormity of their new roles. In the last phase, such placement occurs, and there is a shift in identity among caregivers back to their preferred identity before caregiving.

As the family caregiver progresses through these five stages, “tension develops between caregiving tasks and personal identity standards” (Montgomery et al., 2007, p. 442). Sales (2003) describes the tension as burden, and relates the level of burden to environmental factors and the caregiver’s emotional experience in coping with the disease process. The level of caregiver distress can be moderated by many factors, such as the level of cognitive and behavioral impairment, prior relationship, and the physical and social environment in which they live.

The Role of the ADRD Caregiver

The Alzheimer's Association (2012) reported that over 15 million Americans provide unpaid care for a loved one with ADRD, and 80% of care at home is provided by family caregivers. The 2009 Behavioral Risk Factor Surveillance System (BRFSS) survey found that caregivers of ADRD patients were more likely to be older, female married, and white (Alzheimer's Association, 2012). Caregiving tasks include:

Shopping, preparing meals, driving; helping with bill paying; helping with such personal activities as bathing, dressing, grooming, feeding and bathroom issues; managing safety issues, such as mobility needs and supervision to avoid unsafe activities; finding and using supportive services; hiring and supervising those who provide care; and performing household chores. (Alzheimer's Association, 2012)

The BRFSS survey found that a family caregiver of an ADRD patient is more likely to assist with activities of daily living (e.g., bathing, dressing, etc.) than were caregivers of loved ones with other health problems. The caregiver of an ADRD patient also tends to provide care for a longer period of time than caregivers of older adults with other conditions. Along with the cognitive decline of the ADRD patient were significant behavior changes that were often dangerous, embarrassing, and socially stigmatizing. Caregivers become increasingly responsible for the safety of their loved one, whose behavior is often erratic.

The impact of caregiving for an ADRD patient means increased levels of supervision and assistance, which have been found to be related to high levels of stress. Nationally, 61% of family caregivers of an ADRD patient rated their stress level as high or very high, and 33% reported symptoms of depression (Alzheimer's Association, 2012). The impact of this high level of stress has other negative outcomes for the

caregiver. For instance, caregivers of an ADRD patient were more likely to report their health as poor or very poor (Alzheimer's Association, 2012).

Factors that Impact Caregiver's Perceptions

When considering the caregivers' perception of a difficult behavior such as wandering, it is impacted by many factors such as prior role relationship, availability of supports, and perception of burden. Burden is a reflection of physical, psychological, and emotional factors such as perceived deterioration in personal and social life, embarrassment and anger at a loved one's behavior, and a decrease in emotional support (Ankri et al., 2005).

Another factor influencing the perception of burden is the long trajectory of the disease process. Estimates of the prognosis range from 2 to 20 years, the longest stage is often described as the middle stage, the time when cognition continues to decline and negative behaviors escalate. The length of illness is combined with the aging process of the caregiver, who has less physical and emotional resources available to assist their loved one in an effective manner.

Caregivers are forced to deal with both the cognitive and behavioral changes in their loved one while coping with the loss the relationship they once knew. In her book *The Long Goodbye*, Patti Davis (2004) stated that Alzheimer's disease continues along a downward trajectory as cognitive functioning and behavior continues to deteriorate. The caregiver is grieving the loss of a relationship. But the loss is often multiplied as many other relationships are also impacted. Friends disappear as their loved one is no longer

able to function as before. Family relationships are impacted; some that were strained become further strained, some family members refuse to provide support because they deny that the disease exists.

The caregiver of an ADRD patient is unique in the complexity of their role. As Davis (2004) and others have discussed, they are forced to deal with immense psychosocial pressures such as their own adjustment to their loved one's disease. Their loved one is forced to give up their preferred lifestyle as well. This adjustment in their roles often brings resentment and anger for both; cherished roles and responsibilities are relinquished and the caregiver resents the additional work. The caregiver also becomes responsible for overseeing the medical aspects of the disease, along with increased frailty and other physical concerns. Prior relationships with family and friends are impacted; friends do not know how to cope with the cognitive changes and often disappear. Financial pressures mount. Lifestyles change in various ways. The ability to provide care is impacted because the caregiver is often elderly as well. Caregivers are forced to give up many of the leisure activities that they have enjoyed in the past in order to supervise their loved one's behavior. They take on roles that they often do not understand and do not want to be responsible for, those that their loved one was responsible for previously. The world that they have known is suddenly changed and they struggle to adjust at a time when resources to deal with change are often at a minimum.

This dissertation study specifically examined the caregiver role and wandering, which is considered one of the most difficult behaviors that the caregiver of an ADRD

patient has to deal with. It sought to understand how caregivers perceive their role as it relates to this behavior.

The Issue of Home Safety

One of the aspects of universal concern to the family caregivers in this study was home safety. Since ADRD is progressive and erratic, changes in abilities and, thus, potential safety problems can develop rapidly. Caregivers are often advised by medical professionals such as physical therapists and occupational therapists to adapt the home environment with an eye for potential safety risks (Doraiswamy & Gwyther, 2008). Almost all of the caregivers interviewed in this study focused on making their homes “safe.” There were many reasons that home safety held importance for the family caregivers in this study. A major concern was balance problems and the risk of falling. This concern is based in reality, as the majority of accidental deaths among the elderly are the result of falls (Ferrini & Ferrini, 2008). Increased risk of falling is associated with a number of factors, including such cognitive issues as memory loss, poor judgment, and disorientation (Ferrini & Ferrini, 2008), which are typical symptoms of ADRD.

Safety Concerns

When asked about concern about safety at home, caregivers verbalized numerous issues during the interviews:

- Smoke alarm went off . . . sparks were flying
- Cooking and ironing

- Falling and unable to get up
- I don't know if she would know what to do if there was a fire in the house
- Slipped in the shower
- Knives
- She can't stand up
- There is a tendency to go to the door and look out
- Getting into pills

Twenty of the 22 caregivers interviewed stated that they had modified their homes due to safety concerns. The caregivers made numerous physical changes, including: rugs were picked up, fire alarms were installed, shower bars and chairs were added, and their loved one was no longer cooking.

Wandering as a Safety Concern

Along with home safety, concern about wandering suggested an increased need for monitoring and supervision when their loved one is out of doors and away from the care giver. Confusion occurs even in familiar areas, and can lead to a wandering event.

Evaluation of the home for potential safety risks is discussed in the literature. Safeguards to protect against wandering should be installed before wandering occurs.

The National Institute on Aging (2010) suggests the following:

- Install secure locks on all outside doors
- Place locks high or low on exit doors so they are out of direct sight
- Use a loosely fitting doorknob cover

- Secure the yard with fencing and a locked gate
- Use a door alarm that rings when doorknob is touched
- Divert attention away from using the door by camouflaging
- Use medical identification bracelet that notes Alzheimer's disease on it (p. 8)

Had the caregivers in the study sample ever considered these home modifications? If they were not aware of these, would they consider using? A short paper-and-pencil questionnaire was provided to each interviewee that suggested these eight different potential home modifications related to reducing wandering behavior. The caregiver was asked to indicate how likely, on a 10-point scale from 1 = *not likely* to 10 = *in place*, they would be to consider each of these home modifications. Responses from the 21 interviewees who filled out the questionnaire are described below.

Use of Home Modification Devices

Figure 2 depicts the likelihood of using a simple home modification by caregivers: enclosing the yard (mean 7.0, *SD* 4.0, median 10.0). This modification is a protection for a wanderer, and also provides some independence. About one-half (52% or 11 out of 21) of the caregivers interviewed stated their yard was enclosed. But it is interesting to note that 33% of the caregivers indicated that they were not particularly interested in implementing this protection.

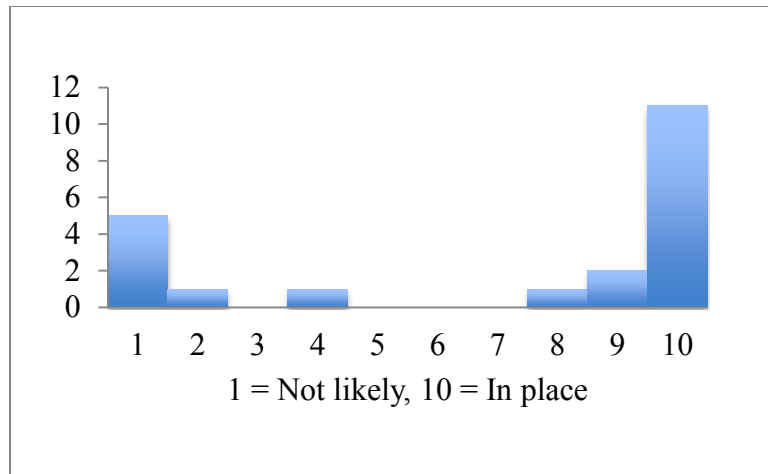


Figure 2. Likelihood of enclosing the yard ($N = 21$).

Figure 3 shows the likelihood that the caregivers in this study would be willing to lock their gates to protect their loved one (mean 6.2, SD 3.7, median 6.0). While nearly one-half (48% or 10 out of 21) of caregivers either already locked their gates, or expressed a strong willingness to lock their gates, again it is interesting to note that 33% (7 out of 21) expressed an unwillingness to intervene in this way.

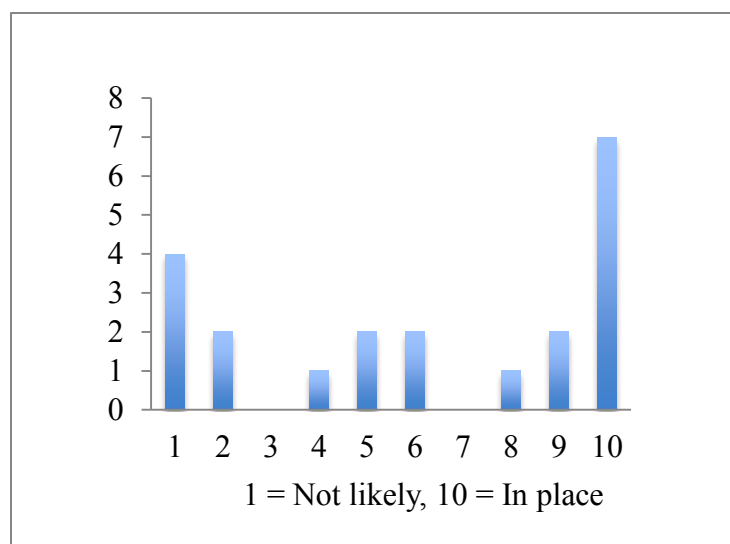


Figure 3. Likelihood of locking gates ($N = 21$).

Figure 4 depicts the likelihood of the caregivers to install door chimes (mean 6.7, *SD* 3.5, median 8.0). Door chimes can be useful because they alert the caregiver when the door opens so they can appropriately monitor where their loved one is, or if they need to take action because their loved one has gone out the door. While this is not something commonly found in the home, door chimes are inexpensive and easy to locate and install. Many caregivers indicated they might consider installing door chimes as a protection, however nearly one-fourth (24% or 5 out of 21) of the caregivers interviewed indicated that installing the chimes was not something they would likely do.

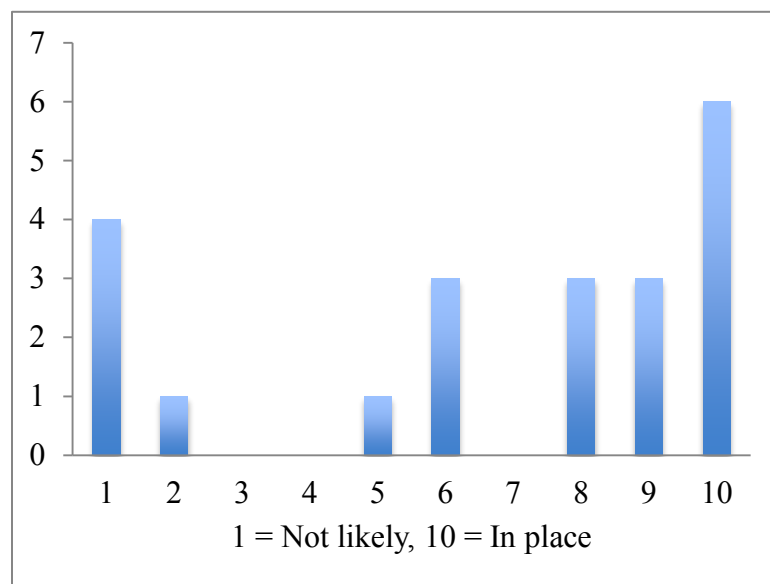


Figure 4. Likelihood of door chime ($N = 21$).

Figure 5 presents the likelihood of caregivers installing child-proof knobs. As the figure shows, on average, the caregivers interviewed expressed unwillingness to take this precaution (mean 4.8, *SD* 3.2, median 6.0). Despite the fact that child-proof door knobs can help decrease wandering incidents, as is much more difficult to open the door, very

few caregivers used them or were willing to install them. Indeed, 38% (or 8 of 21) caregivers interviewed indicated they were not likely to use them.

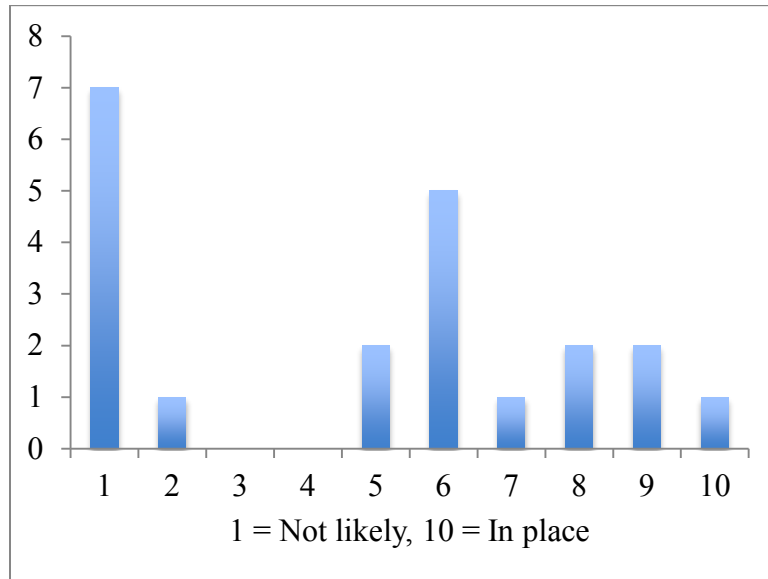


Figure 5. Likelihood of installing child-proof door knobs ($N = 21$).

Figure 6 depicts the likelihood of caregivers camouflaging the doors in their home (mean 3.5, SD 2.8, median 2.0). By painting the door so that it blends in with the rest of the room, or by installing a curtain in front of the door, wandering incidents can be reduced, as the patient with AD/DRD does not recognize that the door exists. As Figure 6 shows, the majority of caregivers expressed unwillingness to camouflag the doors in their home. Over one-half (57% or 12 out of 21) of the caregivers interviewed indicated that they were quite unlikely to do so. Only one caregiver already had this intervention in place.

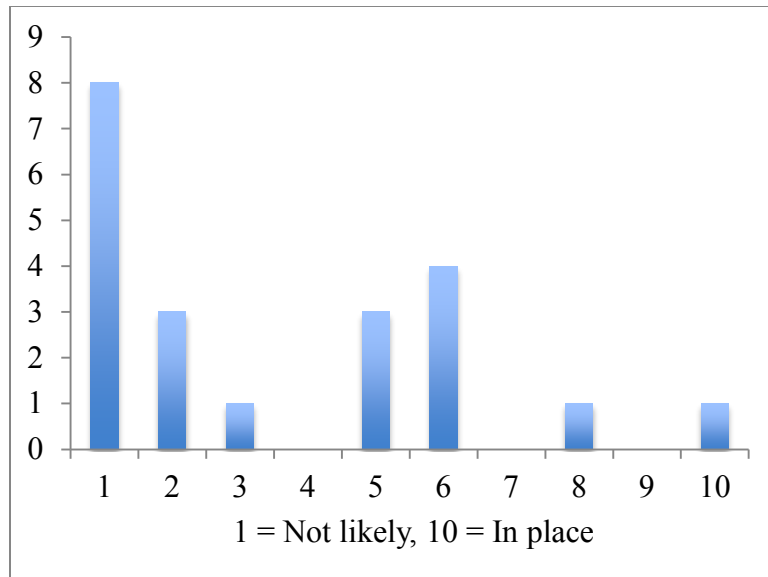


Figure 6. Likelihood of camouflaging doors ($N = 21$).

Figure 7 presents the results of the question regarding the likelihood of using the medic alert/safe return bracelet (mean 8.0, SD 2.4, median 9.0). The identification bracelet is worn by the ADRD patient and contains a code that can be utilized in the case of a wandering event. Since this intervention is widely discussed in the Alzheimer’s Association literature and many of the caregiver interviewees were related to the Alzheimer’s Association, most had probably heard about the device. Indeed, 38% (or 8 of 21) of the caregivers interviewed had purchased and used the identification bracelet system. However, men often expressed resistance to the use of a “bracelet,” thus one caregiver stated she had purchased a “dog tag,” which included her husband’s name, address, and phone number, that he wore at all times. Cell phones were also described as a common method of communication that was easily accessible and worked over a wide area. Two respondents indicated their loved ones carried cell phones. While the cell phone is often used to aid an elderly person to obtain support when needed, it is

sometimes ineffective because the person may not remember how to use it. One caregiver indicated just such concern, stating she did not think her loved one understood how to use the phone.

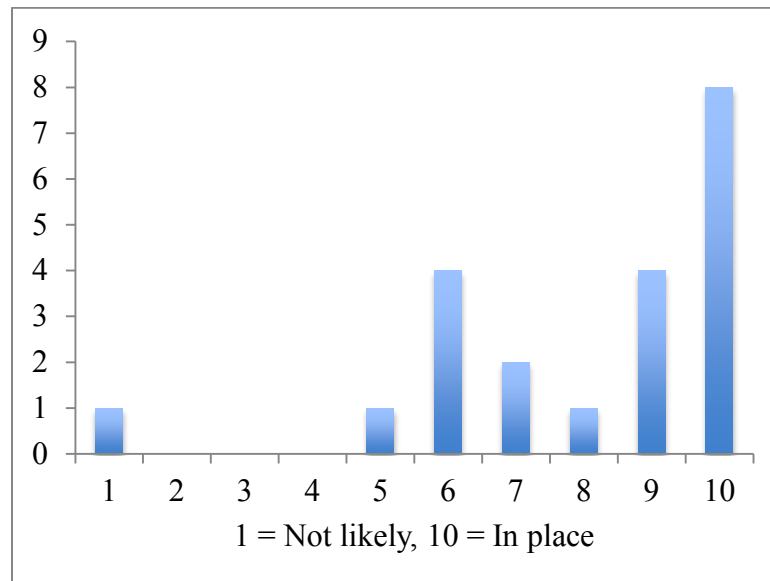


Figure 7. Likelihood of medic alert/safe return ($N = 21$).

Figure 8 presents the results of the likelihood of purchasing an electronic tracking device (mean 6.3, SD 2.8, median 7.0). Technology is quickly providing additional security to the caregiver. The tracking devices use the same networks that provide GPS technology and 911. The tracking devices can be utilized to monitor behavior at home or away from home. These devices allow the caregiver to keep track of their loved one or help locate their loved one if missing. While the majority of the caregivers interviewed stated that they would consider purchasing an electronic tracking device, only 2 had already done so. It is interesting to note that often caregivers indicated that they were not aware of this technology or its effectiveness in providing support.

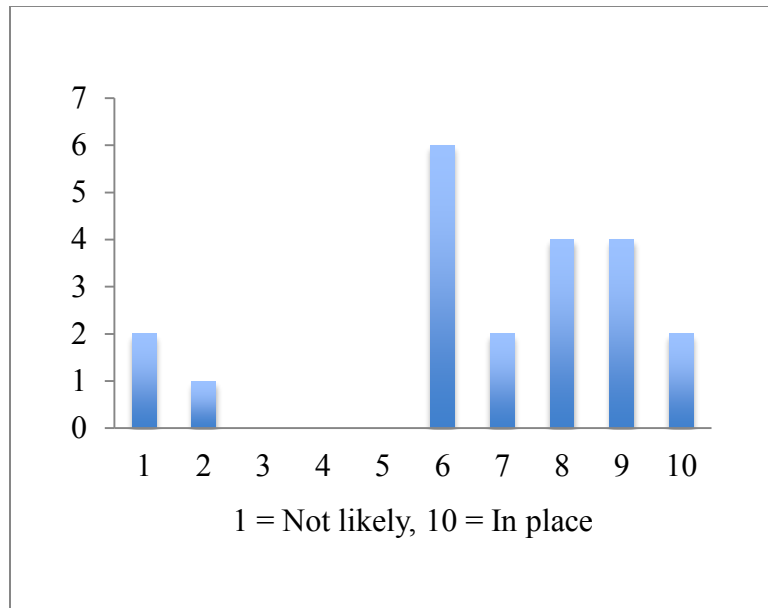


Figure 8. Likelihood of purchasing tracking device ($N = 21$).

Summary

36-Hour Day is a book that has been highly acclaimed as providing easy to understand interventions for caregivers of ADRD (Mace & Rabins, 2006). In this book, Peter Rabins, M.D., discusses environmental changes that are relatively low cost and can provide extra protection against a wandering event (Mace & Rabins, 2006). He suggests that caregivers consider the past behavior of the person with ADRD, and he acknowledges the stress caused the caregiver by constant surveillance (Mace & Rabins, 2006). He suggests there are five categories of devices: (a) things that lock up the home, (b) things that keep the home safe, (c) things that alert the caregiver, (d) things that allow communication, and (e) things to help if a wandering event occurs (Mace & Rabins, 2006, p. 127).

While caregivers in this study were relatively willing to utilize basic safety procedures; the survey data indicates a reluctance to safeguard their homes from a wandering event. There are many potential reasons to explain this reluctance: past behavior had not led the caregiver to concern, denial of the behavior, reluctance to take away their loved one's independence, discomfort using a device that is perceived as deceiving their loved one, and shame that such physical changes would indicate the seriousness of the potential threat of wandering. However, their reluctance to adequately address these safety issues increases the threat of a wandering incident.

Wandering: Significant Problem for Caregivers

This study was undertaken because of the severe consequences of a wandering event when related to ADRD. Wandering has been acknowledged in the literature as being one of the behaviors that commonly develops with the diagnosis of ADRD. When a cognitively impaired person gets lost, they often do not know how to get back home or remain safe. If a wanderer is not found within 24 hours, the probability increases that they will be found seriously hurt or dead (Alzheimer's Association, 2010b).

What is Wandering?

As defined earlier, wandering is a "foray . . . in the community without the supervision of the caregiver" (Rowe & Glover, 2001, p. 344). Wandering can take many forms. Some of the most commonly reported by the caregivers in this study were driving, walking around the neighborhood, getting lost at the mall, or leaving home and

being unable to get back safely. How did the caregiver perceive wandering behavior? What actions were taken to protect their loved one from a wandering incident? The caregiver's perception of wandering was complex and related to the myriad of terms used to describe wandering, the perceived level of concern that wandering might occur, past wandering behavior and the outcome of the wandering incident, the caregiver's perception of their loved one's right to independence and autonomy, and the amount of support they received. Wandering has been described as appearing as simple behavior, but when related to ADRD it is a complex behavior "a multifaceted pattern of human activity...a fascinating and elaborate behavior that is difficult to define" (Algase, Moore, Vandeweerd, & Gavin-Dreschnack, 2007, p. 686). The Algase et al. (2007) study included a meta-analysis of 183 journal articles. Multiple databases were reviewed and a conceptual map of wandering was developed. Their review found that while "locomotion was always present, the degree of awareness attributed to the wanderer differed" (Algase et al., 2007, p. 689). In another study, researchers interviewed 29 caregivers and 9 typologies of wandering behaviors emerged:

- Checking/trailing: subject seeks whereabouts of caregiver; an extreme form of checking in
- Pottering: Attempting to carry out household tasks in an ineffective way
- Aimless walking: Walking with no evidence of purpose
- Walking directed towards inappropriate purpose: Walking appears to directed purpose, but the purpose is inappropriate
- Walking directed toward an appropriate purpose, inappropriately frequently: Walking is directed toward an appropriate person with inappropriate frequency
- Excessive activity: On the move excessively

- Night-time walking: Walking inappropriately at night
- Needs to be brought back home: Has been brought back home at least once
- Attempts to leave home: Attempting to leave home, but prevented by caregivers (Hope & Fairburn., 1990, p. 241)

Another study examined the professional caregiver's perception of wandering versus the family member's perception, and found that the family caregiver was much more likely to allow wandering to continue, as they valued independence for their loved one over harm reduction (Robinson et al., 2007, p. 395). The complexity of the behaviors that fall within the category of wandering tends to be underestimated by the caregiver (Hope & Fairburn, 1990).

I have borrowed aspects of Hope and Fairburn's (1990) typology to classify the wandering behavior that caregivers described during the interviews. In Table 1, the behaviors are classified under three categories: aimless walking; walking directed toward an appropriate purpose, inappropriately; and needs to be brought back home. The most frequent was the second category, walking directed toward an appropriate purpose, inappropriately.

As noted earlier, "family caregivers try and find a balance between autonomy for their loved one and his or her independence and protection" (Robinson et al., 2007, p. 394). The caregivers interviewed in this study justified their loved one's independence by denying the seriousness of their loved one's behavior:

The only place she would half-way get lost . . .

Because he was turning at the wrong streets. He wasn't lost, he was just turning before he should have to go home . . .

I know that's a directional thing, so there's some evidence of lostness, but not in the usual sense of he goes and wanders and can't get back home . . .

Table 1

Classification of Reported Wandering Behaviors Using Hope and Fairburn's (1990) Scheme

Category	Behaviors
Aimless walking	Lack of recognition of familiar objects
	Leaving the store and crossed the parking lot; rescued by a stranger
Walking directed toward an appropriate purpose, inappropriately	Lack of recognition of familiar objects
	Leaving the store and crossed the parking lot; rescued by a stranger
	Getting on elevator to leave a building because he felt he had been forgotten
	Getting on the wrong elevator and not knowing where he was
	No longer understanding directions to specific locations
Needs to be brought back home	Taking the wrong train and being found in another city
	Trying to walk home from a strange location
	Going to unfamiliar place, became confused and walked away; lost for two hours
	Trying to walk home from a strange location
	Not coming back from a walk when he should
	Taking the dog for a walk and not knowing where he is and how to get home

Further complicating this important issue of autonomy versus protection from harm was the diversity of the disease processes that fall within the umbrella term of dementia. Each type of dementia presented with different behavioral symptoms. Consequently, caregivers often differed in their struggle with the potential risk versus the

freedom and autonomy that is at stake. Fronto-temporal dementia often involved behavior problems. While one caregiver interviewed described behavior problems, she felt he was safe to walk on his own:

I: OK. Has he ever gotten lost?

C20: No.

I: OK, so he goes out on walks by himself, and he can find his way back home?

C20: ALWAYS.

I: Always . . . and there's just never, that's just not what impacts . . .

C20: In the books, in the books, that's just not an issue for him.

She stated that the definition of fronto-temporal dementia does not include wandering as problem behavior. However, she expresses concern about his behavior while walking:

I was worried about . . . you know he loves flowers, absolutely adores flowers, so that's what he goes for a walk for, to see the colors and so I could just imagine a few years ago, him going up to somebody's front doorstep to see the flowers, and getting accused of being a peeping Tom or trying to play ball with a child, and getting accused of something else . . .

These behaviors were serious and potentially dangerous, and represented the challenge that caregivers face. What is the risk level of the behavior that their loved one exhibited? In the face of dangerous behaviors, the threat level of wandering may seem low.

Driving and ADRD

Driving can be dangerous for not just the person with ADRD, but the public at large. Driving becomes troublesome for seniors due to changes in eyesight and reaction

time (Carr et al., 2009). Even symptoms of mild ADRD have been found to be associated with worse performance on such driving measures as collision avoidance, and impaired visual reaction times (Frittelli et al., 2009). Driving cessation is particularly difficult because it means a loss of independence and autonomy for seniors. Often the task of driving cessation is complicated by ADRD itself; the discussion occurs with people who are cognitively impaired and often lack the judgment to understand the need to stop driving. According to one study, nearly 30% of cognitively impaired adults continue to drive (Kennedy, 2009). In fact, in about 60% of cases, “caregivers stated that they were unable to discuss their concern about driving issues prior to the cognitively impaired driver having an accident” (Kennedy, 2009, p. 19). There were many unsafe driving incidents that caregivers in the sample for the dissertation described during the interview process:

- Getting lost on the way to a doctor’s appointment, and being lost for 22 hours
- No longer understanding directions to specific locations
- Driving on the wrong side of the road
- Multiple car accidents
- Getting off at the wrong exit while driving
- Taking unsafe chances while driving

Kennedy (2009) talks about the increased psychological and practical burdens when driving is given up; the caregiver becomes responsible for yet another task; driving. “Concerns for safety trump autonomy when the circumstances are extreme” (Kennedy, 2009, p. 20). Yet, there were also legal and financial issues that may develop in the case

of unsafe driving. The concern about the potential legal issues as well as increased recognition regarding safety issues impacted many caregivers interviewed for this study to act. Many of the caregivers, such as Caregiver 2, used a driving event as a catalyst for change:

We had many conversations, and he was very resistant because he said he knew he was still a good driver and he had never had a ticket, which was true. And so I said well, we'll just keep watching it, and we will get to a point when I will say this isn't a good idea anymore. And in my head I thought, if he gets a ticket, if he gets in an accident, if there are any unexplained scratches, dents, dings on the car that will be the day that I say we just can't do this anymore, and that's what happened. I was getting out of the car, and I noticed that "Oh gosh, there's a big scratch on the side" . . . I said to him, "you know it's time." As I say he was . . . he didn't want to, he said he didn't think it was fair, he said he didn't think it was time . . . but he did. And I was fairly lucky because that's all it took.

Caregivers often use such professionals as the family physician to intervene when dementia prevented a realistic assessment of the risk (Kennedy, 2009, p. 19). Caregiver 8 described using the physician to assist her in initiating role change related to driving:

. . . He was still driving and he was not coming back, and he was not coming back, and we could not reach him, and I called the police, and . . . and they found him right away, he had no idea where he was, he was all the way down at SMU, but fortunately he had just stopped on the side of the road down there, and they sent an SMU security office over and he stayed with him until the Dallas police came, and they escorted him. That's when I instigated the appointment with the neurologist. You know I called the office and they said, oh, the next appointment isn't for four, five months, and I said no, you need to see him now . . . my husband . . . it's dangerous, he cannot be driving and I can't be the one to tell him.

The Impact of Burden on Caregiving

For most caregivers, the interview question "In what ways is it harder at home?" was their opportunity to describe the behavioral issues that had developed and their emotional reaction to changes. The concept of burden encompassed both the physical

and emotional components of caregiving. Table 2 below lists the objective and subjective aspects of burden that the ADRD caregiver is likely to experience.

Table 2

Sales (2003) Dimensions of Caregiver Burden

Category	Dimension
Objective Burden	Direct tasks of care
	Indirect tasks
	Effects of caregiving on other aspects of life
	Family interaction
	Family routine
	Leisure
	Work/employment
	Mental Health
	Physical Health
	Social network
	Others outside household
	Children
Financial consequences	
Subjective Burden	Personal reactions to caregiving
	Distress
	Stigma
	Worrying
	Shame
	Guilt

Note. Adapted from Schene et al., 1996

Many of the issues described by caregivers were aspects of burden, and impacted the caregiver's perception and level of concern regarding wandering. These factors included prior role relationship, long-distance caregiving, the availability of formal and informal supports to assist with their loved one's care, financial concerns, employment

issues, relationship with extended family members, history of past wandering events, and perception of their loved one's right to independence and autonomy.

Additional household role responsibility has been found to mean less available time for other activities that were important to the caregiver (Montgomery et al., 2007, p. 426). Caregiver 3 described one aspect of burden, the additional responsibility:

I: You're now doing everything?

C3: I have to cook, wash the clothes, wash the dishes, make sure she takes her pills, make sure she gets dressed, make sure she gets in her night clothes, make sure she takes her medicines, all of that . . . in terms of what I have to do, yes . . . I have to do more, and she needs . . . it's gotten to the point that she needs a lot more direction . . .

The caregiver's past relationship with the care recipient impacted the ability to cope with role change. Caregiver 2 described the impact of prior role relationship: "Well, we have been married 50 years this year, and so I don't even think of myself as a caregiver (laugh) . . . I am just his wife."

When caring for a parent, one family member takes on the primary role of caregiver. Daughters are twice as likely as sons to be primary caregiver (Street, 2007).

Caregiver 6 recognized her mother's behavior was dangerous but taking action was complicated by long distance:

I have been a full time caregiver for my mom for 10 years long distance, so many hospital visits and back and forth from Dallas to F, Dallas to F, more in the last five years, in the last three years increasingly more.

Caregivers reported from 1 to over 25 prior wandering events. In many cases, the wandering event precipitated change in the household, but not always. Caregiver 3 described her reluctance to further reduce her loved one's freedom and independence:

He did get lost a couple of times when he went a different route . . . he did go on a walk by himself yesterday . . . I was real busy and he said “I just want to go on a walk around the block” and I said OK . . . and I always watch how long he’s been gone, and I think he went around the block twice and it was fine . . . and I wasn’t real worried about that but I do worry about it . . .

Has Placement Been Considered?

Placement is often described as a common outcome of the severe behaviors associated with ADRD such as wandering. While some caregivers mentioned the possibility of placement, it was only randomly discussed and described as a last resort.

Caregiver 3 described the discussion regarding placement that she and her loved one had:

But that’s the last option for me, we had talked about it, we had long term care insurance because of our family history, but he said with tears in his eyes, I don’t want to be a burden to you, which is what other family members have said, and I said I understand that. I said I just don’t know what I’m going to be able to handle, but if the wandering starts, and I don’t think I can manage it with whatever means are available, to keep him safe, I would place him to keep him safe.

Caregivers considering placement described feelings of loss and failure at the prospect of placement. Caregiver 6 talked of the guilt she is feeling about her decision to place her mother:

. . . My family has told me it’s time to place her. I don’t want to. She’s my mother and I would take care of her until her last day. And if I lived on my island, I would take care of my mother until she died, but I have people who don’t want to do that with me . . . She does not want to be placed . . . it’s going to be brutal. Since I’m a little girl, she’s told me I will never let you leave me at a place like that, and now I can’t do that . . . In a perfect world, in her demented place, I wouldn’t want this to happen until she didn’t know me anymore. . . .

Four of the interviewees had placed their loved one, stating physical frailty and falling, not concern about a wandering event, as the reason for placement.

Support for Caregivers

The availability and use of formal and informal supports also has impact. Respite care services such as adult day programs, hired caregivers, family who are available for respite support are additional factors. Caregiver 10 talked about her need for additional support and the difficulty in getting it from friends who have other obligations and often do not understand ADRD: “I wish I had more support, definitely, to be able to call up a friend and say hey...but most of my friends are married, you know. They are not familiar with the disease.”

A number of caregivers described extended family relationships. Many had children who they described as supportive, but lived out of town, or had their other family obligations, such as a child or a job, that were a priority. While the family was supportive, they were often not available to help in the ways that caregivers needed. Caregiver 2 described her sadness that family has not been more supportive:

We moved here at the invitation of my daughter . . . she called and said why don't you and dad think about moving here . . . I'm home you can get to know my kids better, its less expensive here . . . So we made the decision to move . . . and it hasn't turned out the way we had hoped . . . I think part of it is remaining baggage for her childhood and the relationship that she and I have had, and part of it was she really didn't think about what she was asking and she was thinking that the fact that we were in close proximity was good, but it really hasn't done much if she isn't there. . . .

Research indicates that caregivers who used formal support services for respite were able to continue in their caregiving role for a longer time period (Montgomery et al., 2007, p. 433). Such services as home health services, adult day care, education programs, and counseling assisted the caregiver with both physical and emotional

support. Many of the caregivers interviewed for the dissertation used adult day programs and help in the home. Caregiver 12 talked about the use of adult day programs:

I found Friend's Place because I realized that I couldn't be with him 24 hours a day 7 days a week all the time, so I knew I had to find some place that would be safe for him to be when I had to do something else. The main thing was to realize that he had to be protected.

Many of the caregivers interviewed stated that they attended support groups.

Some of the benefits of support groups included education, companionship, discussion of common experiences, and ideas about care strategies that worked for other caregivers.

Caregiver 8 described her experience at a support group:

Partly it's just being with people who are going through what I'm going through, so not feeling as alone and then just information wise, different people sharing what they've seen and they're trying to do and so forth . . . it just gives little hints . . . things that would panic me before . . .

The need for education about specific disease, care skills, and behavior management is particularly important for the caregiver who wishes to keep their loved one at home (Montgomery et al., 2007, p. 435). I asked caregivers where they received education about the disease. They stated such resources as books, on-line searches, support groups, and adult day programs. In most cases, doctors did not provide information about either the disease process or services within the community. Caregiver 10 described the difficulty she had in receiving information:

I: Did you receive information about the disease?

C10: Not . . . with the mild cognitive impairment, none, and my husband has had a geriatric doctor for a number of years, and none there, which is why I finally found a neurologist because I felt that I had to have more information about what was going on, and what to expect and what I needed to do, and from that doctor I did get some more, but I would say

most of my information has come from Friend's Place and the support group.

Summary

During the 22 interviews, family caregivers described cognitive, affective, and behavioral changes in their loved ones that impacted all aspects of their daily lives. They described changes to their homes because of safety concerns, their experiences with wandering and driving behaviors, and the increased burden they experienced because of the diagnosis of ADRD. Caregivers interviewed in this study perceived wandering in terms of the new role in the relationship with their loved one. The perception of role change is reflective of their prior role relationship, financial concerns, employment issues, availability of informal supports, such as family and friends, and formal supports to provide respite. Chapter 5 further discusses the issue of role change as its centrality to the family caregiving experience.

CHAPTER 5

THE IMPACT OF ROLE CHANGE ON THE ADRD CAREGIVER

The willingness to accept increased responsibility and take on additional role responsibility was a key determinant in how caregivers perceived the issue of wandering. Caregivers who acknowledged behavior change in their loved one and their need to become pro-active for their loved one's safety were much more likely to increase both the monitoring and additional supports. Previous role relationship was an important factor impacting the caregiver's ability and willingness to assume additional role responsibilities. Access to both formal and informal supports such as respite services was also an important consideration. Other important issues that impacted role change were financial concerns, employment issues, long-distance care giving issues, family support/conflict, and denial or minimization of the severity of the behaviors.

Role Change Defined for ADRD

The caregivers interviewed for this study became responsible for many of the household tasks and responsibilities of their loved one. Disease progression and declining cognitive status often led to problematic behavior, further impacting role change. The willingness to accept increased responsibility and additional roles was a key determinant of successful role change. Role change was described by a daughter acting as caregiver for her mother: "I think in my life, in my 50 years this is my biggest challenge, THIS is my challenge and it will be until she dies . . ."

Theory Related to Role Change

Life course theory is useful in describing the adaptation of the family caregiver's behavior which is being impacted by his or her own aging process as well as coping with the disease process of their loved one. One study found that caregivers were likely to maximize gains and minimize losses through compensation designed to maintain desired levels of functioning for both the caregiver and the ADRD patient (Baltes et al., 1999). Similar to this study, Montgomery and Kosloski (2000) utilized caregiver identity theory to understand the conflict that arises along with the assumption of additional roles. The caregiver was forced to take additional responsibility in the relationship that the caregiver did not want, while the ADRD patient relinquished power and control. With increasing functional and cognitive impairment of the ADRD patient, the caregiver was forced to assume increasingly difficult tasks. When behaviors that were particularly difficult to cope with such as wandering developed, the caregiver often had no knowledge or experience to cope with these behaviors.

Many of the reactions to role change were described in grief theory (Kubler-Ross, 1969). Throughout the interviews, caregivers described feelings of denial, anger, and sadness at the behavior change. Denial is a psychological defense mechanism in which confrontation with a personal problem or with reality is avoided by denying the existence of the problem or reality ("Denial," 2012). Caregivers verbalized denial related to many aspects of ADRD: the diagnosis, the severity of the behaviors being exhibited by their loved one, the definition of wandering, and the existence of wandering events. In some

cases, denial allowed caregivers to continue to act “as if” their loved one was safe in various environments from being home alone to driving in the car.

Stages of Grief: Denial, Anger, and Depression

Caregiver 18 denied her mother’s cognitive changes, but she found herself taking on additional roles that had previously belonged to her mother:

I really didn’t know much about it, and wasn’t concerned with finding out much about it because I was in denial. . . . I was there every day, the constant contact . . . anything that we did . . . together . . . I didn’t worry about it, because she was still doing so well I was in such denial that really Mother had Alzheimer’s until I just, I didn’t understand it, I thought how in the world could she get confused on these instructions?

Anger was described as a reaction to behaviors that caregivers did not understand or know how to cope with. Anger was described as a reaction to negative behaviors that were exhibited by their loved one, and the unwelcome change in their lifestyle.

Caregiver 18 described the anger that she felt at the behavior change:

It was frightful and irritating because I didn’t realize what was going on . . . I didn’t realize I was in denial, I was just flat aggravated because she wasn’t following instructions and not realizing that there was a reason that she wasn’t following instructions.

Depression was described by many caregivers related to the loss of relationship with their loved one and the decisions they now have to make without their loved one’s input. Caregiver 8 described the impact that ADRD has had on her relationship with her husband, and how she experienced the relationship loss:

For me, it’s been devastating. I’ve lost my life’s partner, I’m lonely . . . I’m alone . . . everything takes twice as long as it did before . . . you let go of any concept of the way things need to be done, and for me, I’m a very organized . . . actually,

maybe it's been helpful, it loosened me up a little bit (laughs) . . . no, it's been devastating, essentially very sad, very devastating very lonely.

Caregivers also discussed helplessness they felt because of the gradual deterioration in cognitive status that seemed to never end. Caregiver 8 described the unique nature of grieving when their loved one has ADRD: "They say it's the longest goodbye and it is, Grieving has a process and Alzheimer's doesn't give you a grieving process, because it's endless, you never, never know when you can turn the page."

Caregivers described grief at the change in their loved one's personality that was brought on by ADRD. Caregiver 18 described the impact of her mother's change in personality:

. . . Knowing how my mother was and seeing her as the professional she was, and knowing the preciseness and what all she did and was involved with and all of the sudden to see that that was something that she was not going to be able to handle . . . that was a SHOCK. And something I guess I didn't want to, I didn't want to believe it.

Support or Lack of Support

The support of extended family was often described as very important to the caregiver who needed respite. While most caregivers talked about family, in many cases caregivers described their support as minimal. The reasons varied from distance to lack of time and resources of the family member, the lives, and other responsibilities of the family member. The issue of denial was described as impacting the support that family provided. Caregiver 4 talked of how her children's denial led to conflict:

My children at first did not accept it AT ALL, particularly the older one . . . he's just "there is nothing wrong with my dad" . . . on the phone, that was it. That was very hard for me. It's very hard when you are trying to deal with it, and the other

people who are close to the person, they don't want to accept it . . . they don't know what you're talking about . . .

Family conflict often developed or deepened because of the denial of cognitive changes, and the need for increased role responsibility. Conflict developed among caregivers regarding the appropriate way to provide care. Caregiver 21 described family conflict that developed since her mother's diagnosis: "I guess the other impact it had on me was that I realized my brothers were not doing their job as a family, I realized my mother needed more care. . . ."

Prior Relationship Factors Related to Burden

Both the prior relationship and the personality style of caregiver had an impact on role change. In some cases, the more egalitarian relationship in the past led to an easier time with the new, additional roles, but the enormity of the role shift brought burden.

Caregiver 3 described the additional burden:

I've been doing the driving for many years, I've been paying the bills for many years . . . I've been used to doing STUFF, I would say that it is more difficult for me to have to do EVERYTHING. The sprinklers were leaking, I had to have someone there this morning to fix couple of sprinklers; I had to do it . . . I didn't physically do it, but I had to source it out, arrange to have it done, I had to be there, I had to do everything of that nature, and sometimes, I just get tired. . . .

Prior role relationship and perceived power in the relationship impacted caregivers who were forced to accept roles that their loved one was no longer able to do.

Caregiver 4 described a more traditional role relationship with her spouse in the past, and how difficult role change with the ADRD diagnosis was for both:

He was very quiet and shy and the real smart one in high school, and I wasn't (laughs) . . . he was an accountant by degree, an MBA . . . he was a Colonel in the

army . . . I still have not been able to get control of the finances . . . course he wants it all on the computer, which is very hard for me. I have a tablet so it's all written, course it's all changed since we've been here. And I'm having a little bit harder time getting him to bring me in and know the new systems. . . .

The impact of cognitive and behavioral changes in their loved one with ADRD often meant that caregivers had to change their normal daily routines. Caregiver 8 describes that as the disease has progressed, she was forced to modify her routine as her husband often disrupted it: “. . . and for me, I'm a very organized . . . actually, maybe it's been helpful, it loosened me up a little bit (laughs). . . .”

Summary

Family caregivers reacted to increased role responsibility based on a number of factors including personality style, the nature of the prior relationship with the care recipient, and their emotional reaction to the changes in their loved one brought on by ADRD. The availability and use of supports was key, and the caregiver's perception of lack of available support increased his or her perceived stress and burden, and often led to minimization of behaviors that were potentially dangerous. This research found that caregivers reacted to increased role responsibility and burden in different ways. Their individual level of burden impacted their understanding, willingness, and ability to take on additional roles. Chapter 6 presents case studies to illustrate the three basic ways the family caregivers in my study coped with the additional role responsibilities associated with a loved one's ADRD diagnosis and problem behaviors such as wandering.

CHAPTER 6

PERSPECTIVES OF ROLE CHANGE: CASE STUDIES

Grief theory reminds us that a major lifestyle change such as the one brought on by ADRD brings on a grief reaction. The grief cycle has five stages: denial, anger, bargaining, depression, and acceptance (Kubler-Ross, 1969). As mentioned in Chapter 5, the caregivers interviewed in this study expressed the grief they felt at the numerous losses brought on by ADRD. They were at different stages of the grief process. Some caregivers denied the severity of the disease, while others accepted the changes brought on by ADRD. All of the caregivers I interviewed expressed sadness at the loss of the relationship they had known. As illustrated in Chapter 5, role change is a complex process for the caregiver to navigate, since it usually occurs as negative behaviors escalate and cognition deteriorates. ADRD impacts cognition, which means activities and tasks become too difficult to perform, so the caregivers take on household tasks, and personal care tasks including safety monitoring of their loved one. However, not everyone takes on role change in the same way.

Some scholars and practitioners refer to the changes that occur as *burden* (Sales, 2003). Not only does the caregiver become responsible for the care of their loved, every area of life is impacted; relationships, preferred leisure activities, social activities. The caregivers' reactions are impacted by their own subjective response; they are forced into roles they do not want and forced to give up roles they enjoy. The primary relationship with their loved one is forever altered as they take on roles that their loved one is forced

to give up. The loss often goes unrecognized and unresolved for both caregiver and their loved one as they struggle to deal with changes brought on by ADRD. Aspects of caregiver burden were described in Chapter 4. Sales (2003) described the many stressors that impact on the caregiver's ability to provide appropriate care. Objective burden includes direct care tasks and the myriad of lifestyle changes that are brought on by ADRD. Subjective burden is the negative emotional reaction experienced by the caregiver to their changed role.

Wandering is one of the most difficult behaviors that develop with ADRD. The impact of wandering on perception of burden is enormous, as it means constant diligence in monitoring the behavior of the person with ADRD. Constant monitoring meant no respite unless the caregiver utilizes support through formal or informal networks.

The 22 family caregivers who were interviewed fell into three categories regarding their perception of ADRD behaviors such as wandering and the level of role change that had occurred due to ADRD. The first group, caregivers struggling with role change, appeared primarily passive and reactive to negative behavior. They described numerous stressors that impacted their role and perceived limited supports. There was limited action to change the environment, even when their loved one developed dangerous behaviors. Essentially, they *acted as if everything was normal*.

The second group of caregivers was primarily proactive; that is, they *took charge* and were more aggressive in the face of behavior change and the risk of wandering. Typically, there was an incident that prompted action. These caregivers often utilized

formal support to assist them to provide the type of monitoring that they felt was necessary. They tackled the issues *head-on*.

The third *mixed* group responded both proactively and reactively. These caregivers described environmental stressors, and limited supports to assist them in providing care. They were *doing the best they could*.

These representative case studies are a compilation of the 22 interviews within the study. These case studies illustrated the encounters between me as the interviewer and the caregivers interviewed—their perception of their roles and the difficulties they encountered acting as caregiver to a loved one with ADRD. These interviews provided a detailed snapshot of how caregivers viewed their role, the difficulties they perceived in that role, and the amount of support they perceived as available to assist them.

The interviews ranged from 30 minutes to 90 minutes and were held in various locations including coffee shops, restaurants, and residences. The caregivers interviewed self-selected for participation in the study, and thus were aware of the general topic I was researching. They gave their time and perspectives regarding caregiving willingly, and their honesty about their roles was reflective in the interviews.

Group 1: Caregivers Struggling with Role Change

Four of the caregivers interviewed struggled with their loved one's behavior change and described numerous stressors in their daily life. In some cases, caregivers verbalized reluctance to confront that ADRD had altered the relationship between themselves and their loved one, in the face of continued dangerous behaviors. At times,

both the caregiver and care receiver appeared to deny the need for change. Conflicts in the prior role relationship as well as other stressors led the caregiver to continue *acting as if everything was normal*. In these interviews, the caregivers noted that loved ones were involved in repeated events involving dangerous behaviors while driving and in the home. However, there were minimal interventions, and driving continued. Caregivers appeared reactionary to negative behavior, and minimal action was taken to bring about role change.

The Impact of Relationship and Communication Style on Role Change

Caregiver 2 and her husband had been married for over 50 years. In this interview, she described a long marriage in which her role had little power, the relationship between she and her husband was often full of conflict:

Usually when he's alone he will do something that I wouldn't want him to do if I was there . . . laugh . . . that's a habit of his. If I'm not around to complain about what he's doing, he'll do that thing. . . . Yesterday the smoke alarm went off in our house . . . because he's deaf also so he couldn't hear it . . . so I went in screaming in the bathroom and he had kind of a thing that was removing a nail from the wall and there were sparks flying everywhere and I screamed at him . . . that was unsafe . . . And he screamed back at me, because you see he doesn't believe anything he does is unsafe . . . He's one of these opinionated, stubborn people who is 88 and I don't know how to change him. We've been married 50 years.

This caregiver talked about how she felt powerless to control her husband's behavior, which was risky and dangerous. She expressed concern about how unsafe his behavior was, but had no alternative behavioral or communication strategies to deal with them, and no power to assume additional roles in relation to him. She felt she impacted his behavior by arguing with him:

- C2: I don't feel that he's lost so much time and capability that he can't understand what I'm saying . . .
- I: So you feel like . . .
- C2: I feel like I need to argue with him while he can still understand what I'm saying.
- I: Um hum, in hopes that he will make some of the changes that he needs to make.

Arguing is defined as *to persuade by giving reasons* in support of an idea or action (Arguing, 2012). ADRD impacts the ability to reason and argue because of the cognitive impairment involved. We see that Caregiver 2 continued to utilize a communication style that was historical in their relationship, but ineffective. She was not able to stop her husband from engaging in highly dangerous behavior, such as driving. During the interview she discussed numerous incidents of unsafe driving behavior, including a severe accident, which left them both injured. Although she acknowledged that his driving was unsafe, Caregiver 2 further reinforced her passive role by continuing to ride with him, but in a *safer* position in the car: "Now, usually when I'm in the car and I see what he's doing . . . I won't ride in the front seat. I call it the suicide seat (laughs)." Thus, while her husband engaged in behavior that could cause bodily harm, she did not intervene in a proactive way, such as driving the two of them herself, but reacted by moving to the back seat while he drove.

While driving was considered dangerous by most caregivers, their perception of other wandering behaviors varied. Often, they did not acknowledge behavior as a wandering incident, or discounted the potential safety consequences of the behavior. For example, Caregiver 2 denied concern about wandering because of past history, he hadn't gotten lost: "No, he doesn't wander off by foot . . . he finds his way back from wherever

he was . . .” She justified allowing driving to continue by denying that driving is a form of wandering, which provided rationalization for not acting.

Stressors Impacting Role Change

Lack of perceived power in the relationship is only one stressor that may cause caregivers to struggle with role change. Caregiver 15, a retired professional, described an egalitarian relationship with her spouse. She described numerous stressors that had resulted since the diagnosis of ADRD: significant negative behavior change in her loved one, loss of friendships because of her spouse’s negative behavior, and a lack of support to assist her with her husband’s care. She instituted minimal role change even while expressing concern about the dangerous behavior her husband exhibited:

My concerns are that he might foolishly pull a weapon when it’s not yet necessary because he has such a high level of anxiety. I worry too because he has a license to carry a concealed weapon and I know that even if I empty the ammunition, if let say a policeman sees him pull the gun, they won’t know he’s not a threat. Mostly it would, he cause violence or be the object of violence. And also would he catch us on fire. He’s not good any longer about controls for the cook top, what’s low and what’s high. For the oven, same, um he put something in the microwave and turned it on and it caught fire.

Caregiver 15 had concerns about her husband’s behavior change since his diagnosis. She described behavior that was erratic and dangerous. She was fearful that his behavior could lead to violence, but felt powerless to intervene. She was fearful of authority figures, because his erratic behavior might lead to a reaction from the police. She felt helpless to control his behavior, leaving her anxious and fearful.

Behavior change in ADRD is complex. Caregiver 15 described two of the most difficult behaviors that develop in ADRD: dangerous behavior and wandering.

Caregivers often had a limited perception of wandering behavior. As occurred with Caregiver 2, Caregiver 15 did not consider that dangerous driving is a form of wandering behavior. She stated that wandering was not an issue, although she acknowledged his driving was dangerous. She reacted to the danger by changing her behavior instead of taking control:

C15: There's some evidence of lostness, but not in the usual sense of he goes and wanders and can't get back home.

I: And he drives?

C15: He does. In a limited area and he doesn't have any passenger but me, and that's seldom, we don't let him drive with the grandchildren in the car.

She described concern about his driving, but actually reduced her ability to influence him by minimizing driving with him. While she acted to protect her grandchildren, she made no intervention for his safety, and the safety of others on the road.

Lack of Financial Resources and Role Change

Lack of financial resources and other stressors also impacted the caregiver's ability to assume additional roles. Even faced with significant cognitive change, one caregiver felt forced to let unsafe behaviors continue. Caregiver 19 described the numerous stressors that impacted her ability to accept role change. These included financial concerns and employment issues; the care recipient, her spouse, was the wage earner. While she was aware of cognitive change, financial pressure kept her from acting:

He was still working, see I think that was the thing we were both . . . denying was how bad it was, because I needed him to keep working because we needed the money we wanted him to keep working. I wasn't working, or I was barely working you know it was just, it was just it got to be really . . .

Caregiver 19 acknowledged that wandering behavior was occurring, and her fear that he was repeatedly getting lost. She described her concern about the wandering incidents:

C19: I definitely got worried about him getting lost. We lived within five minutes of Tom Thumb and it has taken him as much as an hour to go get ice cream and come back and I was for sure he was lost apparently he would just forget how to get back. And I was for sure he was lost. And apparently he would forget how to get back. He would just keep wandering, he would just forget why he was there, he would just keep wandering forget he would just keep wandering his way around until he finally found his way. . . .

I: If you were going to count how many times, I mean roughly, the number times you sent him to Tom Thumb and he didn't come home and he didn't come home. . . .

C19: Any time he went out.

Because the family needed the income and the husband's role as a wage earner, both husband and wife denied the severity of the cognitive change. She needed him to remain as provider. There were numerous incidents of wandering behavior, but she felt powerless to act. An additional environmental stressor developed when this caregiver attended college five hours away from home. She took on additional schooling because of the need to take over the financial responsibility in the family, but was even less available to her husband during the period she was in college.

I went to college in A . . . came up here every other weekend, just drove back every other weekend and fixed meals, put them in the freezer, put them in the fridge I would make him a list at the time, he was still able to read . . . Monday you eat this, Tuesday you eat this, Wednesday eat this for breakfast . . . I would

have a whole list and then once I graduated from college and came back to Dallas full time, probably within two months, he lost his ability even to read, he gotten so he wasn't even reading, so I think he was kind of holding it together while I was away, because he had to . . .”

In order to assume the role of wage earner she was going to college out of town. She had limited formal or informal supports to help her, so she trusted that he would be safe even as his cognitive level declined.

He stopped working and stopped driving. . . . The car died, and I just wouldn't get it fixed . . . it stopped at a friend's house and that made it easier, because he didn't have to see it, we just left it on her driveway. . . .

While she assumed many of her husband's roles, he continued to drive. She assumed a passive role rather than intervening to end this dangerous behavior.

Professional Support to Force Role Change

In some of the interviews, caregivers utilized professional support to bring about role change; either by supporting the caregiver or forcing the caregiver to intervene. In the case of Caregiver 5, police forced the issue of role change because of a concern about public safety. The physician reinforced the concern and advised the caregiver to intervene.

I: So the police have been called?

C5: Yes, they have been. Right there.

I: It sounds like a couple of different times, the police were called.

C5: Yes, uh huh. That's when the doctor said L, this is it, you need to stop driving.

The impact of distance from family, a spouse unable to assume the role of full-time caregiver because of his job which took him out of town, and lack of support in the local

area all combined so that unsafe wandering behavior continued. After three major incidents where she got lost while driving through the mountains of Colorado, the intervention of professionals was needed for change to occur. The spouse assumed additional roles, but only when the change was brought on by the police due to the safety risk that involved not only his loved one, but the community.

Summary

Kuo and Shyu (2010) refer to the process of *ambivalent normalization*, which is attributing the cognitive and behavioral changes that are due to the disease process to normal aging. Caregiver 1 continued her “optimistic appraisal” that she was seeing normal aging and the status quo, and, based on historical relationship problems and tension, continued to deny the need for role change (Kuo & Shyu, 2010, p. 3479). In some cases, the behavioral symptoms led the caregiver to feelings of distress, worry, shame, and guilt (Sales, 2003). Caregiver 2 described her concern about her husband’s behavior, but appeared unable to intervene. Reaction to this sense of burden was overwhelming and immobilizing. Even when faced with significant behavioral symptoms, major stressors such as financial pressure combined with limited formal or informal supports meant that role change was limited. As a result, responses were often reactionary, and in some cases no change occurred. In some cases, role change occurred because of the intervention of professionals.

Figure 9 describes role change of the caregivers described above. The level of burden was high due to emotional and environmental factors, and there was limited

support to assist in their loved one's care. There appeared to be a general lack of acknowledgement of the potential severe negative consequences of wandering behavior among these caregivers. Often, they avoided additional role responsibility by taking no action. In some cases role responsibility was accepted when authorities intervened. When forced to accept additional role responsibility, caregivers utilized additional supports such as family to assist.

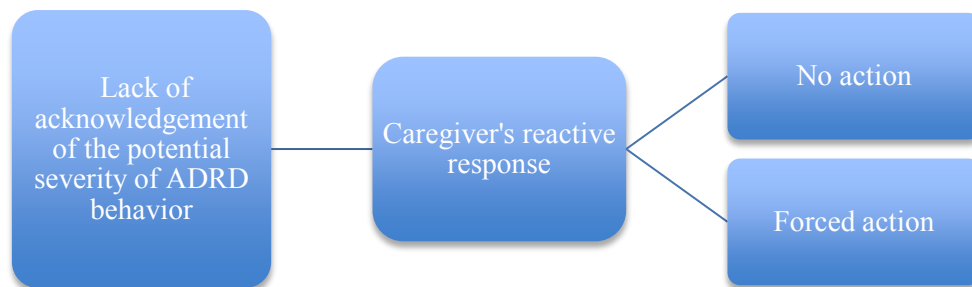


Figure 9. Caregiver's reactive response to ADRD behavior.

Group 2: Caregivers Who Became Proactive

In 8 interviews, caregivers acknowledged behavior change as it was occurring and became pro-active in their approach to caregiving. Given the catalyst of unsafe driving or a wandering event, these caregivers accepted additional role responsibility in order to minimize the likelihood of wandering events. They *took charge* and tackled potential issues *head-on*.

The Catalyst Event and Role Change

Caregiver 9 described the decline in cognitive level that her husband had experienced after his diagnosis of ADRD. One event in particular acted as a catalyst for

role change:

I: Has he gotten lost?

C9: The only time . . . he used to always accompany me when I went to take my mother to her doctor's visits . . . we left him in the waiting room, told him we would be coming back to stay right there . . . we were in a little longer than normal . . . and when we came back out, he wasn't there and as panic set in, we glanced and he was walking toward the elevators, so we hollered and he stopped and went over to him, and he said well, we had been gone so long that he thought that we had forgotten him and he was going to go look for us, now whether he would have gotten on the elevators. . . .

The event in the doctor's office was the catalyst event. She took responsibility for home safety and monitoring of her husband's behavior. She realized that he had the potential for wandering, and she recognized the danger in that behavior. Caregiver 9 went on to describe this realization:

That was the huge wake-up call that, from that point I have never left him . . . because to say to him "wait here," I realize . . . it's not that he doesn't want to do it, fifteen minutes later he forgot that I told him to wait there.

The caregiver proactively instituted safeguards in the home including chimes, alarm systems, and formal supports such as adult day care to assist with her husband's care and keep him safe. She utilized both home monitors and respite to assist her with her husband's care.

Caregiver 21 described a wandering event, which was a new behavior that occurred long after her spouse had voluntarily stopped driving:

We were at church, and church was out, and we were getting to go and I went to do something and I guess he thought I had gone, and so he took it upon himself to drive home, because I think he still had a key and he drove home, and that was scary. He wasn't lost he didn't get lost . . . he came right home, opened up the garage, came back . . . he came here . . . he was here. My concern was . . . he's going to get in a wreck. . . .

Caregiver 21 recognized this new behavior as erratic and dangerous, and it impacted her to take on greater role responsibility to make certain he was safe. She took on additional responsibility for his safety by monitoring his behavior at home.

I: Does he walk around the neighborhood or anything?

C21: No. No, anytime we go out to walk, we will go to the park over to Desoto Park, and we go together. Every now and then, we might walk around the block but we are always together, he doesn't he doesn't do that on his own.

She assumed additional roles and utilizes respite services to assist her. She closely monitors his behavior when he is at home and has installed an alarm system. She utilized adult day care for her husband, but acknowledged that she has less free time, and felt the burden of constant supervision.

Utilizing Professional Support to Assist with Role Change

Professionals can be helpful in two different types of roles; they can assist the caregiver to initiate role change, or they can force role change because of the safety issues to the larger community. Caregiver 6 utilized her husband's physician to initiate role change to gain the support of her spouse, who was resistant to giving up driving:

Well, actually, I instigated the appointment because I didn't want him to be driving anymore. And he had been seen for cognitive decline . . . I told the doctor, "this is not cognitive decline, this is something more" . . . and it's not safe for him to be driving, and it couldn't come from me, so instigated the appointment. . . .

Use of Formal and Informal Services to Assist with Role Change

Caregivers in the *proactive* group appeared knowledgeable about the disease and utilized numerous environmental supports such as respite services and family. Caregiver 6 recognized that she needed support in order to provide the appropriate level of monitoring that her husband needed, and utilized formal support services to assist her in providing care: “. . . He’s never alone at home . . . we initially got somebody to come stay with him before we got Friend’s Place, that person would walk with him . . .”

Informal supports such as extended family were also utilized to effectively bring about role change. Family members worked together to assume additional roles in order to keep their loved one safe. Informal networks that work together can thus provide appropriate monitoring to help the primary caregiver. Caregiver 16 described her family working together as an informal support network. They acknowledged the need for increased role responsibility for their father, and worked together to provide the necessary role change:

I: Do the four of you have a pretty equal distribution of duties with your dad, or do a couple of you kind of take the lead position and the other two support you in that lead position?

C16: I have two sisters who care for him during the day, and then my sister and I, my other sister and I care for him on the weekends. So he comes to my home on Friday and I’ll take him back on Sunday morning.

The family worked together toward role change in order to keep their father safe.

Figure 10 below depicts role change by caregivers in the proactive group. The caregivers described a behavior that was a catalyst event that triggered role change. They became proactive through the use of formal and informal supports or providing increased

monitoring. They were proactive in intervening in the home environment. They utilized appropriate respite supports to help them with role change.

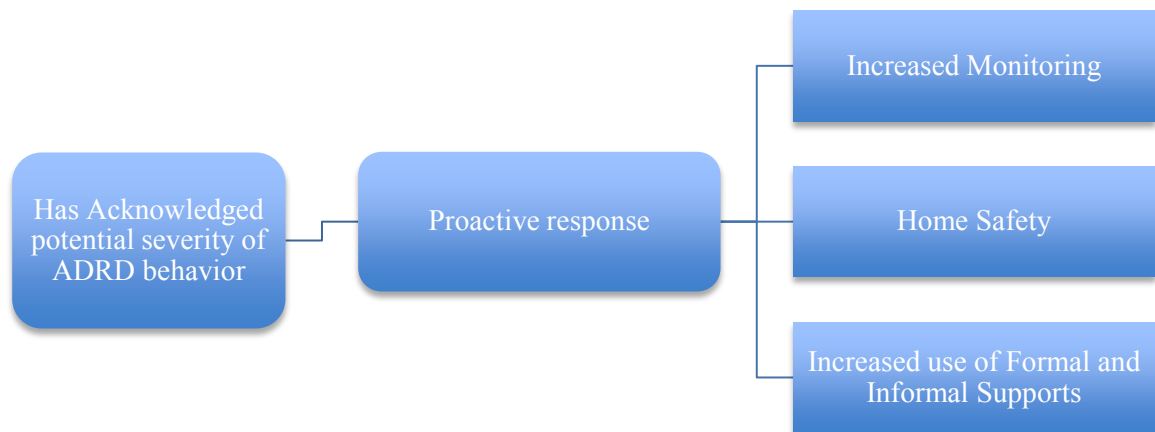


Figure 10. Caregivers' proactive responses to burden.

Summary

ADRD often involves cognitive decline combined with an escalation of negative behaviors. These caregivers dealt with the behavior change by *taking charge*, increasing both formal and informal supports as well as increased monitoring when supports were not available. The caregivers in this group became proactive in the face of behavioral change, and engaged in problem solving behavior to resolve the myriad of issues that result from behavior change. Some of the caregivers hired secondary services such as respite and adult day providers, while others utilized family for support. These caregivers were proactive in instituting change. Both increased monitoring and the availability of an effective support network were key components as they impacted role change.

Group 3: The “Mixed” Group (Caregivers Who Are Doing the Best They Can)

Many caregivers in this sample assumed additional roles, but continued to allow their loved ones some level of independence. In 13 interviews, caregivers acted in a proactive manner regarding some, but not all, issues, and intervened based on their past experience with their loved one. The one issue that was universal with this group was concern about driving. Driving was considered high risk from both a safety, legal, and financial standpoint and was dealt with by the caregiver. In all 13 cases, driving had been eliminated.

Environmental Stressors that Impact Role Change

Caregivers in this *mixed* group exhibited *mixed* acknowledgement of the potential seriousness of wandering behavior. They were often interested in honoring their loved one’s desire for independence and autonomy. They often tried to minimize disruption to established routines. They also described numerous environmental stressors and limited supports to assist them in providing care. They were working professionals, had limited family involvement, and limited resources. Revisiting Sales (2003) description of caregiver burden helps us to understand the caregiver’s decision to limit surveillance and supervision activities. These caregivers described environmental stressors such as full-time jobs. They had limited formal and informal support, which meant they had limited help with their loved one. Not only were they dealing with objective aspects of burden such as direct care, relationship change, and working, but also they had no opportunity to deal with subjective burden, their emotional reaction to caregiving (Sales, 2003). They

made the changes they *could*. When the impact of the caregiving burden outweighed the perceived risks of wandering and other behaviors, this group of caregivers opted to relieve their burden. That is, they *did the best they could*. At times the caregivers were proactive in addressing wandering and other behavioral issues; other times they were more passive and reactive.

Limited Support, and the Need for Routine

Caregiver 1 stated that he felt safe leaving his spouse alone for a limited amount of time in order to go to the gym, a much needed stress reliever for him:

She usually just watches TV, but she's capable of being by herself now and then, a whole lot less than before . . . I might, I might go and work out for 45 minutes, and leave her watching TV, but most of the time, I'm there.

He based his decision on past history; she had never done anything unsafe while he was gone, thus his need for both a mental break as well as exercise outweighed any potential risk.

She doesn't wander, she's afraid to go out by herself anytime, so we don't have any trouble there. I understand that's a problem for some, but not for us . . . my wife is afraid. She won't go because she's just afraid. You know, she said I don't want to be out by myself. Period.

He rationalized that she is afraid to leave the house, thus she would not wander away. Since there was no history of wandering, and no recognized catalyst to change for him, his need to relieve some of the stress of caregiving outweighed safety concern.

Caregiver 20 verbalized that she knows that behavior change in AD/DRD is unpredictable, and can occur at any time, but is reluctant to change a favorite routine of

her loved one, walking in the neighborhood. This caregiver expressed concern about her husband's safety, but she used past experience as her guide:

I: Do you have concerns about your husband's safety at home?

C20: Um, I would say no only in the sense that there have been no accidents or incidents of any kind, I am worried in the sense that I want to be alert to changes in his ability to maneuver and pro-act rather than react to him.

Caregiver 20's response was representative of this group; a reluctance to institute change that would impact the family's routine. Past history was used as their guide for role change; the additional burdens of caregiving are accepted only when absolutely necessary.

Caregiver 4 described reluctance to change her husband's routine, particularly activities that are enjoyable to him such as taking a walk through the neighborhood. This caregiver acknowledged that her loved one's cognitive level is deteriorating, but did not want to take away his independence:

C4: I would call him when I noticed that he should be home I'm very aware of how long he should be gone . . .

I: So when he's out for a walk, does he always have his cell phone with him?

C4: Yes he does, but again its . . . that's another reason why I would prefer that he not walk by himself anymore because occasions when he has been unable to remember how to call me. . . .

She monitored his behavior by watching the amount of time he is away, thus has a plan to intervene if he does not return at the appropriate time. She described another dilemma, protective devices that no longer provide protection. She made sure he was carrying a cell phone as a safety measure, but she acknowledged that he no longer remembered how to use it.

Role Change and Conflict

Caregiver 4 verbalized how stressful the relationship with her spouse became as she attempted role change. This spouse verbalized how difficult it has been for her to assume additional roles because of her spouse's reluctance to relinquish his previous roles:

C12: He's very intelligent, a lot of people don't even know that he has it, and he didn't want them to. Now it's different . . . and I don't like the computer like he does . . . and . . . I hit a wrong button (sighs) and you would have thought I had blown up the Capitol . . . he gets VERY ugly, and I know that's not him, he's not like that . . . but the kids are not seeing that yet. . .

I: Now when you say "ugly", do you mean verbally abusive . . .

C12: Yes, yes, verbally, just ANGRY . . .

I: But no physical . . .

C12: Oh no . . .

He was angry and critical of her as she tries to take on roles that he previously held. This was even more stressful for her because she lacked the support of her children who deny the cognitive change in their father. She described the emotional impact that his behavior was having on their relationship:

I: But becomes angry and said things he shouldn't say to you . . .

C12: And I'm going to admit that this last week when he did that . . . and he just kept getting more angry and more angry, because I wasn't hitting the right button on the computer which seems so silly that I just told him that I had to go and get something at the store. I just had to get away from him. It's very hard to not to not get angry back.

She described the stress on their relationship due to role change, and her need to escape the high level of stress. She assumed roles that she is not comfortable with. She was forced to cope with her loved one's anger that he was forced to give up his preferred

roles. This was further complicated because she did not feel supported by her children. She described both the objective experience of burden such as taking on additional roles and the subjective experience of burden; worry and guilt; and she had little outlet or support.

Using Past Behavior as a Key Factor

Each caregiver had their own unique stressors based on the change in their loved one's thinking and behavior. Some caregivers described limited behavior change that warranted intervention, thus sought to continue some aspects of their *life as normal*. Many caregivers described their need to continue to work. Many of these caregivers spent a limited amount of time away from home, and described their loved one with ADRD as being passive while they were away:

I: Do you worry about him getting lost?

C17: Um, not at this point. He has a problem with his back that makes him not very interested in walking any great distances. I have never known him to go out for a walk on his own. Also I am working from home, so I am home most of the time, and as I say pretty much during the day he sleeps, so . . .

Caregiver 17 described her husband's physical limitations and past history as indicators that her spouse was safe at home alone. She described limited supports to assist her, so she needed time away from home for both socialization and errands. She verbalized concern about his safety, stating that she limited the time away from home.

Role Change with Limited Resources

Increased role responsibility involves greater burden when the caregivers had limited time and finances. Caregiver 10 had to work and couldn't afford the expense of full-time support during the day for her loved one. She utilized the resources that are available to her:

When I leave in the morning, I always lock the backdoor, the garage, and S understands that she's not supposed to leave the house by herself. She can go out in the back yard, that's Ok. I have talked to my neighbor, G, and she's aware of S's disease and she knows if S is out in the front, by herself, it's a good idea to get her into the house and give me a call.

She is aware that her loved one may forget *the rules*, and utilized all the precautions that are available to her. She used her neighbor for informal support to monitor her loved one. She also utilized various safety measures such as locking the garage and backdoor. She took her loved one to an adult day program two days per week in order to provide her with socialization. This presented an additional burden on her time; she came home during her lunch hour and took her to the program, a 45-minute drive. She was an example of a caregiver truly doing the best job she could with limited supports.

Summary

This group of caregivers represented the largest of the three groups, more than half of the caregivers interviewed. These caregivers took on some roles that had previously belonged to their loved one and described less support to aid them in dealing with their stressors. The issue of burden was intensified due to a lack of formal and informal supports to help. The types of burden included such environmental stressors as

financial issues; a number of these caregivers had to work. The emotional strain of caregiving was also described by this group, and without support, they sought ways to relieve their burden. These caregivers acted in both reactive and proactive ways and often based their actions on past behavior. They were aware of their loved one's cognitive impairment, and modified their behavior to be away for only a short period of time. However, they did not tend to take concerted, comprehensive action.

Figure 11 depicts these caregivers. They were proactive in assuming additional role responsibility, but had little additional support, so used past history as their guide. This group exemplified the ADRD caregiver who has limited resources, limited supports, and a high level of burden; they “did the best they could.”

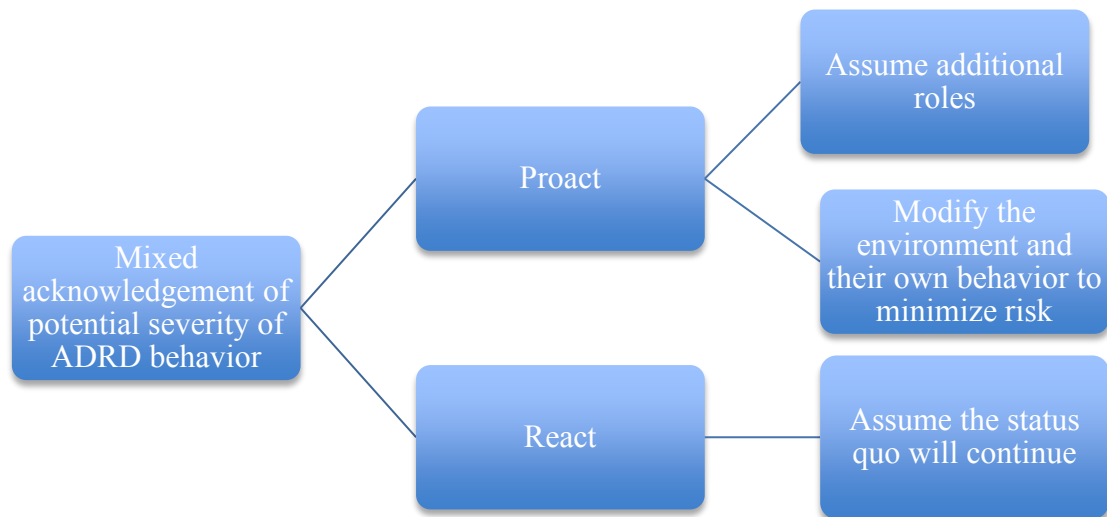


Figure 11. Group 3 - The “mixed” group (caregivers who were doing the best they can).

Discussion

The number of caregivers dealing with a loved one with ADRD is staggering.

80% of caregivers are family members, who are forced to assume additional roles that they did not want and do not understand. There was both sadness and anger in role change because it indicated the progression of ADRD. Caregiving for a loved one with ADRD is an all-encompassing endeavor, involving cognitive loss combined with behavioral change on a downward trajectory for an uncertain period of time.

Figure 12 illustrates the differences between the three groups of family caregivers identified during this study. All three groups described the devastating changes to their lifestyle that resulted from the diagnosis of ADRD. The three groups differed in their response to those changes. In the case of the first group, the reactive, *acted as if everything was normal*, group, the response was minimal, as the caregivers were passive and primarily reacted to the behavioral changes that the diagnosis has brought on.

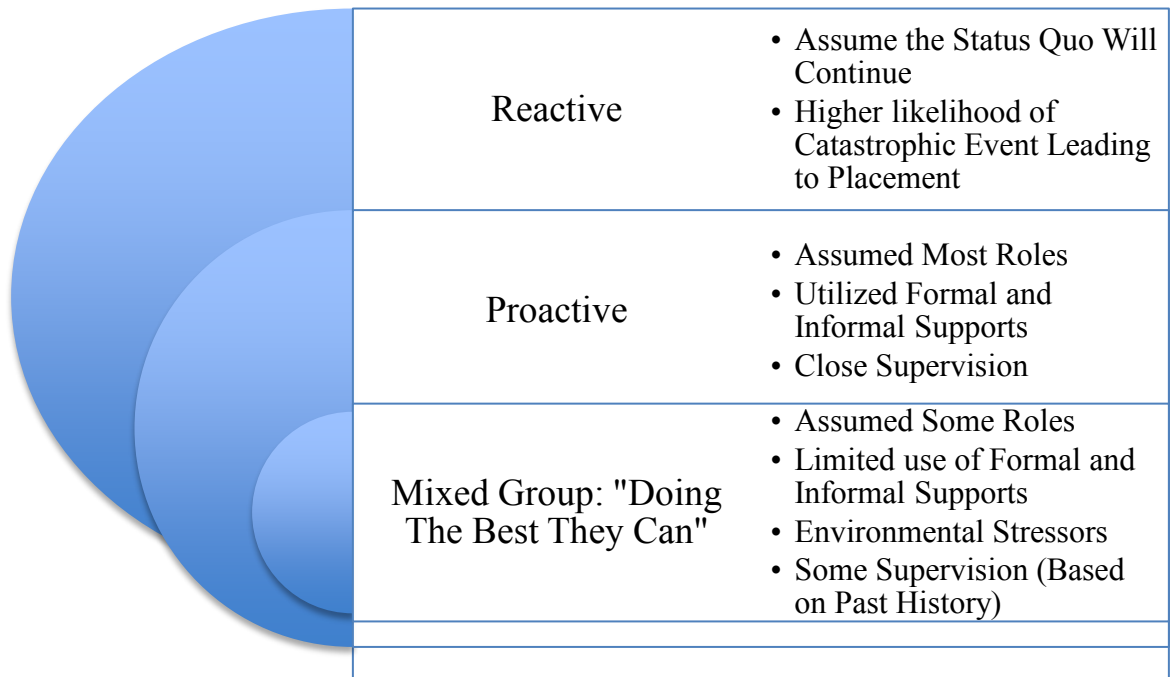


Figure 12. Responses to burden.

In the case of the second group, the proactive, *take charge*, group, the caregivers intervened to maximize the supervision and safety of their loved one, and utilized supports that were available to assist them in this role shift. The third mixed group was the largest group, and exemplified many ADRD caregivers; they were *doing what they could*, but had limited supports and numerous environmental stressors. This group exemplifies many ADRD caregivers.

Sales (2003) talked about the concept of family caregiver burden: “the everyday needs of the person with ADRD; the disruption of household routines and roles; and, the financial and emotional costs that are triggered by the illness” (Sales, 2007, p. 34). One of the most burdensome factors is the dangerous behavior that often develops.

Wandering is a behavior that can be overwhelming for caregivers, and often leads to placement. Placement is expensive and intrusive for all involved. “Families often deny cognitive impairment and delay change until some kind of crisis occurs” (Adams, 2006, p. 6). The difference between caregivers who were proactive and those who were reactive often was their relationship with their loved one and environmental stressors that impacted their perception of burden. Burden was related to such stressors as prior relationship with their loved one, perception of power within the relationship, communication style, support of family and friends, financial concerns, work concerns, level of conflict with their loved one, concern regarding independence for their loved one, and the expense of outside resources such as respite and adult day programs.

Social exchange theory explains relationships through power and dependence (Savundranayagam, Montgomery, & Kosloski, 2011). “Family relationships can be

conceived as a long history of reciprocal exchanges, some more balanced than others, in which the balance of power and resources shift over time” (Savundranayagam et al., 2011, p. 689). The three groups described the impact of the reciprocal exchanges of the past, including the relationship style and communication patterns that continued even when they are no longer effective. ADRD means that role change often shifts to the family member who was subordinate and uncomfortable in their new roles. All interviewees described great difficulty in shifting the balance of power.

The groups reacted to role change in ways that were reactive, proactive, and sometimes both. The first group of caregivers appeared overwhelmed with the behavior changes of their loved one as well as the additional situational stressors that complicated their relationship with him or her. Silverberg (2006) talked about the difficulty that the weaker spouse has in taking on additional roles. “When the controlling spouse with ADRD resisted role change, often the caregiver became fearful about taking over roles” (Silverberg, 2006, p. 227). These caregivers reacted to their loved one’s behavior by making minimal changes. They tended to *act as if everything was normal*. Role change occurred when forced by authorities because of safety concerns.

Many authors have written about wandering as a high-risk behavior. Behavior that is high risk often results in negative consequences of either placement or death (Gaines, 2009; Rowe et al., 2001). Reactive responses increase the risk of these negative consequences.

The second group of caregivers also reacted to negative behavior, but they also *took charge*—they became proactive and instituted changes. They utilized additional

formal and informal supports, and modified their loved one's environment to provide protection. These modifications reduced the possibility of crisis, and increased the caregiver's perception of efficacy in their role. A safer environment and a caregiver who is confident in their role means the caregiver is able to provide care for a longer period of time.

The third group of caregivers had a *mixed* approach; they acted both proactively and reactively at the same time. The caregivers in this group assumed many roles, but often with limited support. The home environment was changed and informal supports were utilized. This mixed group differed from the proactive group both in amount of supports that were used and the surveillance of behavior. They *did the best they could.*"

Askham et al. (2007) discussed three important components to ADRD caregiving in the home. One of the components is surveillance or monitoring of behavior.

Caregivers objected to monitoring of behavior on two grounds; it caused a negative impact on their relationship with their loved one, as well as on the caregiver's lifestyle and preferred roles (Askham et al., 2007). It meant that they "could not do the things they needed and wanted to do, leaving them feeling trapped" (Askham, 2007, p. 13).

The caregivers interviewed in this study weighed the risk of dangerous behavior against the stressors in their environment. For these caregivers, stressors ranged from the need to work to the need to continue at least some of their preferred roles. Researchers found that "family caregivers favored quality of life and independence over potential risks" (Robinson et al., 2007, p. 395). Similarly, in my study, the caregivers interviewed talked about their relationship with their loved one, and struggled with inevitable changes

brought on by ADRD. Caregivers who sought to maintain their relationship as it was often did not recognize the danger of the behavior caused by ADRD (Ablitt et al., 2009). Often it took “a significant negative event to propel them into reality and constructive change” (Ablitt et al., 2009, p. 504).

The 22 caregivers interviewed for this study talked of numerous losses that have been caused by the diagnosis of ADRD. They were losing their loved one slowly and painfully. As cognition declined and behavior changed, they were forced to accept additional roles that they did not want and for which they were not prepared.

Wandering is one of the most difficult behaviors that develop during ADRD because appropriate intervention is all encompassing. Successful monitoring of wandering means constant surveillance. This was objectionable to both caregiver and their loved one for many reasons. These included loss of independence for caregiver and care recipient as well as the expense of appropriate surveillance. In many cases, caregivers chose not to act. The problem is there is no way to know when a wandering event will occur. Wandering is often the reason given for placement. “Denial of wandering increases the likelihood of placement” (Aditya et al., 2003, p. 110). Given that 16 of the caregivers interviewed either denied their loved one’s wandering or were reluctant to use surveillance techniques, we can only guess that many will experience the kind of event that leads to placement of their loved one outside the home.

CHAPTER 7

CONCLUSION

Summary of Findings

The principal purpose of this dissertation was to examine family caregivers' perceptions of wandering behavior after their loved one was diagnosed with ADRD. This dissertation focused on the complex nature of wandering. Wandering develops in 60% of persons diagnosed with Alzheimer's disease and related dementia (Alzheimer's Association, 2012). Wandering is a risky behavior, and its impact is far reaching. Wandering is a concern for professionals, such as physicians, clinicians, and case managers; because of the danger it presents and the difficulty that caregivers have in coping with it. The community is involved either because of safety concerns, such as unsafe driving, which impacts everyone on the road, or when the wanderer becomes lost and a Silver Alert is posted. When the burden of care is too high for the family caregiver, the community becomes responsible for both the provision and payment of care. Placement is expensive, intrusive, and burdensome. When families can no longer afford it, the burden is assumed by society in the form of Medicaid payments to nursing homes. Medicaid payments related to ADRD will be around \$35.5 billion dollars this year (Alzheimer's Association, 2012). The numbers afflicted by ADRD are expected to triple, thus the expense of placement will grow.

Aging in place (and community) is preferred by seniors and often less expensive than placement. Technology is available to provide a safe environment for seniors with

cognitive impairment. The simple home modifications described in this study have been proven to be effective techniques that can make the home safer if wandering has developed. Assisting caregivers to better understand wandering and the negative consequences that can develop, and supporting caregivers to relieve their stress and burden will be necessary if we are to have an impact.

Wandering is a high risk, dangerous behavior that can lead to adverse conditions. These conditions include becoming lost, driving in ways that are dangerous to others, and death. When the caregiver becomes overwhelmed with the behavior, nursing home placement often occurs. Specifically, this research sought to understand how caregivers perceive the behavior of wandering in their loved one with ADRD. It sought to answer broad questions about how caregivers perceive safety, what they define as wandering, and what tools they utilize to help them cope with a complicated and complex set of behaviors that are included within the ADRD diagnosis.

Chapter 3 described the use of the qualitative method of data collection that involved recruitment of ADRD family caregivers who were willing to be study subjects. Flyers were delivered to numerous settings, but primarily to support group meetings for ADRD caregivers. Twenty-two caregivers self-selected into the study by contacting me to schedule an interview. The interviews involved a semi-structured interview process, along with a brief self-administered *home modifications questionnaire*. Data analysis utilized a grounded theory approach. This meant that I was able to use my observations and interactions in order to pursue my hunches and develop analytic ideas about my

hunches. The theme that developed to explain caregiver's perceptions of wandering was the impact of role change on the caregiver.

As a part of the interview process, I observed two Alzheimer's support group meetings. Observation of the meetings revealed little discussion of wandering. However, it revealed the complexity of the emotions caregivers' experience. The support groups provided education and resources and a level of expertise about issues that was otherwise unavailable to the caregivers. The support group setting allowed caregivers to empathize with other caregivers who were also dealing with the complex issues that an ADRD diagnosis in a loved one brings about. It was the empathy that common experience brings that was the most important aspect of the support group.

Alzheimer's disease is devastating because it impacts the totality of a person; it has physical, cognitive, and emotional components. The complexity of the disease and its influence on the caregiver was discussed in Chapter 4. The caregiver becomes responsible for additional roles, such as the supervision and assistance for their loved one. The issue of caregiver burden was introduced. Many factors influence the caregiver's perception of burden. Prior role relationship and the availability of formal and informal supports are key concepts related to burden. Caregivers assumed roles that were previously held by their loved one, who was often resentful and angry at the unwanted role change. Relationships changed, friends disappeared, and family unavailable for the support the caregiver really needed. Subjective burden are the personal reactions to caregiving (Sales, 2003). The caregiver was responsible for increasingly more complicated tasks while dealing with their feelings of distress, shame,

and guilt over the devastating diagnosis that their loved one had received, and its impact on their life.

Research questions sought to understand how caregivers perceived issues of home safety, wandering, driving, use of both formal and informal supports, and placement. Twenty-two interviews were conducted that ranged from 30 minutes to 90 minutes. Caregivers reported at least one incident of wandering, while some described as many as 25 incidents. Driving was often a catalyst event for caregivers. In many cases, caregivers stated their loved one was no longer driving. Placement occurred in four cases. However, in this study, placements were not related to a specific wandering event.

Chapter 5 described role change, or the willingness to accept increased responsibility and take on additional roles by the caregiver. Factors that influenced the caregiver's view of role change included personality style, prior relationship with their loved one, and their emotional reaction to the diagnosis of ADRD. A key factor was whether the caregiver used formal and informal supports to assist them in providing care for their loved one. Were resources available to hire formal supports, or was family available to assist when the caregiver needed help?

Three groups of caregivers emerged from the data. The first group of caregivers struggled with role change and *acted as if everything was normal*. They described behavior that was often dangerous and erratic. They were reactionary in response to their loved one's behavior, and intervention was minimal. Formal and informal supports were not often used to assist them in providing care. They described the stress that they felt due to financial issues, jobs pressure, and limited supports to help them.

The second group of caregivers described a trigger event, which was used as a catalyst for change. They realized that their loved one's behavior had potentially severe consequences and *took charge* to eliminate the safety risk in their home and their loved one's life. They were proactive in their responses to dangerous behavior, and utilized both formal and informal supports to assist them in providing care.

The third group of caregivers was mixed, *doing the best they could* with the resources they had. This group also tended to describe an event that acted as a catalyst for change. Caregivers took on additional roles and made safety modifications to their homes. This group described stressors that impacted role change such as the need to work and limited family support. These caregivers also struggled with loss of their loved one's independence and the disruption of established routines. They often weighed past behavior with the limited supports, and did the best they could to provide protection. Sometimes that meant their loved one was alone, but past history and present realities made that option acceptable to them. They had not perceived wandering as a problem in the past, thus they did not consider wandering as a threat for the present.

Chapter 6 provided examples of case studies in order to understand how the three groups of caregivers viewed their role. All three groups of caregivers were unique in their perception of their role as caregiver, and the factors that influenced their perception. They viewed their role as caregiver through the prism of environmental factors and limited supports. The way they viewed their role impacted how they handled the additional role responsibility required of an ADRD caregiver.

Previous research on wandering focused on describing the wandering event itself, the safety issues inherent in the behavior, and typical interventions to modify the behavior such as pharmacological, the use surveillance, and placement (Kelly, 2009; McShane et al., 1998). Previous research on caregiving focused on issues such as burden, role relationship, depression, and support (Ferrara et al, 2008, Kuo & Shyu, 2010; Silverberg, 2007). This research is unique in combining both of these issues; how do caregivers perceive wandering and what factors contribute to that perception?

The myriad of roles that the caregiver is expected to assume and the environmental support that is available are key factors. Caregivers, who are supported in role change through either community resources, respite services, or family, are able to take on the additional responsibility of behavior monitoring that is essential to prevent a wandering event. Behavior change in ADRD is erratic and unpredictable. To protect against a wandering event means constant diligence, something that is impossible, without support.

Theoretical Grounding of the Research

The grounded theory approach used in this research had its basis in sound sociological theory. “Life course theory provided a framework for how lives are structured given the constraints of society combined with individual history” (Street, 2007, p. 160). This study described the impact of such stressors as employment, finances, and lack of support. Caregivers described dangerous behaviors that they were not equipped to deal with. Micro-level theoretical contributions reminded us that

individual differences such as personality style, and prior issues in the relationship are also key considerations (Street, 2007).

Continuity theory suggested that traits such as treasured activities, roles, and relationships are expected to continue for the elderly person as they adapt successfully into old age. Caregivers are expected to give up the activities that they enjoy in order to assist their loved one. They become responsible for roles they do not especially want, and face the resentment of their loved one for taking them over.

Caregiver identity theory described the process of change in the relationship with a loved one, increasing responsibility for care activities, and a resulting change to the caregiver's identity (Montgomery et al., 2007). Caregivers experienced tension when forced into caregiving activities that were "inconsistent with their views of self" (Montgomery et al., 2007, p. 441). Care tasks were frequently out of alignment with the previous and familiar role, causing tension and frustration. With ADRD, the shift was often severe because of the enormity of behavior change and level of dependency. The role change to caregiver interrupts the process described as successful adaptation to aging. The enormity of the responsibility they must assume often goes unacknowledged by friends, family, and society. The issue of burden described the interplay of such factors as role change, the change in relationship with both their loved one with ADRD and others, and the emotional adjustment that the caregiver is forced to make (Sales, 2003).

Contributions of This Research

This research contributed to the literature regarding both ADRD and caregivers by providing another perspective to the caregiver's role: what happens when the environment does not provide support to offset the additional burden? Caregivers assumed complex roles that they did not want and did not understand. They were forced to give up favored activities, and often friendships ended, because of the awkwardness that developed with the cognitive declines of the ADRD patient. Other family members often denied the existence of the cognitive problems, or were too busy to provide meaningful support. Caregivers had jobs and limited supports. The emotional reaction they had to the myriad of changes often went unrecognized, as they attempted to cope with the day-to-day challenges of the behaviors of their loved one. These factors contributed to the adjustment to the role of caregiver.

Those caregivers who had increased supports had additional tools to support them in their role. Montgomery et al. (2007) describes the phases of the caregiving career. He described the latter phases when "the caregiver feels additional burden and considers placement for their loved one in a nursing home setting" (Montgomery et al., 2007, p. 442). As negative behaviors such as wandering escalate, with limited resources to provide support, placement becomes the only solution. The inclusion of additional resources could mediate that outcome. Resources including information, education, emotional support, and respite support are vital to the caregiver.

The extant literature on role change discusses its impact on caregiver burden. The impact of assuming additional roles when discussing a behavior as difficult as wandering

also needed to be considered. This dissertation fills this need. Role change involves many facets for the caregiver; both giving up their cherished lifestyles as well as taking on responsibility for a behavior that is both dangerous and ubiquitous.

Supporting the Caregiver: The Physician, the Clinician, and the Community

Successful caregiving in the home environment involves education, training, support, and respite. Caregivers need information at diagnosis, as each stage brings on further changes in behavior, and regarding the types of behavioral issues such as ADRD that are common with the disease. There are many arenas for education and support. These include the physician, the case manager/clinician, and the community. Cooper, Cornelius, Orrell, and Livingston (2008) describe coping strategies that help caregivers tolerate stressful events. Assisting the caregiver in acceptance of the diagnosis, education about the disease, and where to get support is key. Cooper et al. (2008) outlines both emotion-focused and problem-focused strategies as important interventions when working with the caregiver. The strategies are detailed below:

- Emotion Focused Strategies
 - Accepting the reality of ADRD and learning to live with it
 - Emotional support and comfort from others
 - Humor
 - Positive reframing
 - Religion
- Problem Focused Strategies

- Active Coping
- Instrumental support: getting help and advice from others about what to do
- Planning: coming up with a strategy about what to do

The Brief COPE. (Carver, 1997 as cited by Cooper et al., 2008, p. 930)

Professionals utilizing these strategies to educate and support the caregiver dealing with role change will impact the caregiver's confidence and outlook on caregiving. When the physician, clinician, and community work together, the caregiver feels supported that he/she is effective in his/her role.

The Physician

The physician supports the caregiver in helping with the problem-focused strategies. Education and information helps set the course. The physician is often the first contact, making the diagnosis, referring to specialists, and supporting the caregiver through the process. ADRD is a psychosocial illness that encompasses cognitive and behavior components. As the first line of intervention, the physician is one of the most important players. The physician's role is vital; they are explaining the disease, normalizing the disease process, and supporting the caregiver to provide appropriate care. The physician assists the caregiver with role change by taking on difficult topics such as driving. Education improves the caregiver's understanding of the disease process. Education informs the caregiver about the disease process, supports the caregiver in how to intervene, and provides comfort that they are not alone. Physicians are the first line provider of information, and while they have limited amount of time, they play an

important role in encouraging the family to seek support through appropriate agencies within the community who can provide additional assistance (Austrom & Lu, 2009; Javadpour et al., 2008).

Caregivers are in dire need of education and they are looking for education and support from professionals such as physicians. Given the necessity and importance of role adaptation, physicians should openly discuss this with caregivers and provide them with resources to assist them in this process.

The Case Manager and Clinician

Case management resources and mental health professionals such as clinicians play a vital role in assisting the caregiver to develop coping tools. The case manager/clinician can assess the caregiver's present level of coping. Austrum and Lu (2009) suggest an assessment tool based on Kubler-Ross (1969) stages of loss:

- Is the caregiver in denial as exhibited by making excuses for their loved one?
- Is the caregiver over-compensating for their loved one's losses?
- Is the caregiver exhibiting anger or embarrassment at either diagnosis or behavior?
Does the caregiver appear to feel guilty because they feel unable to provide appropriate care? (Austrum & Lu, 2009, p. 393)

After assessment of the caregiver's emotional reaction to the diagnosis, there are a number of areas to be addressed. "Family disruptions, such as role changes, role overload, family conflict; Psychological stress; Physical fatigue; Social isolation; Financial concerns and problems; [and] Legal issues, such as conservatorship (Kaplan, 1996, as cited in Austrom & Lu, 2009, p. 397).

Case management services have been minimized in the present political and economic environment in arenas such as hospitals and non-profit agencies, which is detrimental to the patient and family dealing with such a devastating chronic disease as ADRD. When the caregiver seeks information, appropriate information in an appropriate format is vital. Both assessment of the caregiver and style of information processing will aid the case manager/clinician in optimum positive outcomes. There are many resources in the community, and connection to those resources is difficult and cumbersome. Case managers ease the process by compiling and providing quality resources that the caregiver can utilize.

Caregivers who are knowledgeable about problem behaviors and how to deal with those behaviors are more successful in the home environment. Home-based programs assist the caregiver in developing tools to effectively cope with behavior problems. The Environmental Press Skills Building Program was designed to successfully intervene with difficult behaviors such as wandering (Corcoran et al., 2002). The occupational therapist educates and trains the caregiver to utilize appropriate skills to deal with problem behaviors such as wandering. The caregiver learns how to adapt the home for safety and behavior monitoring of wandering. Visual cues and the use of monitors and alarms are utilized to help develop the caregiver's confidence and their loved one's safety.

The Community: Respite and Emotional Support

Caregivers need respite, mental breaks, and emotional support to be successful at

home-based caregiving (Watts & Teitelman, 2005). Emotional support takes many forms. Support groups provide time with other caregivers to both share in the experiences and deal with the emotional issues involved in providing care to a loved one. Support groups that allow for an exchange of experiences, discussion, and information are particularly helpful (Grabel, Trilling, Donath, & Luttenberger, 2010).

Training caregivers to manage their stress regarding the negative behaviors is another important area. Strategies such as distraction and redirecting away from the problem are both important interventions used with the ADRD patient. The response of the caregiver to the behavior is vital. Counseling caregivers to use interventions that reduce their stress reaction to negative behaviors can have long lasting positive consequences (Mittelman, Roth, Haley et al., 2004; Mittelman, Roth, Coon, & Haley, 2004).

Respite services allow the caregiver time of their own. Whether they use the time to rest, take care of their own needs, or attend a support group, they are provided time away. Respite can be as informal as family or friends helping out for a few hours, or formal support, such as in home services, chore services, and companion care. Out-of-the-home respite programs, such as adult day programs, provide caregivers a break and allow for appropriate socialization of their loved one with ADRD.

Respite services serve an important function in providing stress relief to caregivers, which enables caregivers to continue in their role for longer period of time, thus avoiding or preventing placement (Montgomery et al., 2007, p. 435). Formal respite services are expensive and therefore prohibitive for many caregivers. Public services that

support the family caregiver are vital if the caregiver is to be assisted appropriately to keep their loved one in the home. The National Family Caregiver Support Program was developed under the Older American's Act to provide services and funding for in-home support. Professionals in the ADRD arena must strongly advocate policy makers regarding the needs of the caregiver and the importance of increasing this program to expand both the services it provides and the funds available to assist caregivers.

The religious community is another important stakeholder within the community. Churches should be encouraged in the development of inexpensive, drop-in respite programs. Churches have volunteers, large spaces and loving hearts, all which can be combined to support the elders within their community. North Park Presbyterian Church in Dallas offers the Casa de Vita program, a drop-in respite program for Alzheimer's patients every Tuesday. For a fee of \$10.00 the caregiver can drop their loved one off for a day filled with activities. The caregiver is provided six hours of respite while their loved one is safe. The person with ADRD is provided social opportunities, and the church has found another way to fulfill its mission to its members and the broader community.

Limitations of the Study

There are many limitations of this study that should be noted. While the sample size of 22 family caregivers was within the parameters of a qualitative study, it was small. Most of the family caregivers were seniors themselves, Caucasian, and female. Thus, another limitation was the sample's lack of diversity. While caregiver outreach

included the Dallas metropolitan area including South Dallas and Duncanville, where African Americans and Latinos reside, the interview sample contained few of these race/ethnicities. The interview sample utilized convenience sample, the caregivers contacted me to let me know that they were willing to be interviewed. Thus, the caregivers in my study might differ from the larger population of caregivers in key areas such as acceptance of support and education regarding the disease process.

Conclusion

The caregiver of a loved one with ADRD is faced with numerous additional roles brought on by the physical, cognitive, and behavioral aspects of the disease. Wandering is one of the most difficult of the behaviors that develop. The ability of the caregiver to cope with change is related to the amount of support the caregiver receives. Providing support through both formal and informal networks increase the caregiver's ability to cope. As society ages and the numbers with ADRD explode, it is important as professionals that we work to develop these supports.

APPENDIX A

SCHEDULE OF SEMI-STRUCTURED INTERVIEW QUESTIONS

How old were you at your last birthday?

1. What ethnic group do you consider yourself a member of?
2. When did your loved one get the ADRD diagnosis? What stage of the disease is your loved one?
3. How many years have you been a caregiver for your loved one with ADRD.
4. Did you receive information about the disease? YES
5. What kinds of things do you and your loved one like to do during the day together?
6. What kinds of things does your loved one like to do by him/her self at home?
7. How has your home changed since the diagnosis?
8. What practices do you use to ensure a safe home?
9. Do you have any concerns about your loved one's safety at home?
10. 11. Would you say that your loved one's memory loss has made it harder at home? In what ways do you see him/her having problems due to memory loss?
11. Do you worry about your loved one getting lost?
12. Has your loved one gotten lost? Where did he/she get lost? Was this the first incident, or were there other times? Could you tell me about the other times he/she got lost as well?
13. What kind of an impact did that have on you?
14. How have you changed your loved one's activities because of it?
15. What is your plan to deal with your loved one's wandering/getting lost?
16. Do you attend a support group? How long have you attended the group? What benefits have you gained for participation in the support group? Is the issue of wandering discussed at your support group? Why or why not?
17. Have you contacted the police because your loved one wandered away? What happened?

18. Do you worry about your loved one wandering away? Do you sleep lighter because you're afraid? Have you changed anything else because you're afraid of him/her wandering?
19. What kind of support do you get from your children/friends/relatives about this?
20. As I study the issue of wandering and how it impacts the caregiver, is there else that you want to tell me?
21. Would you look over this list and tell me if any of these strategies look like something you might be able to adopt? Why or why not?

APPENDIX B
HOME MODIFICATION QUESTIONNAIRE

Please circle the number that best indicates the likelihood of using the following home modifications:

1. Enclose patios or yard

(not likely)			(somewhat likely)				(in place)		
1	2	3	4	5	6	7	8	9	10

2. Lock outside gates

(not likely)			(somewhat likely)				(in place)		
1	2	3	4	5	6	7	8	9	10

3. Use child proof knob covers on doors

(not likely)			(somewhat likely)				(in place)		
1	2	3	4	5	6	7	8	9	10

4. Install a door chime

(not likely)			(somewhat likely)				(in place)		
1	2	3	4	5	6	7	8	9	10

5. Change door locks

(not likely)			(somewhat likely)				(in place)		
1	2	3	4	5	6	7	8	9	10

6. Camouflage doors

(not likely)			(somewhat likely)				(in place)		
1	2	3	4	5	6	7	8	9	10

7. Register with the Alzheimer's Association Medic-Alert Safe Return Program

(not likely)			(somewhat likely)				(in place)		
1	2	3	4	5	6	7	8	9	10

8. Purchase a tracking device that utilizes technology such as GPS or 911 to locate your loved if lost

(not likely)			(somewhat likely)				(in place)		
1	2	3	4	5	6	7	8	9	10

INFORMED CONSENT FORM

Before agreeing to participate in this research study, it is important that you read and understand the following explanation of the purpose, benefits and risks of the study and how it will be conducted.

Title of Study: Alzheimer's Patients and Safety: A Study of Caregiver Perceptions

Principal Investigator: Dr. Cynthia Cready, University of North Texas (UNT),
Department of Sociology.

Student Investigator: Patricia Dickson, University of North Texas (UNT),
Department of Sociology, Applied Gerontology Ph.D. Program.

Purpose of the Study: You are being asked to participate in a research study conducted by a UNT faculty member and graduate student. This project is interested in how caregivers care for their loved one with Alzheimer's Disease and Related Dementia (ADRD) in the home.

Study Procedures: The interview will be audio-recorded. You will be asked some questions about demographics, some questions about your lifestyle and some questions about your comfort level with your loved one's present behaviors. How have things at home changed since the loved one's diagnosis? What is your level of concern about the safety of their loved one? Do you worry about your loved one getting lost? Has your loved one gotten lost? How many times? Where? What happened? How did and does the wandering affect you? What are the factors that impact your perception of wandering? How has a wandering event acted as a catalyst for change by you? Has placement of their loved one outside the home been considered? Is wandering behavior considered a primary reason for placement outside the home? How likely are you to use various home-based interventions? We will provide you with a list of interventions to determine those that you are aware of, and those that you need more information about. In some cases, support group meetings may be observed by student investigator to look for interactions among caregivers regarding wandering behaviors.

Foreseeable Risks: No foreseeable risks are involved in this study. However, some questions might cause you some discomfort. Included in these are questions about your level of anxiety about your loved one getting lost, support you receive from family and friends, change in your relationship with your loved one, interface with legal authorities because of a wandering event, lifestyle change because of both the diagnosis of ADRD and your concern about a wandering event. If you become uncomfortable, you can decline to answer, or ask the student investigator to stop the interview. If you feel that you need professional support after the interview, you can ask the student investigator for names of support professionals and resources.

Benefits to the Subjects or Others: This study is expected to benefit others who are working with people with ADRD by providing information about caregivers' perceptions in order to develop appropriate interventions to assist you in developing a safer home environment and better strategies to deal with wandering behavior.

Compensation for Participants: You will not receive any compensation for your participation.

Procedures for Maintaining Confidentiality of Records: Audio-taped records of interviewees will be kept confidential and will remain in a place where only principal investigator and student investigator can access them. The audio-taped records will not be released to unauthorized personnel. Your name will not be included on the audio taped records. Data from the study will be used only for this study. The confidentiality of your individual information will be maintained in any publication or presentations regarding this study.

Questions about the Study: If you have any questions about the study, you may contact principal investigator Dr. Cynthia Cready at 940-369-8791 or Cynthia.Cready@unt.edu or the student investigator Patricia Dickson at [REDACTED]

Review for the Protection of Participants: This research study has been reviewed and approved by the UNT Institutional Review Board (IRB). The UNT IRB can be contacted at (940) 565-3940 for any questions regarding the rights of research subjects.

Research Participant's Rights:

Your signature below indicates that you have read or had read to you all details pertaining to this study and that you confirm the following:

- Dr. Cynthia Cready or Patricia Dickson has explained the study to you and answered all of your questions. You have been told the possible benefits and the potential risks and/or discomforts of the study.
- You understand that you do not have to take part in this study, and your refusal to participate or your decision to withdraw will involve no penalty or loss of rights or benefits. The study personnel may choose to stop your participation at any time.
- You understand why the study is being conducted and how it will be performed.
- You understand your rights as a research participant and you voluntarily consent to participate in this study.
- You understand that some of the questions may cause you discomfort. You have been told that if you become uncomfortable, you can decline to answer the question, or ask the student investigator to end the interview at any time.
- You have been told that you will receive a copy of this form.

APPROVED BY THE UNT IRB
FROM 11/10/11 11/7/12

Printed Name of Participant

Signature of Participant

Date

For the Principal Investigator or Designee:

I certify that I have reviewed the contents of this form with the subject signing above. I have explained the possible benefits and potential risks and/or discomforts of this study. It is my opinion that the participant understood the explanation.

Signature of the Principal Investigator or Designee

Date

APPROVED BY THE UNT IRB
FROM 11/10/11 to 11/3/12
[Signature]

REFERENCES

- Ablitt, A., Jones, G., & Muers, J. (2009). Living with dementia: A systematic review of the influence of relationship factors. *Aging and Mental Health, 13*(4), 497-511.
- Adams, K. (2006). The transition to care-giving: The experience of family members embarking on the dementia care-giving career. *Journal of Gerontological Social Work, 4*(3/4), 3-29.
- Aditya, B, Sharma, J., Allen, S., & Vassallo, M. (2003). Predictors of a nursing home placement from a non-acute geriatric hospital. *Clinical Rehabilitation, 17*, 108-113.
- Algase, D. L., Moore, H., Vandeweerd, C., & Gavin-Dreschnack, D. (2007). Mapping the maze of terms and definitions in dementia related wandering. *Aging and Mental Health, 1*(6), 686-698.
- Alkema, G., Wilber, K., & Enguidanos, S. (2007). *Handbook of gerontology: Community and facility-based care*. Hoboken, NJ: John Wiley and Sons.
- Alzheimer's Disease International. (2010, May). *Dementia-A global epidemic*. London, UK. Retrieved from www.alz.co.uk
- Alzheimer's Association. (2010a). *Facts and figures*. Retrieved from www.Alz.org
- Alzheimer's Association. (2010b). *Medic alert/safe return program*. Retrieved from www.Alz.org
- Alzheimer's Association. (2011). *Facts and figures*. Retrieved from www.Alz.org
- Alzheimer's Association. (2012). *Facts and figures*. Retrieved from www.Alz.org
- Aminzadeh, F., Byszewski, A., Molnar, F., & Eisner, M. (2007). Emotional impact of dementia diagnosis: Exploring persons with dementia and caregivers' perspectives. *Aging & Mental Health, 11*(3), 281-290.
- Ankri, J., Andriew, S., Beaufils, B., Grand, A., & Henrard, J. (2005). Beyond the global score of the Zarit burden interview: Useful dimensions for clinicians. *International Journal of Geriatric Psychiatry, 20*, 254-260.
- Arguing. (2012). *Merriam-Webster collegiate dictionary online* (11th ed.). Retrieved from <http://www.merriam-webster.com/dictionary/arguing>

- Askham, J., Briggs, K., Norman, I., & Redfern, S. (2007). Care at home for people with dementia: As in a total institution? *Aging & Society, 27*, 3-24.
- Austrom, M., & Lu, Y. (2009). Long-term care-giving: Helping families of persons with mild cognitive impairment cope. *Current Alzheimer Research, 6*, 392-398.
- Baltes, P., Staudinger, U., & Lindenberger, U. (1999). Lifespan psychology: Theory and application to intellectual functioning. *Annual Reviews Psychology, 50*, 471-507.
- Bookman, A. (2008). Innovative models of aging in place: Transforming our communities for an aging population. *Community Work and Family, 11*(4), 419-438.
- Carr, D., Muschert, G., Kinney, J., Robbins, E., Petonito, G., Manning, L., Brown, J. S. (2009). Silver alerts and the problem of missing adults with dementia. *The Gerontologist, 50*(2), 149-157.
- Charmaz, K. (2006). *Constructing grounded theory*. Los Angeles, CA: Sage Publications.
- Chee, Y., Dennis, M., & Gitlin, L. (2005). Provider assessment of interactions with dementia caregivers: Evaluation and application of therapeutic engagement index. *Clinical Gerontology, 28*(4), 43-59.
- Cooper, C., Cornelius, K., Orrell, M., & Livingston, G. (2008). Coping strategies, anxiety, and depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric Psychiatry, 23*, 929-936.
- Cooper, C., Katona, C., Orrell, M., & Livingston, G. (2006). Coping strategies and anxiety in caregivers of people with Alzheimer's disease: The LASER-AD study. *Journal of Affective Disorders, 90*, 15-20.
- Corcoran, M., Gitlin, L., Levy, L., Eckhardt, S., Earland, T., Shaw, G., & Kearney, P. (2002). An occupational therapy home-based intervention to address dementia-related problems identified by family caregivers. *Alzheimer's Care Quarterly, 3*(1), 82-91.
- Croog, S., Burlison, J., Sudilovsky, A., & Baume, R. (2006). Spouse caregivers of Alzheimer patients: Problem responses to caregiver burden. *Aging and Mental Health, 10*(2), 87-100.
- Dal Santo, T., Schlarch, A., Nielsen, J., & Fox, P. (2007). A stress process model of family caregiver service utilization: Factors associated with respite and counseling service use. *Journal of Gerontological Social Work, 49*(4), 29-104.

- Denial. (2012). *Merriam-Webster collegiate dictionary online* (11th ed.). Retrieved from <http://www.merriam-webster.com/dictionary/denial>
- Dodds, P. (1994). Wandering: A short report on coping strategies adopted by informal carers. *International Journal of Geriatric Psychiatry*, 9(9), 751-756.
- Doraiswamy, P., & Gwyther, L. (2008). *The Alzheimer's action plan*. New York, NY: St. Martins Press.
- Drentea, P., Clay, O., Roth, D. & Mittelman, M. (2006). Predictors of improvement in social support: Five-year effects of a structured intervention for caregivers of spouses with Alzheimer's disease. *Social Science & Medicine*, 63, 957-967.
- Elder, G. (2001). Families, social change and individual lives. *Marriage & Family Review*, 31, 177-203.
- Elliot, A., Burgio, L., & DeCoster, J. (2010). Enhancing caregiver health: Findings from the resources for enhancing Alzheimer's caregiver health II intervention. *JAGS*, 58, 30-37.
- Family Caregiver Alliance. (2004). *The state of the states in family caregiver support: A 50 state study*. Retrieved from http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1276
- Ferrara, M., Langiano, E., Di Brango, T., DeVito, E., DiCioccio, L., & Bauco, C. (2008). Prevalence of stress, anxiety and depression in with Alzheimer caregivers. *Health and Quality of Life Outcomes*, 6, 93-98.
- Ferrini, R., & Ferrini, A. (2008). *Health in the later years* (5th ed.). New York, NY: McGraw Hill Ryerson.
- Frittelli, C., Borghetti, D., Iudice, G., Bonanni, E., Maestri, M., Tognoni, G., . . . Iudice, A. (2009). Effects of Alzheimer's disease and mild cognitive impairment on driving ability: A controlled clinical study by simulated driving test. *International Journal of Geriatric Psychiatry*, 24, 232-238.
- Gaines, S. (2009, Spring). Finding the wanderers. *Preserving Your Memory: The Magazine of Health and Hope*. Retrieved from <http://www.alzinfo.org/03/pym/ask-the-experts/finding-wanderers>
- Gort, A., Mingot, M., Gomez, X., Soler, T., Torres, G., Sacristan, O., . . . Cabau, J. (2007). Use of the Zarit scale for assessing caregiver burden and collapse in caregiving at home in dementias. *International Journal of Geriatric Psychiatry*, 22, 957-962.

- Grabel, E., Trilling, A., Donath, C., & Luttenberger, K. (2010). Support groups for dementia caregivers-predictors for utilization and expected quality from a family caregiver's point of view: A questionnaire survey PART I. *BMC Health Services Research, 10*(219), 1-8.
- Hayslip, B., Han, G., & Anderson, C. (2008). Predictors of Alzheimer's disease caregiver depression and burden: What non-caregiving adults can learn from active caregivers. *Educational Gerontology, 34*, 945-969.
- Hooker, K., O'Dell, M., Monahan, D., Frazier, L., & Shifren, K. (2000). Does type of disease matter? Gender differences among Alzheimer's and Parkinson's disease spouse caregivers. *The Gerontologist, 40*(5), 568-573.
- Hope, R., & Fairburn, C. (1990, July/August). The nature of wandering in dementia: A community based study. *International Journal of Geriatric Psychiatry, 5*(4), 239-245.
- Hope, T., Tilling, K., Gedling, K., Keene, J., Cooper, S., & Fairburn, C. (1994). The structure of wandering in dementia. *International Journal of Geriatric Psychiatry, 9*, 149-155.
- Javadpour, A., Ahmadzadeh, L., & Bahredar, M. (2008). An educative support group for female family caregivers: Impact on caregivers psychological distress and patient's neuropsychiatry symptoms. *International Journal of Geriatric Psychiatry, 24*, 469-471.
- Kennedy, G. (2009). Advanced age, dementia and driving: Guidance for the patient, family and physician. *Primary Psychiatry, 16*, 19-23.
- Kiely, D., Morris, J., & Algase, D. (2000). Resident characteristics associated with wandering in nursing homes. *International Journal of Geriatric Psychiatry, 15*, 1013-1020.
- Koester, R. I., & Stooksbury, D. (1992). Lost Alzheimer's subjects-profiles and statistics. *Response, 11*(4), 20-26.
- Kubler-Ross, E. (1969). *On death and dying*. New York, NY: Simon and Shuster.
- Kuo, L., & Shyu, Y. (2010). Process of ambivalent normalization: Experience of family caregivers of elders with mild cognitive impairment in Taiwan. *Journal of Clinical Nursing, 19*(23-24), 3477-3484.
- Lai, C., & Arthur, D. (2003). Wandering behavior in people with dementia. *Journal of Advanced Nursing, 44*(2), 173-182.

- LeCompte, M., & Schensul J. (1999). *Essential ethnographic methods: The ethnographer's toolkit* (Vol. 1). Walnut Creek, CA: AltaMira Press.
- Mace, N., & Rabins, P. (2006). *The 36-hour day: A family guide to caring for persons with Alzheimer disease related to dementing illnesses, and memory loss in later life* (4th ed.). Baltimore: Johns Hopkins Press.
- McConaghy, R., & Caltabiano, M. (2005). Caring for a person with dementia: Exploring relationships between perceived burden, depression, coping and well-being. *Nursing and Health Sciences*, 7, 81-91.
- McShane, R., Gedling, K., Kenward, B., Kenward, R., Hope, T., & Jacoby, R. (1998). The feasibility of electronic tracking devices in dementia: A telephone survey and case series. *International Journal of Geriatric Psychiatry*, 13, 556-563.
- Mittelman, M., Roth, D., Coon, D., & Haley, W. (2004). Sustained benefit of supportive intervention for depressive symptoms in caregivers of patients with Alzheimer's disease. *The American Journal of Psychiatry*, 161(5), 850-856.
- Mittelman, M., Roth, D., Haley, W., & Zarit, S. (2004, January). Effects of a caregiver intervention on negative caregiver appraisals of behavior problems in patients with Alzheimer's disease: Results of a randomized trial. *The Journals of Gerontology*, 27-34.
- Montgomery, R., & Williams, K. (2001, May 5). Implications of differential impacts of care giving for future research on Alzheimer care. *Aging and Mental Health*, (Supp. 1), S23-S34.
- Montgomery, R. J. V., & Kosloski, K. D. (2000). Family caregiving change: Continuity and diversity. In R. Rubinstein, & M. Lawton (eds.), *Alzheimer's disease and related dementias: Strategies in care and research* (pp. 143-171). New York, NY: Springer.
- Montgomery, R., Rowe, J., & Kosloski, K. (2007). *Family caregiving. Handbook of gerontology*. Hoboken, NJ: John Wiley and Sons.
- National Institute on Aging. (2010). *Home safety for people with Alzheimer's disease*. Retrieved from <http://www.nia.nih.gov/alzheimers/publication/home-safety-people-alzheimers-disease>
- Olshansky, S., Goldman, D., Zheng, Y. & Rowe, J. (2009). Aging in America in the twenty-first century: Demographic forecasts from the MacArthur Foundation Research Network on an aging society. *The Milbank Quarterly*, 87(4), 842-862.

- Rasquin, S., Willems, C., de Vlieger, S., Geers, R., & Soede, M. (2007). The use of technical devices to support outdoor mobility of dementia patients. *Technology and Disability, 19*, 113-120.
- Robinson, L., Hutchings, D., Corner, L., Finch, T., Hughes, J., Brittain, K., & Bond, J. (2007). Balancing rights and risks: Conflicting perspectives in the management of wandering in dementia. *Health, Risk and Society, 9*(4), 389-406.
- Roth, D., Gitlin, L., Coon, D., Stevens, A., Burgio, L., Gallagher-Thompson, D., . . . Burns, R. (2003). Psychometric analysis of the revised behavior problems checklist: Factor structure of occurrence and reaction ratings. *Psychological Aging, 18*(4), 906-915.
- Rowe, M., & Glover, J. (2001) Antecedents, descriptions and consequences of wandering in cognitively impaired adults and the safe return program. *American Journal of Alzheimer's Disease and Other Dementias, 16*(6), 344-351.
- Sales, E. (2003). Family burden and quality of life. *Quality of Life Research, 12* (Supp. 1), 33-41.
- Savundranayagam, M., Montgomery, R., & Kosloski, K. (2011). A dimensional analysis of caregiver burden among spouses and adult children. *The Gerontologist, 51*(3), 321-331.
- Schensul, S., Schensul, M., & LeCompte M. (1999). *Essential ethnographic methods: The ethnographer's toolkit* (Vol. 2). Walnut Creek, CA: AltaMira Press.
- Silverberg, E. (2006). Introducing the 3A grief intervention model for dementia caregivers: Acknowledge, assess and assist. *Omega, 54*(3), 215-235.
- Sink, K. M., Covinsky, K., Newcome, R., & Yaffe, K. (1994). Ethnic differences in the prevalence and pattern of dementia related behaviors. *Journal of the American Geriatrics Society, 5*(2), 1277-1283.
- Sofaer, S. (1999). Qualitative methods what and why. *Health Services Research, 34*(5), 1101-1118.
- Steinhardt, V. (2012). A sandwich generation caregiver heads back to work. *The New York Times*. Retrieved from <http://parenting.blogs.nytimes.com/2012/05/07/a-sandwich-generation-caregiver-heads-back-to-work/>
- Strauss, A. C., & Corbin, J. M. (2008). *The basics of qualitative research*. Thousand Oaks, CA: Sage Press.

- Street, D. (2007). *Sociological approaches to understanding age and aging. Handbook of gerontology*. Hoboken, NJ: John Wiley and Sons.
- Tornatore., J. & Grant, L. (2002). Burden among family caregivers of persons with Alzheimer's disease in nursing homes. *The Gerontologist*, 42(4), 497-506.
- Watts, J., & Teitelman, J. (2005). Achieving a restorative mental break for family caregivers of persons with Alzheimer's disease. *Australian Occupational Therapy Journal*, 52, 282-292.
- Wilks, S., & Croom, B. (2008). Perceived stress and resilience in Alzheimer's disease caregivers: Testing moderation and mediation models of social support. *Aging and Mental Health*, 12(3), 357-365.